

ADAM MICKIEWICZ UNIVERSITY IN POZNAŃ

INTERDISCIPLINARY CONTEXTS OF SPECIAL PEDAGOGY

26

Academic editor
BEATA JACHIMCZAK



POZNAŃ 2019

INTERDISCIPLINARY CONTEXTS OF SPECIAL PEDAGOGY

The scientific journal of the Faculty of Educational Studies

Adam Mickiewicz University issued as a quarterly

EDITORIAL BOARD

Chief Editor – Iwona Chrzanowska (Adam Mickiewicz University in Poznan)

Assistant Editor – Magdalena Olempska-Wysocka (Adam Mickiewicz University in Poznan)

Secretary – Aneta Wojciechowska (Adam Mickiewicz University in Poznan)

Andrzej Twardowski (Adam Mickiewicz University in Poznan), Agnieszka Słopień (Poznan University of Medical Sciences), Beata Jachimczak (Adam Mickiewicz University in Poznan), Katarzyna Pawelczak (Adam Mickiewicz University in Poznan), Miron Zelina (Univerzita Komenského v Bratislave), Jana Rapuš-Pavel (Univerza v Ljubljani), William Brenton (University of Maine Presque Isle), Jacek Pyżalski (Adam Mickiewicz University in Poznan), Amadeusz Krause (The University of Gdansk), Jarmila Novotná (MBA Dubrnický technologický inštitút v Dubnici and Váhom, Masarykova Univerzita v Brně), Magdalena Olempska-Wysocka (Adam Mickiewicz University in Poznan)

SUBJECT EDITORS

Iwona Chrzanowska (inclusive education, pedagogy of people with special educational needs)

Andrzej Twardowski (psychology of human development, early support of child development)

Agnieszka Słopień (psychiatry of children and adolescents)

Beata Jachimczak (inclusive education, pedagogy of people with special educational needs)

Katarzyna Pawelczak (psychology of people with disabilities)

Aneta Wojciechowska (special education, logopedics)

Miron Zelina (pedagogy, psychology)

Jana Rapuš-Pavel (social pedagogy)

William Brenton (special education)

Jacek Pyżalski (media pedagogy, resocialization)

Amadeusz Krause (special education)

Jarmila Novotná (pedagogy)

Magdalena Olempska-Wysocka (psychology, deaf education, logopedics)

LANGUAGE EDITORS

Karolina Kuryś (Polish)

Wendy Ross (English)

Nicol Ross (English)

STATISTICAL EDITOR Paweł Mleczo

© Uniwersytet im. Adama Mickiewicza w Poznaniu,

Wydawnictwo Naukowe UAM, Poznań 2019

Publication financed by the Faculty of Educational Studies

Adam Mickiewicz University in Poznań

„Tłumaczenie zawartości 8 numerów czasopisma „Interdyscyplinarne Konteksty Pedagogiki Specjalnej” na język angielski – zadanie finansowane w ramach umowy 792/P-DUN/2017 ze środków Ministra Nauki i Szkolnictwa Wyższego przeznaczonych na działalność upowszechniającą naukę”.



Ministerstwo Nauki
i Szkolnictwa Wyższego

ISSN 2300-391X



Contents

Introduction	7
KATARZYNA PARYS, SŁAWOMIR OLSZEWSKI	
Demanding disability - an analysis of opportunities and threats related to the functioning of people with mild intellectual disabilities. Part 1	15
MATEUSZ SZUREK	
Assessment of the capacity to create and understand wordbuilding structures by a child with minor intellectual disability	39
ANIDA SZAFRAŃSKA	
Support Teachers in the Education of Students with Autism and Asperger Syndrome in Integrated and Mainstream Schools	59
MARTA NIEMIEC	
Work of teachers co-organising the process of education of pupils with special educational needs in the opinions of public school teachers	81
MACIEJ JABŁOŃSKI	
Apparent Activities in Special Education. A Critical Analysis of Core Curriculum	103
KRYSZYNA BARŁÓG	
The context of special pedagogy: practical inclusive education or simulated inclusive education?	125

NAVA BAR, BOSHRA KANJ-SIRHAN	
The 'parents' choice': the recent perceptual changes in special education law in israel and its implementation in the field	143
MAGDALENA WAŁACHOWSKA	
Parenting of people with visual disabilities as an interdisciplinary context of contemporary special education	163
KAMIL KURACKI	
Satisfaction with the support received by parents of children with disabilities and the diversity of parental behaviour towards the child	191
JAROSŁAW BĄBKA	
Lifestyles of Intellectually Disabled Adults	217
DOROTA PRYSAK	
The objectification of adulthood of persons with deeper and deep intellectual disability	237
DIANA AKSAMIT, BARBARA MARCINKOWSKA	
My adult son, my adult daughter - reflections of mothers of children with profound intellectual disabilities	255
EDYTA ZIERKIEWICZ, BEATA CYTOWSKA	
Doing and undoing gender by women with intellectual disabilities ...	271
HANNA KRAUZE-SIKORSKA	
Children and adolescents with a chronic condition in the public school space - in search of an effective model of psychopedagogical support	295
MAŁGORZATA PAPLIŃSKA	
The Competence of Teacher Assistants in the Context of Working with Visually Impaired Students. Needs of the Environment and the Vision of Change	319
MONIKA SKURA	
The perception of people with a physical disability towards those with a different kind of disability	343
SARA KNAPIK-SZWEDA	
The Significance of Qualitative Research - Arts-based Research in Special Needs Education and Music Therapy	369

MARZENNA ZAORSKA, ADAM ZAORSKI

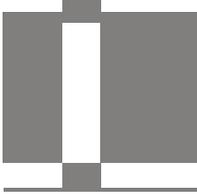
Issues related to the statutory ban on eugenic abortion in Poland (in the opinion of representatives of the community of people with disabilities) 389

BOGUSŁAW ŚLIWERSKI

On the phenomenon of scientific work of Zbyszko Melosik 405

OLGA CHRZANOWSKA

The role of sketching within the process of creative maturation of an architect in 21st century – sketching from nature in cognitive development 443



Introduction

*Multithreading of (special) education:
multi-facetedness; multi-leveledness;
diversity; non-uniformity; variety;
universality; versatility;
complexity; heterogeneity¹*

Presenting you with the next issue of Interdisciplinary Contexts of Special Education, I was wondering about its theme. And the longer I analysed the texts submitted by the authors, the more I tried to organize them according to a personally acceptable “key”, the more I became convinced of the increasing diversity of the problems undertaken in special education and beyond. Hence multithreading (and its synonyms) that I have mentioned is to reflect the character of this publication. However, there is something else that links all these texts. It is a focus on man and his multidimensionality, in the context of needs, possibilities, limitations, age, choices, action, creativity. Such a concentration of scientific texts is in line with what Waldemar Furmanek wrote, pointing out that “the view on the necessity of recognizing the primacy of man (homocentrism) and adopting the assumption of the polyparadigmatic nature of

¹ Synonyms of the word multithreading, <<https://synonym.net/synonym/wie-low%C4%85tkowo%C5%9B%C4%87>>.

research is slowly breaking through in the opinions of researchers”². He then went on to say, “We are going back to the four questions concerning man by I. Kant, who in the *Critique of Pure Reason*, when asking about man, asks: What can I know? What should I know? What can I expect? What (who) is man? (Kant 1957, p. 548)”³.

And despite the paradigmatic changes in special education⁴ oriented on humanist concepts emphasizing the full and equal participation of each person in all dimensions of individual and social life, researchers continue to explore how these assumptions are implemented. The analyses and research results presented in this issue are situated in relation to social change and a deep appreciation of the diversity of the world in which we operate. You will find answers and further questions about the condition of man (in his or her life continuum), not only those with diagnosis of disability, in the context of his or her need for self-fulfilment, passion for creating and looking for opportunities to fulfil social roles, substantive and psychological support, educational and life situation.

I hope that reading the texts will provide you with inspiration to look for solutions that will contribute to building personal competences of each person (including the still small one, still dependent) in the area of self-awareness, self-regulation and motivation, so that they can fully realize themselves in life.

The first part of the texts concerns the *heterogeneity* of problems of people with intellectual disabilities. As Katarzyna Parys and Sławomir Olszewski point out in their text: “The content we discuss is valued ambiguously in subject literature. We do not aim to eliminate the emerging ambiguities, but we do want to expose the existing differences, and we even attempt to question the positions which, because they have been repeated many times, have taken the form of

² W. Furmanek, *Pedagogika wobec wyzwań współczesności*. Annales Universitatis Mariae Curie-Skłodowska, sectio J – Paedagogia-Psychologia, Vol. XXVI, 1-2, 2013, p. 12.

³ Ibid.

⁴ I. Chrzanowska, *Pedagogika specjalna. Od tradycji do współczesności*. Kraków, Oficyna Wydawnicza „Impuls”, 2015, pp. 387-422.

undisputed statements. In this way we see the possibility of a reflective reading of reality. Therefore, when conducting reflections concerning people with mild intellectual disabilities, we will look for and reveal both opportunities and threats to the functioning of these people and their environment".⁵ Subsequent texts further analyse the issues concerning students with intellectual disabilities in educational contexts (M. Szurek, M. Jabłoński) and adults responsible for creating institutional development space for them (A. Szafrńska, M. Niemiec, K. Barłóg). Further analyses refer to the role and tasks of the family of a child with disabilities (N. Bar, B. Kanj-Sirhan) or the parenthood of people with sensory disorders (M. Wałachowska).

Another part I have identified are texts that show the *universality* of adult problems with a particular focus on disability. In one of the texts, Jarosław Bąbka points out that "research by various authors shows that adults with intellectual disabilities, despite changes in their living environment, experience difficult situations related to the realisation of developmental tasks concerning the need for love, sexual drive, independent living, social participation and professional work. The problem is excessive dependence on parents, social helplessness, marginalisation, social exclusion, lack of appropriate support in the environment".⁶ And these themes are developed by Dorota Prysak: The objectification of adulthood of persons with deeper and deep intellectual disability; Diana Aksamit, Barbara Marcinkowska: My adult son, my adult daughter – reflections of mothers of children with profound intellectual disabilities and Edyta Zierkiewicz, Beata Cytowska: Creating and suspending the gender by women with intellectual disabilities.

The next four texts by Hanna Krauze-Sikorska, Małgorzata Paplińska, Małgorzata Skura, Sara Knapik-Szwed and Marzenna Zaorska and Adam Zaorski are an example of the *diversity* of prob-

⁵ K. Parys, S. Olszewski, *Wymagająca niepełnosprawność – analiza szans i zagrożeń związanych z funkcjonowaniem osób z niepełnosprawnością intelektualną w stopniu lekkim. Część I* [Demanding disability – an analysis of opportunities and threats related to the functioning of people with mild intellectual disabilities. Part 1].

⁶ J. Bąbka, *Style życia dorosłych osób z niepełnosprawnością intelektualną* [Lifestyles of Intellectually Disabled Adults].

lems undertaken by educators, special educators and lawyers in terms of support, perception of people with disabilities and ethical considerations regarding eugenic abortion.

The publication ends with two seemingly detached texts, which, however, in my opinion, perfectly sum up the reflections on human condition and point to the *multi-level* and *versatile* search for one's own path of self-development and control of understanding of oneself and the world. Olga Chrzanowska states that, from the point of view of an architect, "having knowledge about the types of concentration and their characteristics we can deliberately choose the cognitive method. By adapting it to our character and the nature of the subject we focus on, we gain control over the form and content of our thoughts. Each field uses specific codes. Field codes are recognisable to everyone at a certain level, but using and transforming them in your work requires an expert knowledge of the elements and principles. Hence, multi-faceted cognition and practicing cognition is important and needed in the work of a professional, including of course an architect".⁷ Bogusław Śliwerski, on the other hand, brings us closer to the phenomenon of Zbyszko Melosik's work, pointing to his scientific associations with multiculturalism, when he writes: "over the years, Poland has also become a more culturally diverse country. The dissertation by Z. Melosik is for us not only a chance to properly prepare for change, but also a kind of passport to our own conscience and culture, to preserve our own identity in a "minority" scope, in one way or another. It is also an excellent comparative study of different cultures, which can be used by politicians and educators to eliminate the remnants of fundamentalism or even ethnic or racial hatred from the process of bringing up young generations, to oppose the creation of closed cultural and linguistic enclaves".⁸

⁷ O. Chrzanowska, *Rola szkicu w twórczym dojrzewaniu architekta w XXI wieku – szkic z natury a warsztat poznawczy* [The role of sketching within the process of creative maturation of an architect in the 21st century – sketching from nature in cognitive development].

⁸ B. Śliwerski, *O fenomenie twórczości naukowej Zbyszko Melosika* [On the phenomenon of scientific work of Zbyszko Melosik].

I hope that the deliberations undertaken by the Authors in the presented publication will become an inspiration for parents, teachers, therapists, people without disabilities and those with disabilities to look for opportunities for self-development, but also for areas of cooperation with others in co-designing their own life path or any other person who needs support in this area.

Beata Jachimczak
Scientific Editor of the volume



ARTICLES



Demanding disability – an analysis of opportunities and threats related to the functioning of people with mild intellectual disabilities

Part 1

ABSTRACT: Katarzyna Parys, Sławomir Olszewski, *Demanding disability – an analysis of opportunities and threats related to the functioning of people with mild intellectual disabilities. Part 1.* Interdisciplinary Contexts of Special Pedagogy, no. 26, Poznań 2019. Pp. 15–38. Adam Mickiewicz University Press. ISSN 2300-391X. DOI: <https://doi.org/10.14746/ikps.2019.26.01>

The thesis considered in the article is the statement that mild intellectual disability is a demanding disability. Three dimensions were distinguished in the description of the situation of persons with a mild intellectual disability:

1. Attributes of the phenomenon of mild intellectual disability
2. Attributes of the population of people with mild intellectual disabilities
3. Attributes of selected elements of the mesosystem of people with mild intellectual disabilities

The key phenomena for these dimensions were analysed. The ambiguity of these phenomena has become the basis for considering the opportunities and threats that they may pose.

Due to the extensiveness of the issues raised, the issues discussed are presented in two parts. The present text considers the first two of the dimensions listed.

KEY WORDS: mild intellectual disability, educational disability, 'intellectual disability' label

Introduction

The objective of considerations making up the present article is to highlight the complexity of the situation of persons with mild intellectual disability, and, hence, to issue a reminder to provide them with the necessary attention. It seems that the specifics of the property of the population, the characteristics of the communities in which people with mild intellectual disability function, the influences that they are subjected to, give rise to the threat of neglect by their environment. In relation to the challenges generated by mild intellectual disability it is substantiated to refer to it as a „demanding disability”.¹ The quoted thesis shall be verified by the arguments referred to and analysed.

Striving to present the situation of persons with mild intellectual disability, the following dimensions of description were assumed²:

- Attributes of the phenomenon of mild intellectual disability
- Attributes of the population of people with mild intellectual disabilities
- Attributes of selected elements of the mesosystem of people with mild intellectual disabilities.

The content discussed by us is variedly assessed within subject literature. We do not aim at eliminating the ambiguities that emerge, but we hope to expose the existing differences, and we even make an attempt at questioning attitudes, which, due to them having been repeated over and over again, took on the form of statements being accepted as the truth. We see in this mode of progress the possibility of thoughtful reflection on reality. Hence, dur-

¹ The usage of this term does not equal the consideration of mild intellectual disability as being more demanding than other forms of disability.

² Due to the breadth of the issues, the topics analysed shall be presented in two parts. The dimension “Attributes of selected elements of the mesosystem of people with mild intellectual disabilities” shall be presented in the article entitled *Demanding disability – an analysis of opportunities and threats related to the functioning of people with mild intellectual disabilities. Part 2*. The Reader shall find a summary of the discussed issues there.

ing our analysis concerning persons with mild intellectual disability, we will seek and disclose both opportunities as well as threats for the functioning of these people and their environment.

Properties of the phenomenon of mild intellectual disability

Educational disability

Mild intellectual disability is a phenomenon tightly related to the education process. Difficulties stemming from the inability to handle education requirements become the basis for undertaking diagnostic work, as a result of which the discussed disability is more often than not discovered, with education and rehabilitation activity taken afterwards. Mild intellectual disability is hence diagnosed due to and for the purposes of the education process. Disclosed and named in the school period, after the conclusion of the obligatory education stages it ceases to be the object of attention of the environment, it “disappears”.³ This type of phenomenon can be referred to be as the “paradox of mild intellectual disability”.

As a consequence of the above, mild intellectual disability should be identified with the concept of “educational disability” as introduced by Ulrich Bleidick.⁴ It also emerges in a situation of discrepancy between requirements of the school on the one hand and the capacity to cope with these requirements by the pupil without special paedagogical aid, if this discrepancy cannot be tolerated by the school (due to its long duration, extensiveness and intensity).⁵ It must be noted that within the Polish realm, the existence of this

³ K. Parys, *Osoby z diagnozą upośledzenia umysłowego w stopniu lekkim – w kręgu pytań i odpowiedzi*, [in:] *Poznajemy ludzi z niepełnosprawnością*, ed. by D. Gorajewska, Stowarzyszenie Przyjaciół Integracji, Warszawa 2007, p. 21.

⁴ U. Bleidick 1977, za: G. Szumski, *Integracyjne kształcenie niepełnosprawnych*, Wydawnictwo APS, Wydawnictwo Naukowe PWN, Warszawa 2009, pp. 112–113.

⁵ *Ibidem*.

phenomenon was described by Małgorzata Kościelska⁶, who suggested that children “diverging” from the common education system due to mild mental disability should be referred to as educationally-disabled children.

How can the mentioned discrepancy be minimised for pupils diagnosed with mild intellectual disability? On the one hand, the organisational assumptions of education of pupils with mild intellectual disability do not diverge from those based on the education of their fully-able peers (common curriculum of general education, the same stages of education, common assessment or external exam system). On the other hand, the label of intellectual disability that is valid throughout the education period allows for the introduction of solutions actually implementing the possibility of coping with such requirements. Among the solutions foreseen by the legislator aimed at the adaptation of teaching to the mental and physical skills of the pupil and the pace of teaching that would be appropriate for them, one can list the following:

- the obligation to execute multi-field assessments of the level of functioning of the pupil, and the preparation of an individual educational and therapeutic programme on this basis, aimed at the analysis of potential, and, as a result, the selection of suitable forms of individualisation of teaching. In this manner, described is the scope and mode of adaptation of education requirements to individual development and educational needs as well as the psychological and physical capacities of the pupil, in particular through the usage of suitable methods and forms of work with this pupil⁷;
- a selection of exercises being the consequence of the diagnosis made, with the exercises not exceeding the capacities of the

⁶ M. Kościelska, *Upośledzenie umysłowe a rozwój społeczny. Badania uczniów szkół specjalnych*, PWN, Warszawa 1984, p. 101.

⁷ Regulation of the Polish Ministry of Education of 9.08.2017 *on the conditions of organisation of education, upbringing and care for disabled, socially maladapted and threatened by social maladaptation children and youths*, Polish Journal of Laws of 2017, item no. 1578, § 6.

- pupil, so as not to reduce the motivation to cope with challenges⁸;
- the option of extending the time of execution of the individual stages of education⁹;
 - execution of additional educational activities (re-validation classes), aimed at the equalisation of shortcomings and reinforcement of resources held by the pupil¹⁰;
 - organisation of specialised activities (correction and compensation, speech therapy classes, courses to develop emotional and social competences and other therapeutic classes) as part of psychological and pedagogical aid provided to pupils with special education needs¹¹;
 - a different mode of implementation of the curriculum: learning a second modern foreign language in 7th and 8th grade of primary school does not apply to pupils with mild intellectual disability. In place of learning a second foreign language, the legislator planned a technical handicraft course. However, this is not an obligatory solution – the parent, legal custodian or fully aged pupil may forgo the described change¹²;

⁸ Regulation of the Polish Ministry of Education of 14.02.2017 *on the pre-school curriculum and the basic curriculum for primary schools, including for pupils with moderate or major intellectual disability, the curriculum of general education for industry branch-specific first level schools, general education for special schools preparing for work and general education for post-secondary schools*, Polish Journal of Laws of 24.02.2017, item no. 356.

⁹ Regulation of the Polish Ministry of Education of 28.03.2017 *on the framework curricula for public schools*, Polish Journal of Laws of 31.03.2017, item no. 703, § 5, s. 4.

¹⁰ Regulation of the Polish Ministry of Education of 9.08.2017 *on the conditions of organisation of education, upbringing and care for disabled, socially maladapted and threatened by social maladaptation children and youths*, Polish Journal of Laws of 2017, item no. 1578, § 5.

¹¹ Regulation of the Polish Ministry of Education of 9.08.2017 *on the rules of organisation and provision of psychological and pedagogical aid at public preschools, schools and related institutions*, Polish Journal of Laws of 2017, item no. 1591, § 6.2.

¹² Regulation of the Polish Ministry of Education of 28.03.2017 *on the framework curricula for public schools*, Polish Journal of Laws of 31.03.2017, item no. 703, s. 7.

- adaptation of the form and external conditions of the obligatory exam – the 8th grade exam (test sheet adapted to the dysfunction, extension of the exam time, the modern foreign language exam sheets with an attached CD with a recording adapted to the needs of this group of pupils, meaning, with appropriately extended pauses to get acquainted with the tests controlling listening comprehension and to do them; marking responses to closed questions in the exam task booklet, without having to transfer them over to the answer sheet; assurance of the presence of a disability specialist). For voluntary exams (test confirming qualifications in a profession, maturity exam), the adaptation applies exclusively to the execution conditions. In this regard, foreseen is an extension of the exam duration, usage of specialised equipment and relevant educational resources that the person taking the exam uses every day, including a computer, and assurance of the presence of a specialist in education of intellectually disabled persons¹³;
- education on the first stage industry-specific school level also in professions reserved solely for persons with mild intellectual disability. This applies to the following single-qualification professions foreseen for employees providing simple work: auxiliary employee of hotel services, tailor's auxiliary employee, mechanic's auxiliary employee, locksmith's auxiliary employee, carpenter's auxiliary employee, hairdresser's assis-

¹³ Communication of the general manager of the Polish Central Examination Board of August 20th, 2018 *on the detailed modes of adaptation of conditions and forms of execution of exams of primary school eight-graders and the lower secondary school exam in the academic year 2018/2019*.

<https://cke.gov.pl/images/_KOMUNIKATY/20180820%20E8%20EG%20Komunikat%20o%20dostosowaniach.pdf> [access: 13.05.2019]; Communication of the general manager of the Polish Central Examination Board of August 20th, 2018 *on the detailed modes of adaptation of conditions and forms of execution of exams confirming professional qualifications in the academic year 2018/2019*.

<https://cke.gov.pl/images/_KOMUNIKATY/20180820%20EZ%20Komunikat%20o%20dostosowaniach.pdf> [access: 13.05.2019].

tant.¹⁴ Such a solution is aimed at protecting against failure in the competition on the open job market, adaptation of requirements to pupil capacities. At the same time, however, it may be seen as a sign of certain segregation.

The described solutions may be treated as suggestions of normalisation work that are to lead to social integration, activities that function as an example of normalisation both in terms of personality, as well as the environment.¹⁵ In this context, bringing mild intellectual disability to the sphere of education, perceiving it solely through the lens of time and tasks of formal education, as well as solutions used for pupils touched by the phenomenon of educational disability, may constitute both a source of potential development risks as well as opportunities.

Potential threats must include excess focus on the improvement of orientation and cognition processes. The causes of this state of affairs may be sought in the following facts:

- the image of intellectual disability is dominated by disturbances in orientation and cognition processes;
- the leading role in school education is assigned to tasks based on intellectual faculties;
- the greatest differences between curriculum requirements of the school and the achievements of pupils with mild intellectual disabilities apply to cognitive functioning.

Excess focus on the facilitation of orientation and cognition processes runs the risk of neglecting the stimulation of the remaining areas of functioning, as a result of omission of solutions enabling the optimisation of development.

A further threat needs to be tied to the risk of making the beneficiaries dependent on aid work. Becoming accustomed to special aid during education can in the future lead to continued expecta-

¹⁴ Regulation of the Polish Ministry of Education of 13.03.2017 *on the classification of professions in vocational education*, Polish Journal of Laws of 2017, item no. 622.

¹⁵ Conf. S. Olszewski, K. Parys, *Rozumieć chaos. Rzecz o terminach i znaczeniach im nadawanych w pedagogice specjalnej*, Wydawnictwo Naukowe Uniwersytetu Pedagogicznego, Kraków 2016, pp. 169–171.

tions of aid from the outside, the feeling of helplessness, lack of belief in one's own capabilities, in the effectiveness of activities undertaken of own accord, cause passivity, even cause a sort of secondary disability. The consequences of these last threats seem to be the most pressing. They lead to resignation from activities facilitating development, the struggle to self-development.

Solutions used in the education of pupils with mild intellectual disability, however, create a chance to establish conditions facilitating the coping with the same requirements that are set for fully able pupils. The assumptions suggest that they allow efficient execution of education tasks, allow the experience of success, and, in the further perspective, preparation ahead of independent functioning in adult life with the label of disability. The presented assumptions are as logical and substantiated from the point of view of didactic indications as they consider the fluid movement from the stage dominated by outside aid to the stage of independent coping with requirements of the world. The gradual acquisition of independence in actions is in place to acquire in the end a form of functioning that remains in line with rules in force for the entirety of society, without the need of excess "specialising" aid.

It would be worthwhile if these assumptions didn't only remain in the area of theory, and if they actually constituted the basis for practical activity, in course of which the focus, and, at the same time, the key to effectiveness of progress would be placed in the period of education. In order for the activities undertaken in this period to be effective, in order for them to fulfil perspective objectives, they should be substantiated by understanding the foundations of actions, by seeking the sense of them, by the conviction of their reasonability and correctness.

Distinguishing label

The discrepancy between pupil capabilities and requirements of the school is a problem situation for all entities experiencing the discrepancy (pupil, parents, siblings, teachers, the peer group).

A chance of solving this problem is to name the problem and finding the causes that lie at its core. As a result of diagnostic work, a medical certificate may emerge that would confirm the need for special education, which begins to play the role of a *label*. The presence of a label in turn can cause diverse consequences, provoke the assignment of new meanings to the phenomenon that it describes, shape the perception of persons distinguished through the label and, through this, influence actions undertaken with them and with respect to them.

A different threat that must be tied to the diagnosis of disability can be difficulties in accepting the diagnosis, both by the person stigmatised in this way as well as by their environment. An expression of these difficulties may be shock, rebellion, consequently leading to resignation or undertaking excess activity.

The fact of acquisition of a medical certificate is related to the risk of the perception of such a person being dominated by the label that *marks* them. This may facilitate generalisation, as a result of which activities may be undertaken that are inadequate, not adapted to the capacities and needs of that person, and, hence, ineffective, such as: excess focus on the problem or unfounded reduction of requirements related to the imposition of development limitations, and, as a consequence, limiting development.¹⁶ Due to the way that such a label is treated by its users, the risk that its presence brings with itself can be related to the label functioning as a replacement of the process of getting to know the pupil, as an alibi or as a poison.

Treating the label as a replacement of the process of getting to know the pupil is equal to a weakening of the conviction of the need to know a person, any sort of omission of verification of the information included in the label. The label, formed as a result of specialised diagnostic work, may impose a specific mode of perceiving of

¹⁶ Conf. A. Sadownik, *Na rozstajnych drogach. Studium etnopedagogiczne kontrastowych karier szkolnych młodzieży*, Wydawnictwo Naukowe Dolnośląskiej Szkoły Wyższej, Wrocław 2011.

a person, excessively aligning daily diagnostic work or even contributing to it being simulated. Hence, the label may replace any reliable, comprehensive, development-oriented diagnosis of the education capacities and needs of aid.

The label functions as an alibi if its existence is perceived as the justification of the lack of effects of rehabilitation stemming from the use of improper solutions or the failure to undertake any actions at all. Responsibility for failure is shifted onto the disability, as a result of which "it becomes possible to treat individual events in pupil school careers as stemming specifically from intellectual disability".¹⁷

The label functions like poison of the awareness of its existence and of being perceived through the lens of the disability deepens or in certain times creates the conviction about one's own difference, more limited capabilities. Releasing, shaping and reinforcing low self-esteem, it may as a consequence lead to passivity or disturbances in behaviour. In case of persons with mild intellectual disability, the label of "intellectual disability" seems to be particularly hurtful. The state of self-awareness that these people have allows them to compare themselves with others, to evaluate themselves against the background of others, both belonging to the same group as well as to persons outside it. This comparison allows them to notice similarities and differences, and, as a result, build an image of themselves on the foundation of remaining identification with the group to which they were assigned. The unfavourable effect of comparisons, the awareness of own shortcomings, can cause or reinforce emotional difficulties aligning with the clinical presentation of mild intellectual disability.¹⁸

The consequences of the appearance of the label can be also seen in the emergence or reinforcement of the phenomenon of learned helplessness, or the demanding attitude. This phenomenon may

¹⁷ A. Sadownik, op. cit., p. 155.

¹⁸ Conf. R. Kościelak, *Psychologiczne podstawy rewalidacji upośledzonych umysłowo*, PWN, Warszawa 1989, p. 53.

concern not only people with disabilities, but also their environments. The effect of a label being assigned to a person may also cause their environment to undertake efforts at segregation, most likely leading to exclusion.

A label is distinguishing. However, this distinction need not necessarily be negative, it need not be a mark or stigma. One may even conclude that a label should not be considered branding at all, but stimulus generating specific expectations¹⁹, as a result of which development chances may arise for individuals distinguished in this way. Consideration of the label of intellectual disability in positive categories allows one to notice within it an ordering factor of reality that potentially facilitates development. This applies to many people who were branded in this way, including their families, teachers or even peers. The label „demands” or “claims” the person distinguished by it. It exposes this person, it attracts attention to them. The presence of the label is a chance at solving a problem, makes the possibility of success much more real. One must thus conclude that the label of intellectual disability can fulfil diverse, complementary and intertwining functions. Among these, one can name: the causative, informative, motivational, the ergonomisational and the protective function.

The label allows one to obtain aid, and, in case of certain types of aid, it is even necessary in order for it to be provided (causative function of the label). Without the branding it caused, it would be impossible, in the current education system, to organise and implement aid work. The disability label is related to specific privileged, for instance, the right to make use of solutions reserved for the selected group (special education, higher education financing).

The label is a form of message concerning the causes of difficulties experienced by the given person (informative function of the label). Diagnosing of intellectual disability makes one aware of the

¹⁹ G. Stobart, *Czy psychologia potrafi uzasadnić ideę integracji dzieci o specjalnych potrzebach?*, [in:] *Integracja dzieci o specjalnych potrzebach. Wybrane zagadnienia etyczne*, ed. by G. Fairbairn, S. Fairbairn, CMPPP, Warszawa 2000, p. 56.

source of the problem, shifts responsibility for the emergence of difficulties from the person to the disability that was assigned to them.

The emergence of the label causes interest in the labelled person, mobilises one to make an effort, obligates one to undertake action, forces activity of all the participating entities (motivational function of the label).

The label creates a chance at ergonomisation of activities (ergonomising function of the label), allowing the creation of homogeneous groups. It thus becomes simpler to seek solutions suitable for the needs of all persons making up the relevant group. At the same time, this group creates a much more real chance at individualisation of influences than a heterogeneous group. In addition, from the point of view of education authorities, the presence of a label allows the estimation of the resources that are necessary. The functioning of the label "introduces greater system clarity and facilitates the evaluation of its efficiency, and finally – a fact that cannot be underappreciated – it simplifies the execution of scientific research in the area of special education".²⁰

The presence of the label secures each component of the school system against the voluntarism of teachers in terms of organisation of activity, selection of curriculum assumptions, forms of work and methods of education of disabled pupils²¹ (protective function of the label).

Discovery time

A symptom leading to the discovery of mild intellectual disability are difficulties experienced by the pupil during the execution of tasks imposed by requirements of the curriculum. The expansion of

²⁰ A. Firkowska-Mankiewicz, G. Szumski, *Pedagogika specjalna i system kształcenia osób z niepełnosprawnościami w Polsce*, [in:] D.D. Smith, *Pedagogika specjalna*, vol. 2, Wydawnictwo APS, Wydawnictwo Naukowe PWN, Warszawa 2008, p. 335.

²¹ A. Firkowska-Mankiewicz, G. Szumski, op. cit., p. 335.

education requirements at subsequent stages of education causes that the group of pupils that are unable to cope with these requirements becomes more and more numerous, as a result of which diagnostic work is being undertaken²² that more often than not leads to the conclusion of mild intellectual disability. In relation to the above, along with the individual stages of education, the number of pupils with certified mild intellectual disability rises.²³ Diagnosing this disability takes place at different stages in course of education²⁴ sometimes only during vocational education. Irrespective of the time, when the diagnosis of mild intellectual disability is conducted, it must be concluded that it is a late diagnosis. It is usually performed following the period when the brain's flexibility is greatest.²⁵ Hence, it may be difficult to seek solutions stimulating development suitably early on so as to counteract the solidification of existing problems in functioning. As a consequence of late diagnosis, and, hence, the lack of suitably early rehabilitation work, a sort of "vicious cycle of pathology" may perhaps be started up, some "empty years" can emerge in the education process – years that go wasted from the point of view education and development stimulation.²⁶

The time of diagnosis also constitutes a factor conditioning the mode of reception of the diagnosis, and, accordingly, the actions undertaken as a result. The later the diagnosis is made, the more probable becomes the awareness of shortcomings, the lack of belief in the possibility to make up for the lost time, resulting in discouragement, passivity. A different rule, however, may also take hold. It is founded on the struggle to make up for the accrued backlog at all cost, and expresses itself through hyperactivity entailing the

²² It must be noted that diagnostic work may be initiated only following the motion of the parents, legal custodians or the pupil themselves.

²³ A. Firkowska-Mankiewicz, G. Szumski, op. cit., p. 336.

²⁴ A. Sadownik, op. cit., p. 108.

²⁵ O. Speck, *Niepełnosprawni w społeczeństwie. Podstawy ortopedagogiki*, Gdańskie Wydawnictwo Psychologiczne, Gdańsk 2005, pp. 443–444.

²⁶ M. Kościelska, op. cit., p. 103.

acceptance or initiation of tasks exceeding the current capacities of the individual.

It is a paradox that late diagnosis of mild intellectual disability may also have positive consequences. The later the defining label emerges, the shorter it will cause stigma, the more difficult it is to "settle in" into disability, the lower the risk of identification with the disability, and the transformation of identity will be less permanent. The risk of perception of that person through the lens of the disability that accompanies them becomes lower, and will be more delayed in time.

Properties of the population of people with mild intellectual disability

Population size

Mild intellectual disability concerns the largest group within the population of disabled pupils²⁷ as compared to other types of disabilities. At this stage of compulsory education, every third disabled pupil is a pupil with mild intellectual disability (conf. table 1).

Considering potential opportunities and threats that are provoked by the ubiquity of the phenomenon, one must note that mild intellectual disability, specifically due to its ubiquity, is a social problem. As a result, this phenomenon cannot be omitted, glossed over or downplayed. This in turn should imply searching for organisational and legal, didactic and educational as well as rehabilitation solutions foreseen for the discussed group of people. In addition, the ease of access to persons with mild intellectual disability makes undertaking research exploration much more probable. The fact of ubiquity of the phenomenon should also be tied mainly to its cost intensity, generation of a higher volume of resources that allow the

²⁷ A discussion only with respect to pupils substantiates the fact that the diagnosis of mild intellectual disability is made only for education purposes.

Table 1. Number of pupils belonging to individually distinguished groups due to the type of disability – obligatory education stage (primary and lower secondary schools)

	2015/2016		2016/2017		2017/2018	
	N	%	N	%	N	%
Deaf	1182	1.1	1094	1	1088	0.9
Hard of hearing	6748	6.4	6939	6.3	7351	6.3
Blind	153	0.2	149	0.1	133	0.1
Visually impaired	5684	5.4	5763	5.3	6051	5.2
Persons with mobility disability, including aphasia	10 272	9.8	11 203	10.2	12 630	10.9
Persons with mild intellectual disability	33 704	32.1	33 726	30.8	33 670	29
Persons with moderate or significant intellectual disability	15 921	15.2	14 895	13.6	13 970	12.1
Persons with autism, including Asperger syndrome	12 458	11.9	15 627	14.3	19 542	16.9
Persons with multiple disabilities	18 790	17.9	20 005	18.3	21 537	18.6
Total	104 912	100	109 401	100	115 972	100

Source: own work based on *Oświata i wychowanie w roku szkolnym 2015/2016*; *Oświata i wychowanie w roku szkolnym 2016/2017*; *Oświata i wychowanie w roku szkolnym 2017/2018*.

securing, appropriately for a large population, of the education process. The ubiquity of the phenomenon, when it is studied and analysed, can contribute to its ‘normalisation’, both in the social as well as in the individual perception. There is no doubt that this encourages acceptance of disability, and reduces the consequences of branding. At the same time, persons with mild intellectual disability have a chance at not feeling alienated. The ubiquity of the phenomenon, however, may at the same time result in acquaintance with the problem, the emergence of passivity with respect to it, and, as a result, ignorance towards it.

Selected bio-psycho-social properties of persons with mild intellectual disability – an aggregated view of the population

The consideration of properties of functioning of a specific group of people bears with itself the risk of making simplifications, generalisations. Not all properties assigned to persons with mild intellectual disability emerge with the same intensity in each person diagnosed as having mild intellectual disability. Some of the discussed properties are primary characteristics, some are their derivatives, making up the consequences of interactions of primary characteristics and properties of the environment.

The majority of indicated properties is usually considered unilaterally as undesirable properties, hindering functioning in the environment, threatening one's development. It is, however, worth thinking, whether this is the only possible mode of looking at these properties, could they not perhaps bring with themselves a chance of development, of good functioning, or even fulfil the role of a unique stimulator in the difficulties of development. Such a perception, however, requires the reality around us to be provided with different meanings, it requires breaking with stereotypes, changes to the solidified mode of thinking about man, the reevaluation of expectations against them, their deuniformisation. In persons with mild intellectual disability, the act of transforming the earnings of selected bio-psycho-social properties allowed them to be seen not only as threats, but also as opportunities (table 2).

Table 2. List of potential opportunities and threats generated by way of bio-psycho-socially properties of persons with mild intellectual disability

Consequences Properties	Threats	Opportunities
No visible differences in external appearance, disability invisible	failure to see lesser opportunities, making unreasonable demands	removal of the risk of stigmatisation, one's image doesn't constitute a factor decisive for the removal
Disturbances to orientation and cognition processes	risk of education failures, The limitation of possibilities with respect to one's education career, some of its ranges, commonly associated to	The resources held: <ul style="list-style-type: none"> - do not indicate functional illiteracy - allow self-realisation, independent and good functioning in life com-

Consequences Properties	Threats	Opportunities
	success in line (higher education, occupations allowing one to acquire a higher social status), become unavailable.	manding respect in life; they prevent exclusion. The quality of functioning in reality are also decisive for other properties, e.g. emotional intelligence, which for the discussed group does not have to be impacted upon.
Domination of re-creative imagination over creative imagination	difficulty undertaking creative activities, blocking of these by the tendency towards acting according to routines, higher helplessness in new situations	reliance on the experienced situations, realism of thinking, of acting, protects against removal from reality in the perception of the same, against escape into a world of fiction, fantasy
Well-functioning mechanic memory	difficulty making logical connections between phenomena noticed earlier. Reduced memory capacity prevents the collection of content necessary for efficient functioning in various situations	possibility of learning and effectively recalling information as well as repetitive, schematic skills allowing the automation of actions
Ability to make comparisons, noticing imperfections in own functioning	low self-esteem, frustration, passivity	Ability to make comparisons allows the acquisition of information and skills. Noticing imperfections of own actions can form mobilisation to undertake the effort necessary for development
Difficulty in the estimation of consequences of own actions	risk of taking reckless, risky actions, and, as a consequence, risk of making errors, risk of becoming the object of ridicule, risk of failure	Higher courage in action, no blocks or limitations crossing borders, taking risks that might end in success
Holding on to routines in thinking and in actions	- difficulty adapting to changes, acquiring new skills (e.g. difficulty requalifying in work) - holding on to fixed habits	chance of social acceptance, of solidified modes of thinking and of acting enjoy social approval, failure to consider acquired, fixed rules, modes of thinking and acting, not questioning them helps to understand the world, bring reality in order, gives rise to a feeling of safety repetitive activities ending in success gain the approval of the executor and the environment
Frequent failures	blocking diagnostic information about own capacities and skills, forgoing activity, low general success expectation level, expectation of failure reducing the capaci-	under the right conditions (own motivation, favourable ambient reactions) it may result in multiple attempts, shape the perseverance towards achieving goals, resistance to difficult situations,

Consequences Properties	Threats	Opportunities
	ty to oppose difficulties, reduction of self-esteem	the ability to cope with negative emotions, teaches valuing success, joy of achievements possibility of analysing the causes of failures, drawing conclusions, learning from errors
Lack of faith in the possibility of success	passivity, avoiding task-based coping strategies	protection of self-esteem against its reduction, dismay
Domination of an external feeling of control, susceptibility to outside influences	susceptibility to socially unacceptable environmental influences lack of initiative, passivity, solidification and expansion of learned helplessness	respecting the attitudes of others dispositions for the effective functioning as executor of commands
In case of encountering difficulties - usage of avoidance strategies (changing the topic, engaging in replacement activity)	inability to solve problems, reduction to replacement solutions	Ability to reduce emotional tension, protection against failure, emerging problems
Feeling of own disability	awareness of limitations leading to passivity, lack of faith in own power, feeling of helplessness, even frustration and the feeling of injustice	chance at a rational suitable evaluation of own resources and shortcomings planning activity according to own capacities that could lead to avoidance of failure or even to success in activities

Source: own work.

The executed analysis makes one aware of the possibilities that can lie in negatively valuated properties of persons with mild intellectual disability, and shows that in certain situations these properties can become assets. The suggested mode of thinking allows one to tame this difference, this *otherness*, and notice in the described properties a chance at changing the environment by perfecting its actions, by undertaking uncommon methods of work, by increased flexibility of utilised resources and at the same time the expansion of their range.

Inter-group differentiation

The group of pupils with mild intellectual disability is not homogeneous; it is made up by persons representing various levels of psycho-social functioning, from a level similar to the one characterising persons in the intellectual norm, all the way to a level more like persons with deeper intellectual disability. The heterogeneity within the group is also influenced by differentiation of individual and environmental resources. As a result, even among pupils representing a comparable level of functioning one could find people exhibiting dysfunctions of various intensity (from the clear ones that significantly hinder functioning, to lighter ones that are barely noticeable) as well as persons experiencing different levels of care by the environment (persons not cared for by their environment as well as those experiencing a lot of support from the environment they function in). Awareness of this rule forces one to note both individual persons making up a group as well as subgroups distinguished due to various criteria. It is only on this basis that it becomes possible to undertake activities corresponding to the needs of these persons and subgroups.

The existence of differences within the group, making up a particularly significant factor from the point of view of organising and executing educational activity and its effectiveness, provokes one to voice their opinion on the issue of individualisation. This opinion may be placed along a continuum, the ends of which are described by opposing modes of perception of mild intellectual disability. One end can be identified with maximum individualisation, focusing only on differences, stressing uniqueness, with the other describing generalisation related to noticing exclusively similarities, downplaying differences, completely omitting individualisation.

Individualisation of influences utilised in the work with persons with mild intellectual disability creates an opportunity at adapting work to the needs and capacities of these persons, their subjective treatment, and, accordingly, the hope for real effectiveness of the relevant procedures. At the same time, however, individualisation

may be a factor hindering development, threatening well-being; indeed, due to the consequences that emerge in stressing existing differences, individualisation can be seen as a factor facilitating stigmatisation, isolation, a factor that could shape helplessness²⁸ or even egotistical or demanding attitudes.

Inter-group differentiation may also form a unique asset. It motivates through the possibility of referring to examples of persons included in the same group, conquering limitations, achieving successes, being examples to be followed. It can encourage not only pupils, but also their parents or teachers, to make an effort.

It must be noted, however, that the use of individualisation, due to the context that accompanies it, may prove to be too difficult, even impossible to execute. Its implementation requires preparation, thoroughness, skill, knowledge and time.

Closeness to the norm – no uniqueness, no spectacularity

Greater similarity to the norm than in case of persons with other disabilities, lack of clear symptoms that are associated solely with intellectual disability, make mild intellectual disability invisible to the environment, and, hence, illegible. The indicated situation may provoke the emergence of wrong environmental attitudes, expressed as erroneous evaluations or through the lack of interest leading to failure to note the problem and to neglect it.

Within this context, it is worth recalling the relationship between the clear presentation of disability and the number of years of delay in education, as noted by Małgorzata Kościelska who analysed the situation of pupils attending special schools.²⁹ The mentioned author formulates and considers the following thesis: the clearer the symptoms of disability are for the environment, the low-

²⁸ Z. Gajdzica, *Antynomie edukacji integracyjnej – od idei do praktyki*, [in:] *Integracja edukacyjna. Oczekiwania i rzeczywistość*, ed. by M. Klaczak, Wydawnictwo Naukowe Uniwersytetu Pedagogicznego, Kraków 2010, pp. 15-16.

²⁹ M. Kościelska, op. cit., p. 102.

er the delay in education as expressed in years. Kościelska explains the indicated rule by earlier undertaking of diagnostic and rehabilitation work in case of disability that is more clearly seen. Referring to this explanation, one could conclude that aid becomes clearer in a situation, if difficulties emerge more clearly. It is their visibility, and, hence, readability, that implies the reactions of the environment.

The lack of spectacularity of the presentation of mild intellectual disability may reduce the motivation to make an effort, and may also be the cause, or the justification, of the failure to undertake diagnostic and rehabilitation work. In addition, the invisibility of the described disability makes failures or lack of success in work with persons with mild intellectual disability difficult to accept by the environment.

On the other hand, a consequence of the lack of spectacularity may be lack of interest, protecting against activities that stigmatise this group of people. As a result of the failure to note the difference, the tendency to focus on similarities to the norm becomes clear, facilitating the treatment of persons with mild intellectual disability just like others, without differentiating them, “[s]ocial expectations of them will hence be analogous as those of the general population”.³⁰ These expectations may be expressed both in the formulated objectives of education as well as the resources of execution. A situation of this kind may form a hazard factor if expectations are excessive, exaggerated or constitute a chance at development, if expectations fit in with the capacities of the person. Failure to individualise activities undertaken with respect to persons with mild intellectual disability, failure to stress their uniqueness, failure to brand them, all of this allows the stimulation of development, the activation of available potential. A slight difference from the norm in case of the discussed group of persons causes that work with

³⁰ B. Jachimczak, *Spółeczno-edukacyjne uwarunkowania startu zawodowego młodych osób niepełnosprawnych. Studium empiryczne z regionu łódzkiego*, Oficyna Wydawnicza „Impuls”, Kraków 2011, p. 143.

these persons does not require one to undertake any sort of excess additional effort related to searching for different, specialised solutions that could be applied with respect to persons with other disabilities. The task that is to be faced when commencing work with persons with mild intellectual disability usually entails the implementation of standard solutions. However, one cannot exclude the necessity to introduce necessary modifications, in terms of the implemented solutions or the modes of their application.

The fact that differences in biopsychosocial functioning of persons with mild intellectual disability is not as clearly visible as is the case in persons with other disabilities, reinforces the probability of cooperation, and even allows one to undertake a challenge on equal footing, enabling success at the same time. Thanks to this, the risk of alienation is reduced, and the perception of difference – less threatening.

Bibliography

- [1] Firkowska-Mankiewicz A., Szumski G., *Pedagogika specjalna i system kształcenia osób z niepełnosprawnościami w Polsce*, [in:] *Pedagogika specjalna*, vol. 2, ed. by D.D. Smith, Wydawnictwo APS, Wydawnictwo Naukowe PWN, Warszawa 2008, pp. 319–346.
- [2] Gajdzica Z., *Antynomie edukacji integracyjnej – od idei do praktyki*, [in:] *Integracja edukacyjna. Oczekiwania i rzeczywistość*, ed. by M. Klaczak, Wydawnictwo Naukowe Uniwersytetu Pedagogicznego, Kraków 2010, pp. 8–19.
- [3] Jachimczak B., *Spoleczno-edukacyjne uwarunkowania startu zawodowego młodych osób niepełnosprawnych. Studium empiryczne z regionu łódzkiego*, Oficyna Wydawnicza „Impuls”, Kraków 2011.
- [4] Communication of the general manager of the Polish Central Examination Board of August 20th, 2018 on the detailed modes of adaptation of conditions and forms of execution of exams of primary school eight-graders and the lower secondary school exam in the academic year 2018/2019, <https://cke.gov.pl/images/_KOMUNIKATY/20180820%20E8%20EG%20Komunikat%20o%20dostosowaniach.pdf> [access: 13.05.2019]
- [5] Communication of the general manager of the Polish Central Examination Board of August 20th, 2018 on the detailed modes of adaptation of conditions

- and forms of execution of exams confirming professional qualifications in the academic year 2018/2019, <https://cke.gov.pl/images/_KOMUNIKATY/20180820%20EZ%20Komunikat%20o%20dostosowaniach.pdf> [access: 13.05.2019].
- [6] Kościelak R., *Psychologiczne podstawy rewalidacji upośledzonych umysłowo*, PWN, Warszawa 1989.
- [7] Kościelska M., *Upośledzenie umysłowe a rozwój społeczny. Badania uczniów szkół specjalnych*, PWN, Warszawa 1984.
- [8] Olszewski S., Parys K., *Rozumieć chaos. Rzecz o terminach i znaczeniach im nadawanych w pedagogice specjalnej*, Wydawnictwo Naukowe Uniwersytetu Pedagogicznego, Kraków 2016.
- [9] *Oświata i wychowanie w roku szkolnym 2015/2016*, Statistics Poland, Warszawa 2016.
- [10] *Oświata i wychowanie w roku szkolnym 2016/2017*, Statistics Poland, Warszawa 2017.
- [11] *Oświata i wychowanie w roku szkolnym 2017/2018*, Statistics Poland, Warszawa 2018.
- [12] Parys K., *Osoby z diagnozą upośledzenia umysłowego w stopniu lekkim – w kręgu pytań i odpowiedzi*, [in:] *Poznajemy ludzi z niepełnosprawnością*, ed. by D. Gorajewska, Stowarzyszenie Przyjaciół Integracji, Warszawa 2007, pp. 11–23.
- [13] Regulation of the Polish Ministry of Education of 14.02.2017 *on the pre-school curriculum and the basic curriculum for primary schools, including for pupils with moderate or major intellectual disability, the curriculum of general education for industry branch-specific first level schools, general education for special schools preparing for work and general education for post-secondary schools*, Polish Journal of Laws of 24.02.2017, item no. 356.
- [14] Regulation of the Polish Ministry of Education of 13.03.2017 *on the classification of professions in vocational education*, Polish Journal of Laws of 2017, item no. 622.
- [15] Regulation of the Polish Ministry of Education of 28.03.2017 *on the framework curricula for public schools*, Polish Journal of Laws of 31.03.2017, item no. 703.
- [16] Regulation of the Polish Ministry of Education of 9.08.2017 *on the conditions of organisation of education, upbringing and care for disabled, socially maladapted and threatened by social maladaptation children and youths*, Polish Journal of Laws of 2017, item no. 1578
- [17] Regulation of the Polish Ministry of Education of 9.08.2017 *on the rules of organisation and provision of psychological and paedagogical aid at public preschools, schools and related institutions*, Polish Journal of Laws of 2017, item no. 1591.
- [18] Sadownik A., *Na rozstajnych drogach. Studium etnopedagogiczne kontrastowych karier szkolnych młodzieży*, Wydawnictwo Naukowe Dolnośląskiej Szkoły Wyższej, Wrocław 2011.
- [19] Speck O., *Niepełnosprawni w społeczeństwie. Podstawy ortopedagogiki*, Gdańskie Wydawnictwo Psychologiczne, Gdańsk 2005.

- [20] Stobart G., *Czy psychologia potrafi uzasadnić ideę integracji dzieci o specjalnych potrzebach?*, [in:] *Integracja dzieci o specjalnych potrzebach. Wybrane zagadnienia etyczne*, ed. by G. Fairbairn, S. Fairbairn, CMPPP, Warszawa 2000, pp. 49–63.
- [21] Szumski G., *Integracyjne kształcenie niepełnosprawnych*, Wydawnictwo APS, Wydawnictwo Naukowe PWN, Warszawa 2009.



Assessment of the capacity to create and understand wordbuilding structures by a child with minor intellectual disability

ABSTRACT: Mateusz Szurek, *Assessment of the capacity to create and understand wordbuilding structures by a child with minor intellectual disability*. Interdisciplinary Contexts of Special Pedagogy, no. 26, Poznań 2019. Pp. 39–58. Adam Mickiewicz University Press. ISSN 2300-391X. DOI: <https://doi.org/10.14746/ikps.2019.26.02>

The research conducted on language of children with intellectual disability (ID) shows that they exhibit language dysfunctions on every level of language. Up to now, literature did not include linguistic studies concerning issues of wordbuilding in the language consciousness of pre-school children with intellectual disability. The objective of the article is the assessment of the level of wordbuilding competences of a child at pre-school age with minor intellectual disability (MID) concerning the creation and comprehension of nominal derivatives in the area of selected wordbuilding categories (case study). In addition, the author wishes to stress that the assessment of the level of wordbuilding competences should be a component on comprehensive logopaedic diagnosis.

KEY WORDS: intellectual disability, word formation, word formation competences

1. Wordbuilding competence tests

In foreign-language literature, a popular experiment aimed at testing the level of acquisition of wordbuilding rules by children was the *WUG study* conducted by Jean Berko¹ (the author tested

¹ J. Berko, *The child's learning of English morphology*, "Word" 1958, no. 14, pp. 150–177.

capacities spanning the creation of nominal diminutives, names of actors in activities, nominal adjectives and compound nouns). Wordbuilding structures were also handled e.g. by *Eve Clark* and *Ruth Berman*.² All studies concerned exclusively children in the intellectual norm.

In Poland, wordbuilding in linguistics was analysed by e.g. *Maria Chmura-Klekotowa*³ (she collected material made up of 5000 examples of wordbuilding neologisms), *Maria Zarębina*⁴ (described the creation of the child's language system and conducted an analysis of texts created by children at pre-school age and younger), *Halina Zgółkowa*⁵ (described the functions of neologisms in the development of language in preschool-age children), *Ewa Muzyka-Furtak*⁶ (analysed and assessed the capacities to comprehend and create wordbuilding structures by deaf children), and in terms of psycholinguistics and psychology – e.g. by *Ewa Haman*⁷ and *Amelia Dzi-*

² E.V Clark., R.A. Berman, *Structure and use in the acquisition of word formation*, "Language" 1984, no. 60, pp. 542-590; E.V Clark, R.A. Berman, *Types of linguistic knowledge: interpreting and producing compound nouns*, "Journal of Child Language" 1987, no. 3(14), pp. 547-567.

³ M. Chmura, *Uwagi o rozwoju mowy dziecka*, „Poradnik Językowy” 1962, no. 9-10, pp. 449-456; M. Chmura-Klekotowa, *Neologizmy słowotwórcze w mowie dzieci*, „Poradnik Językowy” 1968, no. 1, pp. 19-25; M. Chmura, U. Napiórkowska, J. Nowak, *Z badań nad słownictwem dziecka rozpoczynającego naukę szkolną*, „Życie Szkoły” 1970, no. 7-8, pp. 21-26; M. Chmura-Klekotowa, *O różnicach w zasobie słownikowym dziecka siedmioletniego i dwunastoletniego*, „Prace Filologiczne” 1975, no. 25, pp. 239-242.

⁴ M. Zarębina, *Kształtowanie się systemu językowego dziecka*, Wyd. Ossolineum, Wrocław 1965; M. Zarębina, *Rola wyrazów w słowniku i w tekście (na materiale polskim)*, „Język Polski” 1970, p. 43; M. Zarębina, *Język polski w rozwoju jednostki. Analiza tekstów dzieci do wieku szkolnego. Rozwój semantyczny języka dziecka*, Wydawnictwo Naukowe WSP, Kraków 1980.

⁵ H. Zgółkowa, *Funkcje neologizmów w rozwoju języka dzieci przedszkolnych*, [in:] *Język osobniczy jako przedmiot badań lingwistycznych*, ed. by J. Brzeziński, Wydawnictwo Wyższej Szkoły Pedagogicznej w Zielonej Górze, Zielona Góra 1988, pp. 259-276.

⁶ E. Muzyka-Furtak, *Konstrukcje słowotwórcze w świadomości językowej dzieci niestyszących*, Wydawnictwo Uniwersytetu Marii Curie-Skłodowskiej, Lublin 2010.

⁷ E. Haman, *Słowotwórstwo dziecięce w badaniach psycholingwistycznych*, „Język. Poznanie. Komunikacja” 2013, vol. 19, Warszawa.

urda-Multan.⁸ All quoted studies were conducted exclusively among children in the intellectual norm.

Up to now, subject literature did not include broad linguistic studies dealing with wordbuilding structures in the consciousness of children with ID.⁹ Issues concerning wordbuilding in children with MID are at the stage of preliminary development.¹⁰

The conducted research on language of children with ID shows that they exhibit language disorders on every level of language¹¹, hence, in the area of wordbuilding. The acquisition of wordbuilding rules and categories is closely tied to one's cognitive categories. Even though relations in the acquisition of cognitive and wordbuilding categories are noted, they were not analysed in detail until now – attempts were only made to discern between concept categories that are expressed in the Polish language by wordbuilding.¹² Beside close ties between the acquisition of wordbuilding rules and cognitive functioning, mechanisms and techniques of derivation, which

⁸ A. Dziurda-Multan, *Dziecięce sposoby tworzenia nazw*, Wydawnictwo KUL, Lublin 2008.

⁹ The researchers described language disorders in children with ID, however no study takes on issues concerning wordbuilding competences. Researchers working with the development of speech in children with ID include: A. Szuniewicz (1967), E. Minczakiewicz (1984, 1989, 1993a, 1993b, 1994), S. Sadowska (2006), L. Bleszyńska (2006), Z. Tarkowski (1988), H. Nadolska (1993, 1994), J. Bałachowicz and J. Paluszewski (1995), A. Rakowska (2003), U. Jęczeń (2005, 2007), M. Michalik (2006, 2011), K. Kaczorowska-Bray (2013, 2017), D. Krzemińska (2012), J. Bleszyński (2013, 2016), A. Wątopek (2014).

¹⁰ R. Marciniak-Firadza, *Kilka uwag o potrzebie badań kompetencji słowotwórczych dzieci z niepełnosprawnością intelektualną w stopniu lekkim „Interdyscyplinarne Konteksty Pedagogiki Specjalnej”* 2016, no. 14, pp. 29–51.

¹¹ J. Bleszyński, K. Kaczorowska-Bray (ed.), *Diagnoza i terapia logopedyczna osób z niepełnosprawnością intelektualną*, Wydawnictwo Harmonia Universalis, Gdańsk 2012.

¹² B. Szymanek, *Categories and categorization in morphology*, Wydawnictwo KUL, Lublin 1988; R. Grzegorzczkowska, B. Szymanek, *Kategorie słowotwórcze w perspektywie kognitywnej*, [in:] *Współczesny język polski*, ed. by J. Bartmiński, Wydawnictwo UMCS, Lublin 2001.

serve the creation of new words, are significant for the purpose of analyses of specific properties of acquisition of wordbuilding categories.¹³

2. Speech development in children with MID

Children with MID go through the same stages of speech development as children in the intellectual norm. In children with MID, however, it is characteristic for the individual stages to appear at a reduced pace and last longer than in their peers in the norm.¹⁴ The majority of preschool-age children is able to master the phonological, semantic and syntactic systems of a language, and thanks to the language resources at their disposal, they are able to initiate and maintain dialogue (make social contacts).¹⁵ Children understand statements by adults well.

The delayed development of speech in children with MID is expressed, among others, by the following:

- persistent incorrect articulation,
- slow pace of vocabulary acquisition,

¹³ A. Heinz, *Fleksja a derywacja*, „*Język Polski*” 1961, no. XLI(5), pp. 343–354.

¹⁴ A. Rakowska, *Język – komunikacja – niepełnosprawność. Wybrane zagadnienia*, Wydawnictwo Naukowe Akademii Pedagogicznej, Kraków 2003; E. Kulesza, *Rozwój poznawczy dzieci z lekkim i umiarkowanym stopniem upośledzenia umysłowego – diagnoza i wspomaganie. Studia empiryczne*, Wydawnictwo APS, Warszawa 2004; K. Kaczorowska-Bray, *Zaburzenia komunikacji językowej w grupie osób z niepełnosprawnością intelektualną*, [in:] *Diagnoza i terapia logopedyczna osób z niepełnosprawnością intelektualną*, ed. by J. Bleszyński, K. Kaczorowska-Bray, Wydawnictwo Harmonia Universalis, Gdańsk 2012, pp. 36–64.

¹⁵ H. Nartowska, *Opóźnienia i dysharmonie rozwoju dziecka*, Wydawnictwo WSiP, Warszawa 1980; A. Rakowska, *Język – komunikacja – niepełnosprawność. Wybrane zagadnienia*, Wydawnictwo Naukowe Akademii Pedagogicznej, Kraków 2003; K. Kaczorowska-Bray, *Zaburzenia komunikacji językowej w grupie osób z niepełnosprawnością intelektualną*, [in:] *Diagnoza i terapia logopedyczna osób z niepełnosprawnością intelektualną*, ed. by J. Bleszyński, K. Kaczorowska-Bray, Wydawnictwo Harmonia Universalis, Gdańsk 2012, pp. 36–64.

- reduced verbal activity,
- difficulty constructing correct sentence structures,
- persistent agrammatisms,
- difficulty speaking spontaneously on a given subject.¹⁶

The vocabulary of a child with MID is poor in abstract terms, as these people do not understand their meaning, hence, they do not take them up into their vocabulary resources.

3. Methodology and subject of own research

The present article constitutes a qualitative analysis of statements by a single child, and it is but an introduction to further extensive research on wordbuilding competences of pre-school children with MID.

3.1. The characteristics of the analysed child

The girl was born in 2012. On the day of the assessment, she was six years and 10 months old. On the basis of a psychological examination, using the *WISC-R* (*Wechsler Intelligence Scale for Children*), it was concluded that the intellectual functioning of the child hovers around mild intellectual disability. The medical statement concerning the need for special education concluded that the MID is most probably the result of the numerous illnesses that the child was diagnosed with. The supplied hospital medical information sheets of the girl indicate that her health significantly affects her cognitive and intellectual development. After an MRI examination of the head, the stabilisation of the optic nerve glioma and of the dysplastic changes within the scope of von Recklinghausen disease was found to have become stable. In addition, the child remains under the care of a neurological practice due to epilepsy, and of a vascular

¹⁶ A. Rakowska, *Język – komunikacja – niepełnosprawność. Wybrane zagadnienia*, Wydawnictwo Naukowe Akademii Pedagogicznej, Kraków 2003, p. 127.

disease specialist due to the condition after deep vein thrombosis of the right extremity. The child attends an integration pre-school, also attended by children in the norm and with specific education needs¹⁷ (e.g. children with MID or with autism).

3.2. Object of research

The object of the analyses are suffix-based noun derivatives created on the basis of various parts of speech (e.g. nouns, verbs and adjectives), representing individual wordbuilding categories. Using classic and still valid linguistic works by Renata Grzegorzczkova and Jadwiga Puzynina¹⁸, the article analyses exclusively mutation derivatives in the following wordbuilding categories: names of activity actors, names of tools, places, products and objects of activities, names of entities bearing specific properties. Names of sets, inhabitants and family relations were omitted due to low productivity in colloquial speech.

3.3. Research tool

Due to the fact that there are no databases of questionnaires, surveys, tests or developed experimental models for testing of wordbuilding competences of children with MID, the study required the creation of a wordbuilding questionnaire on the basis of

¹⁷ The author purposefully uses the term *specific needs* in lieu of the term common in literature – *special needs* – thus arguing in favour of Marzena Zaorska. The researcher states that the term *special* is not fitting, because the global needs of every person are the same, and this *speciality* applies solely to the scope, methods and forms of fulfilment of these needs. In addition, this term is less stigmatising (M. Zaorska, *Aktualne problemy edukacji i rehabilitacji osób z niepełnosprawnością sprzężoną*, „Niepełnosprawność” 2012, no. 7, pp. 9–24).

¹⁸ R. Grzegorzczkova, J. Puzynina, *Problemy ogólne słowotwórstwa. Rzeczownik*, [in:] *Gramatyka współczesnego języka polskiego. Morfologia*, ed. by R. Grzegorzczkova, R. Laskowski, H. Wróbel, Wydawnictwo Naukowe PWN, Warszawa 1999, pp. 361–468.

already developed references.¹⁹ It was composed of two parts – the first one, used to test comprehension, and the second one, used to test the production of wordbuilding structures. The skills in the comprehension of structures was tested using the technique concerning the formulation of a wordbuilding paraphrase, and the skill of production of structures using the technique entailing the recognition of derivatives – on the basis of the presented wordbuilding paraphrase.

3.4. Test procedure

The test was conducted in a quiet room, without the participation of third parties. Due to difficulties in longer-term attention focus in children with ID, and in order to eliminate the probability of a sudden drop in motivation due to fatigue, the test was subdivided into two meetings. According to the rules of skill acquisition in course of language acquisition, understanding structures precedes creation. The research work, however, was conducted in the reverse order. During the first diagnostic session, tested was the skill of production, and during the second – the ability to comprehend. The break between the assessments was at least two weeks, preventing the emergence of the child remembering the wordbuilding structures or modes of their creation discussed during the first meeting, and preventing them from repeating the same formants and analogous modes of production during the second session. The entire test lasted 40 minutes. The tasks from the questionnaire were read to the child, who would then respond. During the test, every effort was made for the child to have the best possible work conditions and to feel free; attempts were made to encourage her linguistic creativity, and she was encouraged to produce wordbuilding structures. The

¹⁹ During development of the questionnaire, wordbuilding assessment methods were used as described and developed e.g. by E. Muzyka-Furtak (2010). The author worked with wordbuilding structures in the language consciousness of deaf children.

study proper was preceded by a so-called “wordbuilding warm-up”, which was meant to help the child comprehend the tasks from the questionnaire and invoke their wordbuilding creativity.

4. Analysis of the material

4.1. Assessment of comprehension of wordbuilding structures belonging to the individual wordbuilding categories – the capacity to produce wordbuilding paraphrases

Comprehension (decoding) is a formal-semantic analysis of structures; decoding the meanings of the constituent components of a formation; interpreting wordbuilding structures, according to social conventions and own experiences; the ability to produce a wordbuilding paraphrase indicating semantic reactions between the basic word and the derivative, thanks to the indication of the constituent components of a formation.²⁰

The wordbuilding paraphrase is an analytical statement equivalent to the derivative, which contains the root word.²¹ The ability to create a wordbuilding paraphrase is identical to the ability to form sentences. Children with MID, due to dysfunctions of the syntactic efficiency of language, have trouble building correct sentences. This translates directly into the skill of creation of wordbuilding paraphrases. This does not mean, however, that persons with MID are not able to build paraphrases at all. They make efforts to define derivatives and discern their meaning. A confirmation of this thesis are examples collected during this assessment, which were analysed.

²⁰ B. Kreja, *Słowotwórstwo a problem tworzenia nowych wyrazów*, [in:] *Z zagadnień ogólnych polskiego słowotwórstwa. Studia 3*, ed. by B. Kreja, Wydawnictwo Uniwersytetu Gdańskiego, Gdańsk 2000, p. 192.

²¹ R. Grzegorzczkowska, J. Puzynina, *Problemy ogólne słowotwórstwa. Rzeczownik*, [in:] *Gramatyka współczesnego języka polskiego. Morfologia*, ed. by R. Grzegorzczkowska, R. Laskowski, H. Wróbel, Wydawnictwo Naukowe PWN, Warszawa 1999, p. 371.

During the formulation of the paraphrase, the patient used explications of the structural meaning (without components of the real, actual meaning), for instance:

<i>Polish-language original</i>	<i>Approximate English translation</i>
Jadalnia – <i>tam się je</i>	Eating room – <i>where you eat</i>
Samotnik – <i>to jest taki bardzo, bardzo, bardzo samotny</i>	Loner – <i>he is so very, very, very lonely</i>
Brzuchacz – <i>to jest taki, co ma brzucha</i>	Big-belly – <i>someone with a belly</i>
Wąsacz – <i>kto ma wąsy (a ja widziałam prawdziwego Mikołaja!)</i>	Moustache-face – <i>one with a moustache (and I saw the real Santa Claus!)</i>

The material used one example of use of explication of the structural meaning with components of the real meaning, for instance:

Pralnia – <i>to miejsce, gdzie nosi się ubrania, no i zamyka się, no i pierze się</i>	Laundry room – <i>it is a place where you wear clothes, and where you close, and where you do laundry</i>
---	---

Most commonly, however, during decoding, the patient indicated the root word with a component of the real meaning, for instance:

Sprzedawca – <i>sprzedaje nam jakieś tam mleko, ogórki, pomidory, sałatę, chrupki</i>	Seller – <i>somebody who sells us things like milk, cucumbers, tomatoes, salad, corn puffs</i>
Sprzątaczką – <i>która sprząta; może sprzątać podłogę, okna, kurze, szybę żeby była czysta (moja mama myje wszystko, nawet szafy)</i>	Cleaning lady – <i>who cleans; she can clean the floor, the windows, the dust, the window, so that it is clean (my mum washes everything, even wardrobes)</i>
Nauczyciel – <i>uczy pływać dzieci, skakać, skakać wysoko</i>	Teacher – <i>teaches children to swim, to jump, jump high</i>
Śpiewak – <i>śpiewa wlaź kotek, ogórek kiszony (ogórek, ogórek zielony ma garniturek...), może śpiewać pieski małe dwa, jagódki</i>	Singer – <i>sings row row, bus wheels (the wheels on the bus...), he can sing itsy bitsy spider, head & shoulders</i>
Słuchacz – <i>że słyszy burzę, wiatr, deszcz, błyskawicę</i>	Listener – <i>that they listen to the storm, wind, rain, lightning</i>
Skakanka – <i>do skakania</i>	Jump-rope – <i>for jumping</i>
Drukarka – <i>do drukowania, wychodzą karty, napisy</i>	Printer – <i>for printing, sheets, writing comes out</i>
Pisak – <i>to pisze się literki</i>	Pen – <i>you can write letters</i>

Suszarka - <i>do suszenia włosów; myjesz, czesze i susze</i>	Dryer - <i>for drying hair; you wash, comb, and dry</i>
Gaśnica - <i>gasi ogień strażak</i>	Fire extinguisher - <i>the fireman extinguishes the fire</i>
Kwiaciarnia - <i>kwiaty można wziąć do domu, zapłacić</i>	Flower shop - <i>You can take the flowers home, and pay</i>
Wycieraczka - <i>do okien i szyb wycierania [dziewczynka pokazywała]</i>	Wash-cloth - <i>for washing windows and glass [the girl showed how]</i>

A different mode of interpreting wordbuilding formations in a child was also the identification of the root word, and, accordingly - linking the meaning of the derivative with the meaning of the root word (created with its use). In this case, the meaning of the root word is more important for the meaning of the given word than the meaning of the formant, e. g:

Leżak - <i>leży się</i>	Beach chair - <i>you lie</i>
Czytanka - <i>czyta się</i>	Reading-book - <i>you read</i>

In one of the examples, the giel used the verb root with a common root morpheme, however, with a different prefix, e.g.:

Grzejnik - <i>do ogrzania domu</i>	Heater - <i>to heat the house</i>
------------------------------------	-----------------------------------

At times, the child would indicate the lexical meaning of the derivatives. Focusing exclusively on reading the real meaning, in the definition she omitted the root word, e.g.:

Lekarz - <i>bada serce, nogi, plecy, uszy, brzuch; wija zastrzyki, a ja tak bardzo nie lubię zastrzyków, no bo boli</i>	Doctor - <i>he examines the heart, the legs, back, ears, stomach; he makes injections, and I don't like injections a lot, because they're painful</i>
Piłkarz - <i>to jak gole strzela</i>	Footballer - <i>how he scores</i>
Odkurzacz - <i>do sprzątania podłogi</i>	Vacuum cleaner - <i>for cleaning the floor</i>

One of the modes of interpretation of derivatives were also associations. They most commonly stemmed from the fact that the child associated wordbuilding structures with situations she experienced in life - when recognising the meaning of derivative words, she based her work on her own experiences, for instance:

Przymierzalnia – <i>ubrania kupować</i>	Fitting-room – <i>buying clothes</i>
Mrożonka – <i>to jest zimno, zimno tam jest</i>	Frozen food – <i>it's cold, it's cold there</i>
Grubas – <i>on jest zabawny</i>	Fatty – <i>he's funny</i>
Lodowisko – <i>można tam śmieci wyrzucać</i>	Skating rink – <i>you can throw away trash there</i>

The last example is an expression of relationship with the word *śmieciowisko* [landfull] – hence the interpretation of the derivate.

4.2. Assessment of the skill of production of wordbuilding structures in the individual wordbuilding categories – the skill to produce structures on the basis of a wordbuilding paraphrase

Production is formal-semantic synthesis of properties making up the structure's meaning; encoding meanings into the wordbuilding structure; production referring specific entities from one's own vocabulary that are formally and semantically tied to the defined set of semantic properties; this takes place on the basis of a wordbuilding paraphrase and a set of semantic properties that were extracted from the structural meaning of the formation.²²

Throughout the majority of the test, the patient created wordbuilding structures belonging to various wordbuilding categories correctly, for instance:

Pan, który maluje – <i>malarz</i>	One who paints – <i>painter</i>
Pan, który pracuje w kuchni – <i>kucharz</i>	One who works in the kitchen – <i>cook</i>
Urządzenie, które służy do kierowania pojazdów – <i>kierownica</i>	Device used to control cars – <i>steering wheel</i>
Urządzenie, które służy do prania – <i>pralka</i>	Device used for cleaning laundry – <i>washing machine</i>
Pokój, gdzie się sypia – <i>sypialnia</i>	The room where one sleeps – <i>bedroom</i>
Miejsce, gdzie ludzie piją kawę – <i>kawiarnia</i>	Place, where people drink coffee – <i>cafe</i>

²² J. Puzynina, *Procesy nadawania i rozumienia komunikatów językowych a słowotwórstwo*, „Prace Filologiczne” 1970, vol. XX, pp. 59–64; E. Muzyka-Furtak, *Konstrukcje słowotwórcze w świadomości językowej dzieci niesłyszących*, Wydawnictwo Uniwersytetu Marii Curie-Skłodowskiej, Lublin 2010, p. 81.

Urządzenie poruszane przez wiatr - <i>wiatrak</i>	Device moved by wind - <i>windmill</i>
Urządzenie do zapalania ognia - <i>zapałki</i>	Device to light a fire - <i>matches</i>
Osoba, która jest bardzo chuda - <i>chudzi- elec</i>	A person who is very thin - <i>a skinny person</i>
Człowiek, który jest goły - <i>golas</i>	A person without clothes - <i>naked</i>

The collected material also includes structures used through application of wrong formants – this stems from insufficient acquisition of the rules of formant repartition, despite the fact of mastering basic skills of creation of word formations, for instance:

Pan, który skacze - <i>skakacz</i>	One who jumps - <i>jumpist</i>
Pan, który biega - <i>biegarz</i>	One who runs - <i>runner</i>
Pan, który mówi - <i>mówiarz</i>	One who speaks - <i>speaker</i>
Pan, który kłamie - <i>kłamarz</i>	One who lies - <i>liar</i>
Urządzenie, które służy do zmywania naczyń - <i>zmywacz</i>	Device used for cleaning dishes - <i>dish-cleaner</i>
Część ulicy przeznaczona do chodzenia/Powierzchnia, po której się chodzi - <i>chodzik</i>	Part of the street used for walking / the surface you walk on - <i>walkway</i>
Człowiek, który lubi zbierać grzyby - <i>grzybaw</i>	Person who likes to pick mushrooms - <i>mushroomer</i>

translator's note: the translations offered above are but attempts at conveying the types of errors made by the patient as transposed to the English language. They are only approximations that should give an image of the issue.

For a child with MID, the addition of random formants characteristic for the category of actors, to intuitively derived root words, does not constitute any changes in meaning – this shows how rules of grammar are abstract for a child with ID, if they do not understand them.

Noteworthy are also structures created with a change of the root words, however, semantically and not formally related, with the root word used in the explication. The patient recalled, on the basis of association, words related to the components of the paraphrase that she understood, e.g.:

Rzecz, która budzi ludzi rano – <i>kogut</i>	Thing to wake us in the morning – <i>rooster</i>
Urządzenie, które służy do kopania – <i>łopata</i>	Device used for digging – <i>shovel</i>
Przyrząd, który służy do otwierania butelek – <i>korek</i>	Item used for opening bottles – <i>cork</i>
Miejsce, gdzie ludzie pieką chleb i bułki – <i>kuchenka</i>	Place, where people bake bread and buns – <i>oven</i>
Książeczka, w której koloruje się obrazki – <i>zeszyt, kartka</i>	Book, in which you colour pictures – <i>notebook, paper sheet</i>
Pan, który ma brodę – <i>Mikołaj</i>	Man with a beard – <i>Santa Claus</i>

At times, the patient did not create derivatives on the basis of the paraphrase she heard, but would only repeat the last word²³, for instance:

Miejsce, gdzie ludzie kupują i jedzą lody – <i>lody</i>	Where people buy ice-cream – <i>ice-cream</i>
Człowiek, który jest biedny – <i>biedny</i>	Person who is poor – <i>poor</i>
Pan, który jest stary – <i>stary</i>	Man who is old – <i>old</i>

One repetition emerged in an altered, declined form, meaning:

Rzecz do jedzenia zrobiona z cukru – <i>cukier</i>	Edible thing made of sugar – <i>sugar</i>
--	---

Within all of the collected material, one structure was created using the wrong root word, and one from the wrong root word with the incorrect formant, e.g.:

Miejsce, gdzie są przyrządy do ćwiczeń na siłę – <i>ćwiczelnia</i>	Place with strength exercise equipment – <i>exercisory</i>
Pan, który łowi ryby – <i>łowiarz</i>	Man who fishes – <i>fishman</i> [see earlier translator's note]

One of the examples saw the girl unable to decide the root word in the presented structure, as a result the last sound was removed;

²³ It is impossible to clearly state whether the child repeated the word being at the same time the root consciously or accidentally.

it was probably accidental and not correct in terms of morphological boundaries, e.g.:

Miejsce, w którym można poczekać na pociąg - poczekalni (-a → ∅) Place, where you can wait for a train - loung(-e)

The girl also used the word formation *szmatka do ścierania 'rzecz, którą ścieramy podłogi'* [*wash-cloth 'thing for washing floors'*].

4. Summary

A child experiencing ID-based language dysfunctions has hindered access to wordbuilding resources. In the presented case, comprehension exceeds production, a phenomenon typical for children in the intellectual norm as well. The child has difficulty forming sentences, which translates into difficulty formulating wordbuilding paraphrases. In the majority of cases, the girl indicated the root word with a component of the actual meaning - however, the paraphrase was only made up of components necessary for the identification of the meaning of the derivate. Disturbed abstract thinking and specific/image-based thinking contribute to the fact that when the girl formed paraphrases, she referred to specific designators, frequently listing them (e.g. *the seller sells us things like milk, cucumbers, tomatoes, salad, corn puffs; the cleaning-lady can clean the floor, the windows, the dust, the window, so that it is clean*). Maintaining at the stage of specific and specific-functional operations also influences frequent prevalence of associations that are based on the child's life experiences.

The child managed to produce correct structures on the basis of recalled wordbuilding paraphrases. One can surmise, however, that these were names the child could have come across earlier in life. The low level of acquisition of the rules of formant repartition, despite mastery in the basic skills of creation of formations, shone through in the creation of structures with wrong formants, frequently added at random and intuitively. Structures were also seen made

using a different root word, which continued to be semantically related to the root word used for the explication. If the patient was unable to produce the correct formation, she repeated a part of the presented wordbuilding paraphrase.

Even though the child was able to express specific semantic and pragmatic intentions, she did not sufficiently acquire syntactic efficiency. Due to the failure to master, in the appropriate time, the rules of grammar, the patient, with quite an extensive vocabulary if one would consider the described dysfunction, continues to have problems producing word combinations and sentences. It may thus be surmised that all dysfunctions named above also translate to a reduced level of wordbuilding competences spanning comprehension and creation of wordbuilding structures.

Conclusions were drawn on the basis of a single assessment, hence they require confirmation with a higher number of cases – the conducted studies shall be executed in more detail and subjected to a much more thorough linguistic analysis. A broader perspective of the single case described here can allow the description of differences between comprehension and production skills concerning wordbuilding structures by children with MID and describe their level of wordbuilding competences. In addition, any detailed view of the research focused on the modes of production and understanding of noun derivatives in the area of the selected wordbuilding categories, and a comparison of the results with scores by children in the intellectual norm (on the basis of own research and with reference to the developed knowledge and the research history), would allow the determination of whether children with MID master mechanisms and techniques of derivation in the same way as children in the norm, and what is their level of wordbuilding competences. The collected material will also allow a comparison of wordbuilding competences of children with MID with wordbuilding skills of children with other disabilities/ dysfunctions.

To conclude, it must be noted that an assessment of the level of wordbuilding competences should be a component of a comprehensive logopaedic diagnosis (it is, however, frequently omitted in

diagnosis). It is he more important that with children with language dysfunctions (including oligophasia), the observation of acquisition of wordbuilding rules allows more precise determination of speech therapy, the purpose being e.g. the reduction of interference in communication and the development of a suitable level of language competences and capacities.

Bibliography

- [1] Bałachowicz J., Paluszewski J. (ed.), *Sprawności językowe dzieci upośledzonych umysłowo w stopniu lekkim*, Wydawnictwo WSPS, Warszawa 1995.
- [2] Berko J., *The child's learning of English morphology*, "Word" 1958, no. 14, pp. 150–177.
- [3] Bleszyńska L., *Zasób słownictwa uczniów z niepełnosprawnością intelektualną w stopniu lekkim klas gimnazjalnych – diagnoza i propozycje rozwiązań*, [in:] *Nauczanie uczniów z niepełnosprawnością intelektualną w stopniu lekkim. Wybrane problemy z teorii i praktyki*, ed. by S. Sadowska, Wydawnictwo Edukacyjne Akapit, Toruń 2006, pp. 153–162.
- [4] Bleszyński J., Kaczorowska-Bray K. (ed.), *Diagnoza i terapia logopedyczna osób z niepełnosprawnością intelektualną*, Wydawnictwo Harmonia Uniwersytetu Gdańskiego, Gdańsk 2012.
- [5] Bleszyński J., *Niepełnosprawność intelektualna. Mowa – język – komunikacja. Czy iloraz inteligencji wyjaśnia wszystko?*, Harmonia, Gdańsk 2013.
- [6] Chmura M., Napiórkowska U., Nowak J., *Z badań nad słownictwem dziecka rozpoczynającego naukę szkolną*, „Życie Szkoły” 1970, no. 7–8, pp. 21–26.
- [7] Chmura-Klekotowa M., *Neologizmy słowotwórcze w mowie dzieci*, „Poradnik Językowy” 1968, no. 1, pp. 19–25.
- [8] Chmura-Klekotowa M., *O różnicach w zasobie słownikowym dziecka siedmioletniego i dwunastoletniego*, „Prace Filologiczne” 1975, no. 25, pp. 239–242.
- [9] Chumura M., *Uwagi o rozwoju mowy dziecka*, „Poradnik Językowy” 1962, no. 9–10, pp. 449–456.
- [10] Clark E.V., Berman R.A., *Structure and use in the acquisition of word formation*, "Language" 1984, no. 60, pp. 542–590.
- [11] Clark E.V., Berman R.A., *Types of linguistic knowledge: interpreting and producing compound nouns*, "Journal of Child Language" 1987, no. 3(14), pp. 547–567.
- [12] Dziurda-Multan A., *Dziecięce sposoby tworzenia nazw*, Wydawnictwo KUL, Lublin 2008.
- [13] Grabias S., *O ekspresywności języka. Ekspresja a słowotwórstwo*, Wydawnictwo UMCS, Lublin 1980.

- [14] Grzegorzycykowa R., Puzynina J., *Problemy ogólne słowotwórstwa. Rzeczownik*, [in:] *Gramatyka współczesnego języka polskiego. Morfologia*, ed. by R. Grzegorzycykowa, R. Laskowski, H. Wróbel, Wydawnictwo Naukowe PWN, Warszawa 1999, pp. 361–468.
- [15] Grzegorzycykowa R., Szymanek B., *Kategorie słowotwórcze w perspektywie kognitywnej*, [in:] *Współczesny język polski*, ed. by J. Bartmiński, Wydawnictwo UMCS, Lublin 2001.
- [16] Haman E., *Słowotwórstwo dziecięce w badaniach psycholingwistycznych*, „*Język. Poznanie. Komunikacja*” 2013, vol. 19, Warszawa.
- [17] Heinz A., *Fleksja a derywacja*, „*Język Polski*” 1961, no. XLI (5), pp. 343–354.
- [18] Jęczeń U., *Językowa projekcja emocji na przykładzie wypowiedzi dzieci upośledzonych umysłowo i dzieci w normie intelektualnej* (unpublished dissertation), Lublin 2005.
- [19] Jęczeń U., *Językowa projekcja emocji. Emocje w zachowaniach językowych dzieci upośledzonych umysłowo i dzieci w normie intelektualnej*, [in:] *Język – interakcja – zaburzenia mowy. Metodologia badań*, ed. by T. Woźniak, A. Domagała, Wydawnictwo UMCS, Lublin 2007, pp. 133–171.
- [20] Kaczorowska-Bray K., *Kompetencja i sprawność językowa dzieci z niepełnosprawnością intelektualną w stopniu znacznym, umiarkowanym i lekkim*, Wydawnictwo Uniwersytetu Gdańskiego, Gdańsk 2017.
- [21] Kaczorowska-Bray K., *Wyrażenia przyimkowe w mowie dzieci upośledzonych umysłowo w stopniu umiarkowanym i lekkim*, Wydawnictwo Harmonia Universalis, Gdańsk 2013.
- [22] Kaczorowska-Bray K., *Zaburzenia komunikacji językowej w grupie osób z niepełnosprawnością intelektualną*, [in:] *Diagnoza i terapia logopedyczna osób z niepełnosprawnością intelektualną*, ed. by J. Bleszyński, K. Kaczorowska-Bray, Wydawnictwo Harmonia Universalis, Gdańsk 2012, pp. 36–64.
- [23] Kreja B., *Słowotwórstwo a problem tworzenia nowych wyrazów*, [in:] *Z zagadnień ogólnych polskiego słowotwórstwa. Studia 3*, ed. by B. Kreja, Wydawnictwo Uniwersytetu Gdańskiego, Gdańsk 2000, pp. 191–195.
- [24] Krzemińska D., *Język i dyskurs codzienny osób z niepełnosprawnością intelektualną*, Oficyna Wydawnicza „Impuls”, Kraków 2012.
- [25] Kulesza E., *Rozwój poznawczy dzieci z lekkim i umiarkowanym stopniem upośledzenia umysłowego – diagnoza i wspomaganie. Studia empiryczne*, Wydawnictwo APS, Warszawa 2004.
- [26] Marciniak-Firadza R., *Kilka uwag o potrzebie badań kompetencji słowotwórczych dzieci z niepełnosprawnością intelektualną w stopniu lekkim*, „*Interdyscyplinarne Konteksty Pedagogiki Specjalnej*” 2016, no. 14, pp. 29–51.
- [27] Marciniak-Firadza R., *Kilka uwag o stanie badań nad kompetencją słowotwórczą dzieci z niepełnosprawnością intelektualną*, „*Interdyscyplinarne Konteksty Pedagogiki Specjalnej*” 2017, no. 18, pp. 145–163.

- [28] Michalik M., *Diagnozowanie kompetencji lingwistycznej ucznia szkoły specjalnej*, Wydawnictwo Naukowe Akademii Pedagogicznej, Kraków 2006.
- [29] Michalik M., *Kompetencja składniowa w normie i w zaburzeniach*, Wydawnictwo Naukowe Uniwersytetu Pedagogicznego, Kraków 2011.
- [30] Minczakiewicz E., *Kształtowanie i usprawnianie mowy dzieci upośledzonych umysłowo w stopniu umiarkowanym i znacznym*, „Szkola Specjalna” 1984, no. 3, pp. 186–191.
- [31] Minczakiewicz E., *Rozwój języka mówionego uczniów młodszych klas szkoły specjalnej dla lekko upośledzonych umysłowo w toku zamierzonych oddziaływań stymulacyjnych*, „Logopedia” 1994, no. 21, pp. 37–46.
- [32] Minczakiewicz E., *Z badań nad zaburzeniami mowy u dzieci upośledzonych umysłowo*, [in:] *Z zagadnień oligofrenopedagogiki*, ed. by J. Pańczyk, vol. 2, Wydawnictwo WSPS, Warszawa 1989.
- [33] Minczakiewicz E., *Zaburzenia mowy i ich odbicie w piśmie uczniów młodszych klas szkoły specjalnej dla lekko upośledzonych umysłowo*, „Logopedia” 1993, no. 20, pp. 113–119.
- [34] Minczakiewicz E., *Zaburzenia mowy u osób z upośledzeniem umysłowym*, „Scholasticus” 1993, no. 1, pp. 57–63.
- [35] Muzyka-Furtak E., *Konstrukcje słowotwórcze w świadomości językowej dzieci niesłyszących*, Wydawnictwo Uniwersytetu Marii Curie-Skłodowskiej, Lublin 2010.
- [36] Nadolska H., *Kompetencja narracyjna uczniów o różnym poziomie intelektualnym. Przejawy, uwarunkowania, tendencje rozwojowe*, Wydawnictwo Erbe, Białystok 1995.
- [37] Nadolska H., *Poziom inteligencji a sprawność narracji*, „Roczniki Pedagogiki Specjalnej” 1994, no. 5, pp. 43–61.
- [38] Nadolska H., *Poziom inteligencji a sprawność relacjonowania zdarzeń. Wybrane aspekty badań nad kompetencją narracyjną dzieci pełnosprawnych i upośledzonych umysłowo w stopniu lekkim*, „Kultura i Edukacja” 1993, no. 4, pp. 91–102.
- [39] Nartowska H., *Opóźnienia i dysharmonie rozwoju dziecka*, Wydawnictwo WSiP, Warszawa 1980.
- [40] Puzynina J., *Procesy nadawania i rozumienia komunikatów językowych a słowotwórstwo*, „Prace Filologiczne” 1970, vol. XX, pp. 59–64.
- [41] Rakowska A., *Język – komunikacja – niepełnosprawność. Wybrane zagadnienia*, Wydawnictwo Naukowe Akademii Pedagogicznej, Kraków 2003.
- [42] Sadowska S., *Uczeń z niepełnosprawnością intelektualną w stopniu lekkim w szkolnej sytuacji komunikacyjnej. O realizacji zadań wspomagania rozwoju umiejętności mówienia i pisanía*, [in:] *Nauczanie uczniów z niepełnosprawnością intelektualną w stopniu lekkim. Wybrane problemy z teorii i praktyki*, ed. by S. Sadowska, Wydawnictwo Edukacyjne Akapit, Toruń 2006, pp. 127–151.
- [43] Szuniewicz A., *Próba badania wad mowy dzieci upośledzonych umysłowo w warszawskich szkołach specjalnych*, „Logopedia” 1967, no. 7, pp. 112–117.

- [44] Szymanek B., *Categories and categorization in morphology*, Wydawnictwo KUL, Lublin 1988.
- [45] Tarkowski Z., *Agramatyzm u uczniów lekko upośledzonych umysłowo*, [in:] *Rewalidacja dzieci ze złożonymi upośledzeniami*, ed. by Z. Sękowska, Wydawnictwo UMCS, Lublin 1988, pp. 81–108.
- [46] Wątopek A., *Kompetencja językowa uczniów z lekką niepełnosprawnością intelektualną*, Wydawnictwo Nomos, Kraków 2014.
- [47] Zaorska M., *Aktualne problemy edukacji i rehabilitacji osób z niepełnosprawnością sprzężoną*, „Niepełnosprawność” 2012, no. 7, pp. 9–24.
- [48] Zarębina M., *Język polski w rozwoju jednostki. Analiza tekstów dzieci do wieku szkolnego. Rozwój semantyczny języka dziecka*, Wydawnictwo Naukowe WSP, Kraków 1980.
- [49] Zarębina M., *Kształtowanie się systemu językowego dziecka*, Wydawnictwo Ossolineum, Wrocław 1965.
- [50] Zarębina M., *Rola wyrazów w słowniku i w tekście (na materiale polskim)*, „Język Polski” 1970, p. 43.
- [51] Zgólkowa H., *Funkcje neologizmów w rozwoju języka dzieci przedszkolnych*, [in:] *Język osobniczy jako przedmiot badań lingwistycznych*, ed. by J. Brzeziński, Wydawnictwo Wyższej Szkoły Pedagogicznej w Zielonej Górze, Zielona Góra 1988, pp. 259–276.



Support Teachers in the Education of Students with Autism and Asperger Syndrome in Integrated and Mainstream Schools

ABSTRACT: Anida Szafrńska, *Support Teachers in the Education of Students with Autism and Asperger Syndrome in Integrated and Mainstream Schools*. Interdisciplinary Contexts of Special Pedagogy, no. 26, Poznań 2019. Pp. 59–80. Adam Mickiewicz University Press. ISSN 2300-391X. DOI: <https://doi.org/10.14746/ikps.2019.26.03>

The article presents a pilot study of the tasks of support teachers in relation to students with autism, including those with Asperger's syndrome. Data contained in the Educational Information System shows a significant increase in the number of students with this type of disorder studying in integrated units and mainstream schools. The education of students with autism and Asperger's syndrome is difficult due to their deficits in the cognitive sphere, as well as problems in social and emotional functioning. When carried out in an appropriate manner, with relevant professional support, the inclusion of autistic children may be beneficial both for the children's intellectual, social and emotional development, as well as other students.

KEY WORDS: autism spectrum disorders, education of students with ASD, integrated and inclusive education, support teacher

Introduction

In accordance with the ICD 10 classification in force in Poland, autism and Asperger syndrome belong to the group of pervasive

developmental disorders (PDD).¹ Currently, the term autism spectrum disorders (ASD), used in the DSM – 5 classification², is applied more and more frequently, blurring the boundaries between the most common pervasive developmental disorders, i.e. autism, Asperger syndrome and PDD not defined otherwise (PDD-NOS).³ In this classification, autism spectrum disorders belong to neurodevelopmental disorders and the axial symptoms include persistent deficits in social communication and social relations in many environments, as well as limited, repetitive patterns of behaviour or activity.⁴ The co-existence of intellectual disabilities which affects 55% of persons with ASD⁵, mental disorders that may be present in 70% of children⁶ and sensory disturbances that can dominate all the activities of a person⁷ are a serious problem. Autism spectrum disorders are a significant social problem. The majority of epidemiological studies conducted after the year 2000 indicate the prevalence of a wide spectrum of autism. They show that the average preva-

¹ *Międzynarodowa Statystyczna Klasyfikacja Chorób i problemów Zdrowotnych. Rewizja 10 (International Statistical Classification of Diseases and Health Problems. Revision 10)*, WHO 2008, p. 248.

² P. Gałecki, Ł. Świącicki, (academic supervision, Polish ed.), *Kryteria diagnostyczne z DSM 5: Desk Reference.*, Wydawnictwo Edra Urban & Partner. Wrocław 2015, pp. 24–28.

³ A. Klin, *Typologia zaburzeń ze spektrum. Aspekty teoretyczne, badawcze i kliniczne*, [in:] *Diagnoza zaburzeń ze spektrum autyzmu*, ed. S. Goldstein, Jack A. Naglieri, S. Ozonoff, Wydawnictwo Uniwersytetu Jagiellońskiego, Kraków 2017, p. 126.

⁴ P. Gałecki, Ł. Świącicki, (academic supervision, Polish ed.), *Kryteria diagnostyczne z DSM 5...*, op. cit., pp. 24–25.

⁵ L.G. Klinger, S.E. O’Kelly, J.L. Mussey, *Diagnoza funkcjonowania intelektualnego w zaburzeniach ze spektrum autyzmu*, [in:] *Diagnoza zaburzeń ze spektrum autyzmu, ...*, op. cit. pp. 262.

⁶ R.E Rosenberg, W.E. Kaufmann, J.K. Law, P.A. Law, *Parent Report of Community Psychiatric Comorbid Diagnoses in Autism Spectrum Disorders*, “Autism Research and Treatment”, 2011 Aug. 18, <<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3420588/>> accessed 8 February 2018. Cf. M. Płatos (ed.), *Ogólnopolski spis autyzmu. Sytuacja młodzieży i dorosłych z autyzmem w Polsce*, Wydawca Stowarzyszenie Innowacji Społecznych „Mary i Max”, Warszawa 2016, pp. 38–40; pp. 77–79.

⁷ B. Nason, *Porozmawiajmy o autyzmie. Przewodnik dla rodziców i specjalistów*, Kraków 2017, p. 149.

lence of ASD is 62/10000.⁸ In Poland, there is a noticeable increase in the number of children assessed as requiring special education due to the diagnosis of autism or Asperger's syndrome and their participation in education in integrated units and mainstream schools. Thus, at the end of September 2011 in primary and lower secondary schools a total of 3811 and in 2018 as many as 21 313 students were reported. Without addressing the subject of determinants affecting the increase in the number of diagnoses and issued decisions on the need for special education, it can be said, travestying a statement by I. Chrzanowska, that students with autism spectrum disorders are not a trend but the reality of the Polish school".⁹

Students with autism spectrum disorders

Regardless of the classification adopted, when speaking of pervasive developmental disorders (ICD 10) or, more broadly, autism spectrum disorders (DSM-5), we are talking about early, neurodevelopmental, extensive disorders covering all spheres of social functioning, communication, and various aspects of cognitive and adaptive functioning.¹⁰ F. Volkmar and A. Klin report that "people with PDD may have profound intellectual disabilities, as well as extremely high levels of IQ: lack of speech and excessive talkativeness; extremely strong social isolation and an inability to refrain from making contact with others, albeit in an inappropriate way; and their lives may be both dominated by stereotypical movements or repetitive behaviours, as well as by learning about unusual topics".¹¹

⁸ Quoted after: F. Rybakowski, A. Białek, I. Chojnicka et al., *Zaburzenia ze spektrum autyzmu – epidemiologia, objawy, współzachorowalność i rozpoznawanie*, „Psychiatria Polska” 2014, 48(4), p. 655.

⁹ I. Chrzanowska, *Wstęp*, „Interdyscyplinarne Konteksty Pedagogiki Specjalnej”, 2013, No. 1, p. 7.

¹⁰ A. Klin, *Typologia zaburzeń ze spectrum. Aspekty teoretyczne, badawcze i kliniczne*, [in:] *Diagnoza zaburzeń ze spectrum autyzmu*, op. cit., p. 125.

¹¹ Quote after: A. Klin, op. cit., p. 125.

Students with autism, including Asperger's syndrome, are classified as students with special educational needs. These needs result from social and communication deficits and behavioural problems such as hyperactivity, limited attention, impulsivity, aggression and auto-aggressive behaviour, as well as other disorders, including intellectual disabilities, sensory problems and possible health problems. The diversity and significant intensification of these deficits is a unique challenge for teachers and therapists. When organising the education process of this group of students it is therefore important to recognise the difficulties experienced by individual students and to manage the education process in such a way that they can use their strengths to develop their intellectual, physical and emotional potential.

Education of students with autism and Asperger syndrome¹²

The basic legal act regulating the education of children and youth with disabilities is the Act of 14 December 2016 Education Law.¹³ Detailed rules are contained in the Regulation of Minister of National Education of 9 August 2017 on the conditions of organizing education, upbringing and care for children and youth with disabilities, socially maladjusted and at risk of social maladjustment.¹⁴ According to this document, students with autism, including Asperger's syndrome, assessed as requiring special education may attend special, integrated and mainstream kindergartens and schools.¹⁵ The final decision on the choice of the form of education is made by the parents or legal guardians.

¹² In accordance with the nomenclature used in the educational documents in force and regulations of the Ministry of Education, I will use the terms autism and Asperger syndrome in the further part of the study.

¹³ Journal of Laws of 2017, item 59.

¹⁴ Journal of Laws of 2017, item 1578.

¹⁵ Regulation of the Minister of National Education of 7 September 2017 on opinions and decisions issued by adjudicating panels operating in public psychological and pedagogical counselling centres; Journal of Laws of 2017, item 1743.

The increasing number of students with autism, including those with Asperger's syndrome, in integrated and mainstream education is a reflection of the general trend of moving away from segregated education¹⁶ to integrated and inclusive education. The IBE (Educational Research Institute) Report on educational pathways of people with disabilities provided interesting data. School directors pointed to integrated schools as the most appropriate form of learning for students with autism and Asperger's syndrome. Among the key conclusions were the very good opinions of the vast majority of parents on the schools attended by their children. Positive opinions were expressed particularly in the case of integrated and special schools.¹⁷ However, the report prepared by the Synapsis Foundation shows that in the school year 2005/2006 the majority of autistic children attended mainstream schools.¹⁸

Integration is understood as introducing "previously segregated children to the mainstream", and inclusion refers to the situation where children with disabilities are brought up and educated together with their able peers from the very beginning, and it is the school that adapts itself to their needs...".¹⁹ J. Głodkowska defines inclusive education as "a process of joint education of pupils with special educational needs and their healthy peers, while ensuring a sense of belonging to the school community and providing the necessary support (technical, methodological, psychosocial, organisational) for them as a result of their disability."²⁰ Inclusive education

¹⁶ I. Chrzanowska, *Pedagogika specjalna. Od tradycji do współczesności*, Oficyna Wydawnicza „Impuls”, Kraków 2015, p. 533.

¹⁷ P. Grzelak, P. Kubicki, M. Orłowska, *Realizacja badania ścieżek edukacyjnych niepełnosprawnych dzieci, uczniów i absolwentów. Raport końcowy*, Educational Research Institute in Warsaw, 2014.

¹⁸ Quote after: I Chrzanowska, *Wiedza na temat autyzmu wśród obecnych i przyszłych pedagogów a dylemat wspólnego kształcenia i integracji w wymiarze edukacyjnym*, „Rocznik Lubuski” 2012, Vol. 38, part 2, p. 112 (105–114).

¹⁹ A. Firkowska-Mankiewicz, G. Szumski, *Pedagogika specjalna i system kształcenia osób z niepełnosprawnościami w Polsce*, [in:] *Pedagogika specjalna 2. Podręcznik akademicki*, D.D. Smith, Wydawnictwo PWN, Warszawa 2009, p. 333.

²⁰ J. Głodkowska, *W poszukiwaniu modelu edukacji włączającej*, „Meritum” 2009, No. 2(13), p. 6.

takes place in a district school, in a regular classroom, on the basis of a common but individualised curriculum. The lead teacher is responsible for the education of all students. Both students and teachers can count on the flexible help of a specialist.²¹

The variety of symptoms in the case of children with ASD, and therefore the diversity of needs, means that there is no single educational method or rule that applies to all children with ASD. However, according to Robbins et al., ASD children should be integrated as early as possible into the same educational environment and activities as neurotypical children to facilitate the development of social interaction between peers.²² Inclusion can be beneficial for some students because it supports social, emotional and cognitive development.²³ However, inclusion does not always have positive effects. This happens when the child or pupil does not have sufficient social skills to participate in activities with others, or when the educational environment is not prepared to work with the pupil. Researchers agree that it is not advisable for some students to participate in a mainstream classroom and that they will benefit significantly more from learning in other ways.²⁴ A similar view is represented, among others, by A. Zamkowska and G. Dryżałowska, who mention the factors limiting student participation in integrated education. These are: the type and degree of disability, the level of development, limitations in the family environment.²⁵ Numerous studies on integrated and inclusive education of pupils with ASD reveal

²¹ S. Olszewski, K. Parys, *Rozumieć chaos. Rzecz o terminach i znaczeniach im nadawanych w pedagogice specjalnej*, Wydawnictwo Naukowe Uniwersytetu Pedagogicznego w Krakow, Kraków 2016, p. 193.

²² E. Boujut, A. Dean, A. Grouselle, E. Cappe, *Comparative Study of Teachers in Regular Schools and Teachers in Specialized Schools in France, Working with Students with an Autism Spectrum Disorder: Stress, Social Support, Coping Strategies and Burnout*, *J Autism Dev Disord* (2016) 46, p. 2875.

²³ *Ibid*, p. 2886.

²⁴ J. Evans, I. Lunt, *Inclusive education: are there limits?*, "European Journal of Special Need Education" 2002, 17(1), pp. 1-14.

²⁵ Quote after: I. Chrzanowska, *Pedagogika specjalna...*, op. cit., p. 539.

many barriers to this process also for better-functioning pupils. Research carried out among teachers has provided interesting data. Although all respondents were positive about the inclusion of persons with high-functioning ASD, they also pointed to barriers. These included: the features of a student with ASD, including behavioural problems, peer impact in terms of aggressive behaviour, and staffing resources.²⁶

Teachers are one of the links in the process of school transformation and development of inclusive education. They are the ones who respond to the many expectations and requirements concerning competences and attitudes towards students with disabilities and their education. As Z. Janiszewska-Nieścioruk writes, "the teachers should be perceived as the main creators of this inclusion"²⁷, "the quality of inclusive education... is conditioned by the quality of teaching staff, their professionalism as expressed in their openness to the needs of each pupil..."²⁸ The tasks of the teacher co-organizing the education of students with disabilities, including those with autism and students with Asperger's syndrome include: conducting educational activities together with the teacher, and integrated activities and activities specified in the curriculum together with other teachers and specialists, educational work, as well as participation in such activities as needed; providing assistance to teachers conducting educational activities and to teachers, specialists implementing integrated activities and activities specified in the curriculum, in choosing forms and methods of work; conducting activities appropriate to individual developmental and educational needs and the psychophysical abilities of the students, in particular remedial, rehabilitation and sociotherapeutic activities; participation

²⁶ J.M. Sansosti, F. Sansosti, *Inclusion for Students with High-functioning Autism Spectrum Disorders: Definitions and Decision Making*, "Psychology in the Schools" Vol. 49(10), 2012, p. 929.

²⁷ Z. Janiszewska-Nieścioruk, *(Nie)dojrzałość proinkluzyjnych zmian w kształceniu osób z niepełnosprawnością*, „Niepełnosprawność. Dyskursy pedagogiki specjalnej”, No. 22/2016, p. 56.

²⁸ *Ibidem*, p. 57.

in the work of the IPET development team.²⁹ The list of tasks is quite general and is only a framework for the activities of a teacher co-organising special education.

Own research

The research was conducted in the Upper Silesian Agglomeration in the following cities: Katowice, Chorzów, Tychy, Sosnowiec, Bytom, Piekary Śląskie. The research involved women, 75 teachers, 42 of whom were primary and lower secondary school teachers (one institution) with integrated units and 33 teachers of mainstream primary schools. The selection of the sample was purposeful, the research involved teachers working with students with autism and Asperger's syndrome. The studies were pilot studies.

The aim of the research was to identify the tasks performed by teachers co-organising the process of education of students with autism, including Asperger's syndrome.

The research was conducted by means of a diagnostic survey with the use of a self-developed questionnaire. The research was based on the positivistic research paradigm.

Results of research

The following abbreviations were used in the tables:

IS - schools with integrated units

MS - mainstream schools

In schools with integrated classes, nearly 70% of the respondents are nominated and certified teachers with work experience ranging from 16 to 35 years and experience as a support teacher from 2 to

²⁹ Regulation of the Minister of National Education of 9 August 2017 on the conditions for organising education, upbringing and care for children and youth with disabilities, socially maladjusted and at risk of social maladjustment § 7 section 7 and § 5 section 4 (Journal of Laws of 2017, item 1578).

18 years. In mainstream schools, 51.5% are nominated and certified teachers with 10–35 years of work experience, but with a much shorter period of experience as a support teacher (1–3 years). The differences in the length of work experience in the position of a support teacher between both types of schools result from the provisions of the Regulation³⁰, according to which a teacher co-organizing the education process could be employed only from 2016.

Table 1. Degree of professional promotion

Degree of professional promotion	IS		MS		Total	
	T = 42	%	T = 33	%	T = 75	%
Teacher trainee	2	4.8	5	15.1	7	9.3
Contract teacher	12	28.6	11	33.3	23	30.7
Nominated teacher	7	16.6	7	21.2	14	18.7
Certified teacher	21	50	10	30.3	31	41.3

Source: Own research.

Table 2. Teacher training

Completed faculties	IS		MS		Total	
	T = 42	%	T = 33	%	T = 75	%
Special education	19	45.2	15	45.5	34	45.3
Other faculties	23	54.8	18	54.5	41	54.7

Source: Own research.

Almost half of the respondents in both groups completed their master's studies in one of the sub-disciplines of special education. Among the teachers of integration classes, 19 persons completed studies in oligophrenopedagogy, rehabilitation pedagogy, thera-

³⁰ Journal of Laws of 2017, item 1578.

peutic pedagogy, surdopedagogy (deaf education). The remaining 23 persons graduated from other fields of study, mainly subject studies. Among the teachers of mainstream schools, 15 persons completed social rehabilitation pedagogy, including 4 persons educated in early school education and oligophrenopedagogy, 18 persons completed other fields of study.

All respondents declare that they have additional qualifications obtained during post-graduate studies and/or qualification courses. Among all the teachers, 6 persons completed post-graduate studies in 3 specialisations of special education.

With regard to the qualifications required for a teacher co-organising special education for students with autism, the existing legal regulations³¹ require preparation in the field of special education, but do not specify the specialisation precisely. Taking the above into account, 72 teachers have the required qualifications obtained as a result of graduating from master's or post-graduate studies.

It should be added that all teachers have completed at least several different forms of professional training and most of the respondents have completed specialist training in working with students with the autism spectrum. These include: *social skills training, students with autism in a mainstream school, autism from "a" to "z", how to work with a student with autism, how to support a student with autism and Asperger's syndrome, methods of working with an autistic student, methods of alternative communication.*

The declaration of undertaking further education is also noteworthy.

The included data show that teachers are very interested in professional development. Among those surveyed, 25 teachers of integration units declare the need for further education in the area of working with ASD students. These are people with work experience of up to 25 years. However, 17 persons (40.5%) do not plan or have no opinion on improving their qualifications. This group includes

³¹ <<https://www.nadzor-pedagogiczny.pl/porada/jakie-kwalifikacje-musi-posiadac-nauczyciel-wspoma/9285>>.

Table 4. Declared need for further education

Response categories	IS		MS		Total	
	T = 42	%	T = 33	%	T = 75	%
Yes	25	59.5	33	100	58	77.3
No	7	16.7	-	-	7	9.3
I have no opinion	10	23.8	-	-	10	13.3

Source: Own research.

mainly persons with longer work experience, of over 25 years, but also those with short work experience. In the case of the first group, long work experience and resulting professional experience, as well as a large number of training courses mean that these persons do not see the need for further education. The second group includes people who are facing a decision on staying in a given position or a change. The declaration of further education by teachers of mainstream schools is particularly noteworthy. This need was reported by 100% of respondents.

Teachers of both types of schools are interested in training concerning the following areas: *working with children with ASD, diagnosing these disorders, training in social skills, sexuality of children and youth, methods of working with people with autism, tutoring and special education sub-disciplines other than those already known*. Some of the respondents did not specify the area of further education, expecting proposals from the school. One of the respondents said: *trainings and courses on an ongoing basis, when I realise I have a lack of knowledge, I feel insecure*.

In total, 81 students with autism and students with Asperger's syndrome are assisted by support teachers, including 48 in integration units and 33 in mainstream schools. In the first group, 6 teachers support 2 students, the remaining ones - one. In the case of mainstream schools, this situation does not occur. In integrated units more than half of the students have a diagnosis of autism or multiple disability and 12 persons have a diagnosis of Asperger's syndrome. In mainstream classes, 30 students are diagnosed with

Asperger's syndrome and 3 with autism. It should be noted that teachers from integrated classes also perform their functions in relation to other children assessed as requiring special education.

Table 6. Students with autism, including Asperger's syndrome, supported by a teacher

Response categories	IS	MS	Total
Autism	27	3	30
Asperger's Syndrome	12	30	42
Multiple disability, including: - autism and motor disability - Asperger's syndrome and hearing loss	9	-	9

Source: Own research.

Taking into account the challenges faced by teachers in relation to the specific problems of children with autism and Asperger's syndrome, a question was asked about the way in which students communicate with each other and about the occurrence of difficult behaviours. These two areas of functioning are important for the organization of work in class, both in integration and mainstream classrooms, as well as for building friendly relations.

It was found that in integrated classes 35 out of 48 pupils show difficult behaviours, mainly disruptive behaviours. Teachers mentioned: *loud conversations, refusal to cooperate, refusal to perform a task, slow pace of work, walking around the classroom, laughing, clapping*. 7 students sometimes behave aggressively (*push and hit their peers*) and 2 show aggressive and self-aggressive behaviours (*not specified*), but according to the teachers *these can be controlled*. More serious communication problems occur in the case of 7 students (*quiet speech, single words, gestures*). In mainstream classes, 24 students show disturbing behaviours (*slow pace of work, refusal to perform a task*), including 4 students with additional aggressive behaviours (*harassment, use of vulgar words*). In this group all students communicate verbally, including 2 speaking single words.

Another issue was to identify the special needs of the students in relation to whom the respondents acted as a support teacher. The majority of respondents mentioned the following issues: *problems specific to the functioning of people with autism spectrum disorders, problems with behaviour, problems with mastering emotions*, also stating the resulting needs, e.g. *help in organizing work in class, motivating intellectual effort, anchored attention, calming down, help in planning work, explaining texts, checking the understanding of the text, help in accepting changes by explaining them, calming down, calming down emotions*. 6 persons mentioned *social skills building* and 2 persons mentioned *peer relations building*.

As can be seen, most of the problems identified by teachers are related to the didactic sphere. The survey contains less information on needs resulting from social functioning deficits and emotional problems apart from such general statements as *psychological support, emotional support (2 statements), accompaniment during breaks, conversation in a situation of breakdown (1 statement)*.

Another aspect of the study were actions taken in relation to students.

Table 7. Support for students with autism, including Asperger's syndrome, according to the respondents

Response categories	IS	MS
	number of responses	number of responses
Creating the best possible learning environment	20	10
Creating an optimal stimulating environment	20	8
Recognising and responding to the individual needs of the students	29	18
Adaptation of forms, methods and means of teaching to the abilities and individual needs of the students	42	33
Adaptation of educational requirements	40	22

Source: Own research. Respondents chose more than one response category.

The categories of support for autistic and Asperger syndrome students presented in Table 7 show that most of the choices concern the *adaptation of forms, methods and means of teaching to the abilities and individual needs of the student* (42 and 33), the *adaptation of educational requirements* (40 and 22) and the *recognition and response to the individual needs of the student* (29 and 18). These categories are specific to activities related to the education of students with special educational needs and hence the numerous indications are not surprising. The category most rarely chosen, especially by teachers of mainstream schools, were activities related to the creation of an optimal stimulating environment and the best possible learning environment, which, due to the specificity of functioning of students with ASD, including sensory disorders and behavioural problems is very important.

Table 8. The tasks of support teachers

Response categories	IS	MS
	number of responses	number of responses
Supporting students in their educational activities	42	33
Conducting revalidation classes	15	18
Conducting specialist classes	12	6
Carrying out a multi-specialist assessment of the level of student functioning	32	24
Informing teachers about the progress and difficulties of the student in the classroom	32	22
Helping teachers to adapt their educational requirements	30	19
Participation in the work of a team of teachers and specialists working with students, in the development and modification of IPET	42	33
Preparation of materials and aids for classes,	42	33
Participation in meetings with parents, informing parents about the students' progress, instructing them to work at home	38	28
Other, what kind?	no indications	no indications

Source: Own research. Respondents chose more than one response category.

Most of the responses were related to categories associated with the preparation of documentation concerning the implementation of special education, tasks related to fulfilling the duties of a teacher supporting students during lessons, preparation of didactic materials.

In the next section, teachers were asked to briefly describe the actions they take in relation to students during the educational activities. All the respondents answered this question by mentioning: *formulating simple instructions, avoiding mental short-cuts, metaphors, precise expectations, additional explanations, exercises in reading comprehension, dividing the material into smaller units, choosing didactic aids, preparing additional aids, checking the correctness and completeness of the notes, assisting in organizing work during the lesson, adjusting tests, work cards, explaining, precise expectations and assessments.* One of the respondents wrote: *I am constantly observing, discreetly, I do not impose myself and I react only when necessary.*

As far as the implementation of activities in the social and emotional sphere is concerned, 32 teachers of integration classes and 24 mainstream classes provided their answers. The respondents mentioned: *taking care of a good atmosphere in the classroom, using positive reinforcements, encouraging to work, encouraging to take up activity, reminding students about not interrupting the lesson, motivating them to be as independent as possible, showing approval of proper behaviours, using praise, calming down, controlling emotions, showing how to behave, making sure that the students observe the rules, helping to solve conflicts, helping in contacts with peers.*

No significant differences were noted in the statements of teachers of both groups.

31 teachers of integrated classes and 17 teachers of mainstream classes answered the question about supporting students outside their lessons, mentioning such activities as: *conversations with students, cooperation with parents, involvement in important school events, ensuring safety during events, excursions, group trips, stay in the school common room.* One person answered: *we are in constant contact, even after class,* and another one said: *I give tips on how to use the activity plan, tips for homework, I provide help in doing homework, show how to search for information.*

The statements show that the activities undertaken outside the classroom by the majority of teachers do not exceed the customary activities concerning all students.

An important aspect of the support teacher's work is cooperation with teachers, school pedagogues, parents or legal guardians of the child, as well as other persons related to education and psychological and pedagogical support.

Among the people with whom they cooperate are: *pedagogues and psychologists from the psychological-educational counselling centre, teachers conducting specialist classes and methodologists.*

Another aspect was the evaluation of cooperation with teachers and school pedagogues.

Table 9. Experience of cooperation between support teachers and teachers

Response categories	IS		MS		Total	
	T = 42	%	T = 33	%	T = 75	%
Very good	21	50.0	14	42.4	35	46.7
Good	11	26.2	13	39.4	24	32.0
Correct	10	23.8	6	18.2	16	21.3
Rather negative	-	-	-	-	-	-
Negative	-	-	-	-	-	-

Source: Own research.

Table 9. Experience of cooperation between support teachers and school pedagogues

Response categories	IS		MS		Total	
	T = 42	%	T = 33	%	T = 75	%
Very good	23	54.8	15	45.4	38	50.7
Good	10	23.8	11	33.3	21	28.0
Correct	9	21.4	7	21.2	16	21.3
Rather negative	-	-	-	-	-	-
Negative	-	-	-	-	-	-

Source: Own research.

The data contained in Tables 9 and 10 show that the vast majority of teachers in both types of schools declare good and very good experiences of cooperation with leading teachers and school pedagogues. A positive phenomenon is the lack of negative assessments of cooperation between teachers.

Support teachers also assessed their cooperation with parents, who should be considered as an important link in the education of children with disabilities.

Table 11. Assessment of cooperation between the support teacher and the student's parents

Response categories	IS		MS		Total	
	T = 42	%	T = 33	%	T = 75	%
Very good	16	38.1	9	27.3	25	33.3
Good	14	33.3	12	36.4	26	34.7
Correct	12	28.6	10	30.3	22	29.3
Rather negative	-	-	2	6.0	2	2.07
Negative	-	-	-	-	-	-

Source: Own research.

The analysis of the data contained in the table shows that the vast majority evaluates this cooperation as very good and good, although nearly 30% considered it to be correct and two teachers answered "rather negative". The majority of these persons are teachers with short work experience.

An important factor in working with a student with autism and Asperger's syndrome is the support received. When asked about support in the implementation of tasks of the support teacher, 6 teachers of mainstream schools answered that they do not receive such support, 2 persons receive support from the employees of psychological and pedagogical counselling centres and 25 persons indicated other teachers, as well as the school pedagogue and school psychologist. In the group of teachers from integrated classes,

37 persons receive support, while 15 teachers have more numerous and more diverse sources of support. These include other teachers and persons who are part of teams developing individual educational and therapeutic programmes, including a pedagogue, a psychologist, a speech therapist, employees of a psychological and pedagogical counselling centre. 8 teachers attend meetings of support groups organized by psychological-educational counselling centres. 5 persons from this group do not receive support.

Conclusion

The conducted pilot studies revealed that teachers undertake tasks related to students with autism and Asperger's syndrome resulting from the Regulation.

Almost all the respondents declared completion of master's and postgraduate studies that qualify them to work as support teachers for students with autism and Asperger syndrome. The surveyed teachers undertake activities related to professional development, including broadening and deepening of qualifications. For most of them the motivation for further education includes social needs and the requirements related to the education reform, for others – interest in educating specific groups of students. On the basis of the research it has been established that the most desirable subject matter of training is the broadly understood work with students with autism spectrum disorders. In the surveyed group, some teachers were not interested in further professional development, which may be related to their long work experience, and in other cases, the fact that the position of a support teacher may only be a stage in their professional career.

Research shows that in the integrated and mainstream schools, in which the surveyed teachers are employed, there are children who generally function better, most of them communicate verbally and present a higher level of intellectual functioning (including children with Asperger's syndrome). Most of these students attend mainstream schools.

Teachers correctly identify students' needs, however teachers of integrated classes do it better, which may result from greater experience.

The occurrence of difficult behaviours in students may be worrying, as this is one of the factors hindering the integration process. In this context, teachers' statements about their ability to deal with such behaviours should be read as a mitigating factor.

The respondents mentioned a number of activities undertaken to support students during and after classes, and when describing specific activities they mentioned activities focused on the didactic sphere and, although to a lesser extent, on social and emotional issues.

In the context of the occurrence of difficult behaviours, it is disturbing that less than half of the respondents indicated such elements of supporting the education of autistic students as creating the best possible learning and stimulation environment. The results suggest that most teachers either do not see the need for a well-prepared learning environment or do not see themselves as those who can take action to adapt the place or arrange the space. It may, therefore, be concluded that this aspect of support teachers' work should be given greater consideration in training.

Positive results were obtained in the scope of cooperation between teachers and other teachers, pedagogues, psychologists and employees of psychological and pedagogical counselling centres. Slightly lower ratings were given by the respondents with regard to cooperation with parents, however, also in this area the results should be considered as positive. The importance of cooperation between teachers and parents should be considered as a significant element facilitating the child's education process. Good cooperation builds trust, integrates, creates a platform for joint activities for the benefit of the child and the whole school community.

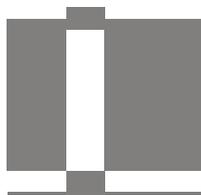
The vast majority of respondents can count on support and assistance in their difficult work, while many teachers have created a network of support consisting of teachers and other people involved in the education of students with autism.

The presented results of the pilot studies have shown many problems which may be an interesting field of research for special educators.

Bibliography

- [1] Boujut E., Dean A., Grouselle A., Cappe E., *Comparative Study of Teachers in Regular Schools and Teachers in Specialized Schools in France, Working with Students with an Autism Spectrum Disorder: Stress, Social Support, Coping Strategies and Burnout*, *J Autism Dev Disord* (2016) 46.
- [2] Chrzanowska I., *Wstęp*, „Interdyscyplinarne Konteksty Pedagogiki Specjalnej”, 2013, No. 1.
- [3] Chrzanowska I., *Pedagogika specjalna. Od tradycji do współczesności*, Oficyna Wydawnicza „Impuls”, Kraków 2015.
- [4] Chrzanowska I., *Wiedza na temat autyzmu wśród obecnych i przyszłych pedagogów a dylemat wspólnego kształcenia i integracji w wymiarze edukacyjnym*, „Rocznik Lubuski” 2012, Vol. 38, part 2, p. 112 (pp. 105–114).
- [5] Evans J., Lunt I., *Inclusive education: are there limits?* “European Journal of Special Need Education”, 2002, 17(1), pp. 1–14.
- [6] Firkowska-Mankiewicz A., Szumski G., *Pedagogika specjalna i system kształcenia osób z niepełnosprawnościami w Polsce*, [in:] *Pedagogika specjalna 2. Podręcznik akademicki*, D. D. Smith, Wydawnictwo PWN, Warszawa 2009.
- [7] Gałęcki P., Święcicki Ł. (academic supervision, Polish ed.) *Kryteria diagnostyczne z DSM 5: Desk Reference*, Wydawnictwo Edra Urban & Partner. Wrocław 2015.
- [8] Głodkowska J., *W poszukiwaniu modelu edukacji włączającej*, „Meritum”, 2009, No. 2(13).
- [9] Grzelak P., Kubicki P., Orłowska M., *Realizacja badania ścieżek edukacyjnych niepełnosprawnych dzieci, uczniów i absolwentów. Raport końcowy*, Educational Research Institute in Warsaw 2014.
- [10] Janiszewska-Nieścioruk Z., *(Nie)dojrzałość proinkluzyjnych zmian w kształceniu osób z niepełnosprawnością*, „Niepełnosprawność. Dyskursy pedagogiki specjalnej”, 2016, No. 22, pp. 47–59.
- [11] Klin A., *Typologia zaburzeń ze spektrum. Aspekty teoretyczne, badawcze i kliniczne*, [in:] *Diagnoza zaburzeń ze spektrum autyzmu*, ed. S. Goldstein, Jack A. Naglieri, S. Ozonoff, Wydawnictwo Uniwersytetu Jagiellońskiego, Kraków 2017.
- [12] Klinger L.G., O’Kelly S.E., Mussey J.L., *Diagnoza funkcjonowania intelektualnego w zaburzeniach ze spektrum autyzmu*, [in:] *Diagnoza zaburzeń ze spektrum autyzmu*, ed. S. Goldstein, Jack A. Naglieri, S. Ozonoff, Wydawnictwo Uniwersytetu Jagiellońskiego, Kraków 2017.

- [13] *Międzynarodowa Statystyczna Klasyfikacja Chorób i problemów Zdrowotnych. Rewizja 10 (International Statistical Classification of Diseases and Health Problems. Revision 10)*, WHO 2008, p. 248.
- [14] Nason B., *Porozmawiajmy o autyzmie. Przewodnik dla rodziców i specjalistów*, Wydawnictwo Uniwersytetu Jagiellońskiego, Kraków 2017.
- [15] Płatos M. (ed.), *Ogólnopolski spis autyzmu. Sytuacja młodzieży i dorosłych z autyzmem w Polsce*, Wydawca Stowarzyszenie Innowacji Społecznych „Mary i Max”, Warszawa 2016.
- [16] Olszewski S., Parys K., *Rozumieć chaos. Rzecz o terminach i znaczeniach im nadawanych w pedagogice specjalnej*, Wydawnictwo Naukowe Uniwersytetu Pedagogicznego in Kraków, Kraków 2016.
- [17] Rybakowski F., Białek A., Chojnicka I. et al., *Zaburzenia ze spektrum autyzmu – epidemiologia, objawy, współzachorowalność i rozpoznawanie*, „Psychiatria Polska” 2014, 48(4), pp. 653–665.
- [18] Rosenberg R.E., Kaufmann W.E., Law J.K., Law P.A., *Parent Report of Community Psychiatric Comorbid Diagnoses in Autism Spectrum Disorders*, “Autism Research and Treatment”, 2011 Aug. 18, <<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3420588/>> [access: 8 February 2018].
- [19] Regulation of the Minister of National Education of 9 August 2017 on the conditions for organising education, upbringing and care for children and youth with disabilities, socially maladjusted and at risk of social maladjustment § 7 section 7 and § 5 section 4 (Journal of Laws of 2017, item 1578).
- [20] Regulation of the Minister of National Education of 7 September 2017 on opinions and decisions issued by adjudicating panels operating in public psychological and pedagogical counselling centres; Journal of Laws of 2017, item 1743.
- [21] Sansosti J. M., Sansosti F., *Inclusion for Students with High-functioning Autism Spectrum Disorders: Definitions and Decision Making Psychology in the Schools*, 2012, Vol. 49(10), pp. 917–931.
- [22] Act of 14 December 2016 Education Law (Journal of Laws of 2017, item 59).
- [23] <<https://www.nadzor-pedagogiczny.pl/porada/jakie-kwalifikacje-musi-posiadc-nauczyciel-wspoma/9285/>> [access: 29 May 2019].



Work of teachers co-organising the process of education of pupils with special educational needs in the opinions of public school teachers

ABSTRACT: Marta Niemiec, *Work of teachers co-organising the process of education of pupils with special educational needs in the opinions of public school teachers*. Interdisciplinary Contexts of Special Pedagogy, no. 26, Poznań 2019. Pp. 81–102. Adam Mickiewicz University Press. ISSN 2300-391X. DOI: <https://doi.org/10.14746/ikps.2019.26.04>

One of the key issues within the area of issues related to contemporary special education is inclusive education. The purpose of the presented article is to analyse the key entities participating in the teaching and upbringing of pupils in the public educational system – the roles, tasks, professional qualifications, predispositions and personality traits of teachers of pupils with special educational needs. The article also presents results of research carried out by the author among teachers at public schools in the Silesian Voivodeship.

KEY WORDS: support teacher, inclusive education, pupil with special educational needs, public educational system

Introduction

Even though the idea of integration was already promoted in Poland by representatives of Polish special education in the 1970s, among others, by Otton Lipkowski or Aleksander Hulek, discourse,

disputes, scientific discussions continue until today as to what it actually is, what should inclusive education be like, what are its core conditions? Ever since the times of professors Hulek and Lipkowski, many theoretically and empirically valuable studies on inclusive educations have emerged¹, in which conditions necessary

¹ Issues of social and education inclusion are touched upon in their papers by, e.g.: Danuta Al-Khamisy, *Kształcenie uczniów ze specjalnymi potrzebami edukacyjnymi w powszechnym systemie oświatowym*, [in:] *Dydaktyka specjalna w przygotowaniu do kształcenia uczniów ze specjalnymi potrzebami edukacyjnymi. Podręcznik akademicki*, ed. by J. Głodkowska, Wydawnictwo Akademii Pedagogiki Specjalnej, Warszawa 2012, pp. 113–139; Iwona Chrzanowska, *Nauczanie inkluzyjne w doświadczeniach polskich – podstawy prawne i społeczne uwarunkowania*, „*Studia Edukacyjne*” 2014, no. 30, pp. 109–117; Beata Cytowska, *Przegląd badań empirycznych nad inkluzją w edukacji*, „*Problemy Edukacji, Rehabilitacji i Socjalizacji Osób Niepełnosprawnych*” 2016, no. 22/1, 189–213; Anna Firkowska-Mankiewicz, *Idea integracyjnego kształcenia i edukacji włączającej w polskiej pedagogice*, [in:] „*Pedagogika specjalna, podręcznik akademicki*” vol. 2, ed. by D.D. Smith, A. Firkowska-Mankiewicz, G. Szumski, Wydawnictwo Akademii Pedagogiki Specjalnej, Wydawnictwo Naukowe PWN, Warszawa 2008, pp. 319–346; Zenon Gajdzica, *Opinie nauczycieli szkół ogólnodostępnych na temat edukacji włączającej uczniów z lekkim upośledzeniem umysłowym w kontekście toczącej się reformy kształcenia specjalnego*, [in:] *Uczeń z niepełnosprawnością w szkole ogólnodostępnej*, ed. by Z. Gajdzica, Wydawnictwo Wyższej Szkoły Humanitas, Sosnowiec 2011, pp. 56–79; Joanna Głodkowska, *W poszukiwaniu modelu edukacji włączającej*, „*Meritum*” 2009, no. 2, pp. 5–8; Zdzisława Janiszewska-Nieścioruk, *(Nie)dojrzałość proinkluzyjnych zmian w kształceniu osób z niepełnosprawnością*, „*Niepełnosprawność. Dyskursy pedagogiki specjalnej*” 2016, no. 22, pp. 47–59; Amadeusz Krause, *Współczesne paradygmaty pedagogiki specjalnej*, Oficyna Wydawnicza „Impuls”, Kraków 2011; Joanna Kruk-Lasocka, *Dostrzec dziecko z perspektywy edukacji włączającej*, Wydawnictwo Naukowe Dolnośląskiej Szkoły Wyższej, Wrocław 2012; Viktor Lechta, *Pedagogika inkluzyjna*, [in:] *Pedagogika. T. 4. Subdyscypliny i dziedziny wiedzy o edukacji*, ed. by Bogusław Śliwerski, Gdańskie Wydawnictwo Pedagogiczne, Gdańsk 2010, pp. 321–335; Grzegorz Szumski, *Edukacja włączająca – niedokończony projekt*, „*Ruch Pedagogiczny*” 2014, no. 4, pp. 127–139; Tamara Zacharuk, *Włączająca edukacja*, [in:] *Encyklopedia Pedagogiczna XXI w.*, vol. VII, ed. by T. Pilch, Wydawnictwo Akademickie „Żak”, Warszawa 2008, pp. 167–173; Anna Zamkowska, *Kompetencje nauczyciela wymagane w pracy z uczniem z niepełnosprawnością umysłową w procesie edukacji inkluzyjnej*, [in:] *Kompetencje pedagoga specjalnego. Aktualne wyzwania teorii i praktyki*, ed. by Z. Palak, A. Bujnowska, Wydawnictwo Uniwersytetu Marii Curie-Skłodowskiej, Lublin 2008, pp. 79–88.

for the emergence of inclusive education are thoroughly analysed in which studies are shown that indicate the reasonability of argumentation both in favour of inclusion as well as against it, and in which diverse hazards and barriers are presented that could prevent the idea of full social or educational participation, the equalisation of changes for persons with special education needs.² At the same time, the majority of authors – researchers and theorists of the discussed issue, unequivocally stress the fact that inclusive education should primarily support the development of all pupils, take into account their diversity, respond to individual needs or design changes in the education system in such a way so that they would not bring all pupils into line, but focus on broadly understood flexibility in education work, with the result being the pupils that need support feeling members of the school. The problematic issue, however, continues to be the lack of semantic clarity of the term of inclusive education, as Iwona Chrzanowska notes in her article when she writes: [...] *Polish law does not contain a clear definition of the term. It is frequently treated synonymously to the concept of integration, and at certain times it is understood as a further, higher stage towards normalisation of not only the education situation of disabled persons.*³ Inclusive education is thus sometimes understood to be a synonym of integration education, a version of integration education or finally an expanded form of integration education.⁴ For instance, the concept of Piero Crispiani describes inclusion as a culture that first encom-

² The mentioned risks are broadly analysed by Grzegorz Szumski in the article „Edukacja włączająca – niedokończony projekt, „Ruch Pedagogiczny” 2014, no. 4, pp. 127–139.

³ I. Chrzanowska, *Nauczanie inkluzyjne w doświadczeniach polskich – podstawy prawne i społeczne uwarunkowania*, „Studia Edukacyjne” 2014, no. 30, pp. 111.

⁴ Terminological discourse on the topic is undertaken in the study by Grzegorz Szumski and Anna Firkowska-Mankiewicz in the book: G. Szumski, with A. Firkowska-Mankiewicz, *„Wokół edukacji włączającej. Efekty kształcenia uczniów z niepełnosprawnością intelektualną w stopniu lekkim w klasach specjalnych, integracyjnych i ogólnodostępnych*, Wydawnictwo Akademii Pedagogiki Specjalnej, Warszawa 2010, pp. 11–28.

passes the disabled person as being integrated, and afterwards, contexts that are open and dispositive to integration. Hence, according to the author, inclusion is not a process, but a culture that is connected to an open integration context. Inclusion requires diverse strategies: early diagnosis (in particular functional diagnosis), special education (ortodidactics), an extensive support system, etc. Integration is a process, in which the disabled person effectively participates in social activities and interpersonal relations.⁵ Viktor Lechta in turn, in his study concerning inclusive pedagogy, clearly differentiates between the terms of integration and inclusion. He associates the first with the concept of tolerance, while linking the other to the concept of full acceptance.⁶ European provisions and rules (e.g. the Luxembourg charter that speaks of a school for everyone) stress the significance of full participation in all areas of social life by persons with diverse disabilities. The UNESCO document of 2009 – *Policy Guidelines on Inclusion in Education*, reads: *Inclusion is thus seen as a process of addressing and responding to the diversity of needs of all children, youth and adults through increasing participation in learning, cultures and communities, and reducing and eliminating exclusion within and from education.*⁷ According to the European Agency for Development in Special Needs Education, the key factors of inclusive education are considered to be the following: active participation of pupils in an education process that is understandable to them; supporting positive attitudes among persons engaged in the education of pupils with a broad range of education needs; proper teacher training; support for participation of pupils and parents when making decisions concerning the education process; development of an Individual Education Plan requir-

⁵ P. Crispiani, *System rehabilitacji i edukacji osób niepełnosprawnych we Włoszech*, [in:] *Spółeczno-pedagogiczne konteksty niepełnosprawności*, ed. by T. Żółkowska, wolumina@pl, Szczecin 2011, p. 123.

⁶ V. Lechta, *Pedagogika inkluzyjna*, [in:] *Pedagogika. T. 4, Subdyscypliny i dziedziny wiedzy o edukacji*, ed. by B. Śliwerski, Gdańskie Wydawnictwo Pedagogiczne, Gdańsk 2010, pp. 321–335.

⁷ UNESCO, *Policy Guidelines on Inclusion In Education*, UNESCO, Paris 2009, p. 7.

ing the utilisation of suitable didactic and educational strategies and solutions; development of a team action system based on cooperation of pupils, teachers, persons employed at the school, specialists and parents; learning and solving problems on the basis of cooperation with others; an individualised approach to every pupil; usage of an assessment system that would support the learning process.⁸ It is easy to notice that practically all factors are largely dependent on the teacher – both on the specialist teacher who should have the proper professional qualifications in terms of special education, competences and skills, but also the course teacher, who should also be required to have appropriate knowledge, competences, skills, properties or personal inclinations.

The role and the tasks of special education paedagogues in public schools

Issues concerning the functions, roles and tasks of special education paedagogues in public schools (including special and integration schools) is inseparably tied to issues related to vocational reparation, directives or demands related to the standards of education of teachers in terms of the future specialist paedagogues being equipped with relevant knowledge, skills, competences, as well as the implementation or verification of these in the school reality. The first part of these thoughts is devoted to the presentation of current laws governing the work of a teacher co-organising the education process for pupils with special education needs, to subsequently focus on an analysis of subject literature concerning the topic at hand on the basis of scientific views and an analysis of selected empirical studies.

In Poland, the status of support teacher is described in the newest Regulation of the Polish Minister of National Education of August 9th, 2017, on the conditions of organisation of education,

⁸ European Agency for Development In Special Needs Education, *Key principles for promoting quality in inclusive education – Recommendations for Policy Makers* Odense, Denmark 2009, pp. 14–19.

upbringing and care for children and youths who are disabled, socially maladapted and threatened by lack of social adaptation and the Regulation of the Polish Minister of National Education of August 25th, 2017, on the mode of keeping of documentation of teaching, education and care work by public preschools, schools and institutions, as well as the types of such documentation. At the same time it must be noted that beginning in January of 2016, on the basis of the Regulation of the Polish Minister of National Education of July 24th, 2015, on the conditions of arrangement of education, upbringing and care for children and youths with disabilities, social misadaptations and threatened by social misadaptation (Polish Journal of Laws of 2015 item no. 1113), changes were made to the rules of employment of support teachers. Beforehand, in order for the indicated teacher to be employed, the consent was required of the authority running the institution. The Regulation of the Polish Ministry of Education of 2016 removed this requirement, thus transferring the decisive significance onto the recommendation of the certificate about the need of special education. The employment of a support teacher thus became obligatory for headmasters of public schools that are attended by pupils with the indicated certificates. Of course, it is the parents or legal custodians of the child who have the final say on the issue of the need to work with a support teacher.

According to the latest regulation of 2017, in addition, teachers are employed qualified in special education in order to co-organise the education process at preschools and public schools with integration departments, integration facilities as well as public preschools and schools, where special education covers pupils having certificates confirming the need of special education issued due to autism, including Asperger syndrome or multiple disabilities or others (in this case, with the consent of the operating authority). The Regulation further sets out the general tasks that a support teacher should execute in their work.⁹ The fundamental areas, to which the tasks of

⁹ Regulation of the Polish Minister of National Education of August 9th, 2017 on the conditions of organisation of education, upbringing and care for children and

the support teacher boil down, can be synthetically listed as: individualisation of the pupil's teaching process, or adaptation of the education requirements to their individual needs on the basis of recommendations indicated in the certificate issued by an education and psychological counselling facility or a different special counselling facility (adaptation of curriculum content, of forms and resources of work, of the modes of evaluation), aid for and cooperation with teachers, parents and other specialists and entities related to the pupil's education, execution of re-validation, social therapy, re-socialisation activities, drawing up and keeping of relevant documentation of the child (e.g. certificates concerning the need for special education, general assumptions for therapeutic and revalidation work as developed individually for every child, opinions, descriptive evaluations that are attached to the end-of-term and end-of-year grades, including a multi-speciality evaluation of the pupil's level of functioning. In addition, the teacher co-organising education should keep a journal, where they record their weekly agenda of activities and activities from the individual days, including information about contact with persons and institutions, with which they cooperate when executing their duties.¹⁰

Analysing the subject literature with respect to the functions and tasks of special paedagogues, one must be reminded of the views of one of the forerunners of Polish special education – Otton Lipkowski. He paid particular attention to specific education activities that should emerge in the education and upbringing process, such as: cooperation of the public school with psychological and paedagogi-

youths who are disabled, socially unadapted and threatened by lack of social adaptation, § 5 p. 4, § 6, § 7 Polish Journal of Laws of 2017, item no. 1578; conf. also: R. Cybulska, H. Derewlana, A. Kacprzak, K. Pęczek, *Uczeń ze specjalnymi potrzebami edukacyjnymi w świetle nowych przepisów prawa oświatowego*, Ośrodek Rozwoju Edukacji, Warszawa 2017, pp. 7–9 and pp. 58–70.

¹⁰ Regulation of the Polish Minister of National Education of August 25th, 2017 on the mode of keeping of documentation of teaching, education and care work by public preschools, schools and institutions, as well as the types of such documentation, § 18, § 19 Polish Journal of Laws of 2017, item no. 1646.

cal counselling facilities or therapeutic facilities; cooperation with the closest family, should an improper family environment be the cause of the pupil's wrong development; organisation at the public school of individual aid for persons with learning difficulties; organisation of education teams; offering of corrective exercise in the area of speech therapy, posture, motor development.¹¹ Without a doubt, these are clear suggestions describing the need to act in terms of education in order to include pupils with development and education difficulties to the functioning of the school. Lipkowski also assigned much significance to functions of dynamisation that should characterise the entire didactic and education process of pupils with learning difficulties, for the implementation of which teachers should be responsible. These functions are: stimulation, acceleration, compensation or culture creation¹². Studies concerning the functions of support teachers and their actual implementation in school practice were conducted by Magdalena Korneluk and Milena Nazarczuk. The studies were conducted on a group of 42 support teachers working at integration classes of primary schools and schools above the primary level in Siedlce, Poland. The authors were able to show that the majority of tasks and functions were actually executed by the support teachers. The most commonly indicated tasks of special paedagogues were: development and preparation of education aids for able pupils as well as organisation of good cooperation with the pupil's home environment. The greatest difficulties and problems encountered by the studied support teachers in their work are: insufficient teaching aids for pupils with special education needs, incorrect attitudes of healthy pupils with respect to the disabled, undesirable behaviour of disabled pupils, difficulty understanding teacher commands by pupils, attention focus deficiencies, difficulty communicating with the disabled pupil. Data acquired by the study authors also showed that the majori-

¹¹ O. Lipkowski, *Pedagogika specjalna*, Wydawnictwo PWN, Warszawa 1981, p. 107.

¹² O. Lipkowski, *Pedagogika specjalna*, Wydawnictwo PWN, Warszawa 1981, p. 18.

ty of support teachers noted the need of change of attitudes with respect to the special paedagogue, because, in their opinion, this work is in many cases not appreciated. The majority of support teachers also did not satisfactorily evaluate their cooperation with the remainder of the teachers at the school, indicating that it frequently lacks partnership, understanding and respect.¹³ Within the context of the quoted study results, a further interesting study conducted in the year 2013 in the Świętokrzyskie Voivodeship of Poland may also be presented here, analysed in the article entitled *Mainstream school as a meeting space of teachers and special educators – promoting the idea of inclusive education*, by Mirosław Rutkowski and Karol Bidziński. The researchers write, among others, about special paedagogues as *(un) necessary specialists*, using the following argumentation: the analysed support teachers had professional qualifications gained mainly through qualification courses, to a lesser extent in course of post-diploma or field-specific studies, in addition, they were educated according to the biomedical disability model, and evaluating their material and methodical competences, they primarily indicated preparation for work with persons with intellectual disabilities, evaluating much lower their diagnostic, planning, execution or evaluation competences with respect to support for the development of pupils with special education needs that stemmed from social misadaptation, risks of social misadaptation, pupils with special learning difficulties or particularly gifted pupils. The results of tests conducted among 405 teachers of public schools indicated limited effectiveness and availability of support by special paedagogues for course teachers. The respondents expressed the opinion that a special paedagogue is not necessary as an important and effective source of support. Teachers of public schools themselves did not feel competent to work with pupils with individual education needs that stemmed from disability. They saw the cause in the lack

¹³ M. Korneluk, M. Nazarczuk, *Zakładane i realizowane funkcje nauczycieli wspomagających w klasie integracyjnej*, „Student Niepełnosprawny. Szkice i Rozprawy” 2008, no. 8(1), pp. 189-215.

of sufficient preparation during studies. In their conclusions, the authors of the quoted study noted that communication difficulties, deficiencies in terms of professional competences and primarily lack of full consent to the idea of implementation of inclusive education can form a barrier in the establishment of a community of teachers of public schools and special paedagogues.¹⁴

Within the context of thoughts on the professional competences of special paedagogues (including future support teachers), particular attention needs to be paid to the aspect of competences. This describes both competences related to knowledge in the area of special education, psychological and paedagogical, diagnostic, therapeutic, education and didactic competences, but also personal competences (related to personal traits and dispositions) or finally social and emotional competences. In her study, Anna Zamkowska – referring, among others, back to Aleksandra Maciarz and studies on these issues – writes about dispositions to work as a support paedagogue and properties characterising successful teachers in the area of inclusive education. Such persons should have a suitable scope of knowledge about the different categories of disabilities, but also the skills to provide care, educate and teach disabled children and youths, express positive emotional attitudes with respect to them, be characterised by sensitivity to a pupil's individual needs and be convinced about the value of inclusive education and teaching of children and youths with special education needs. In addition, special paedagogues working within inclusive education should have such personal traits as: patience, perseverance, a good attitude, resistance to stress.¹⁵ Danuta Al-Khamisy indicates the need to perfect the following competences and skills among inclusive education

¹⁴ M. Rutkowski, K. Bidziński, *Szkoła ogólnodostępna przestrzenią spotkania nauczycieli i pedagogów specjalnych – realizatorów idei edukacji włączającej*, „Niepełnosprawność. Dyskursy pedagogiki specjalnej” 2018, no. 29, pp. 43–65.

¹⁵ A. Zamkowska, *Kompetencje nauczyciela wymagane w pracy z uczniem z niepełnosprawnością umysłową w procesie edukacji inkluzyjnej*, [in:] *Kompetencje pedagoga specjalnego. Aktualne wyzwania teorii i praktyki*, ed. by Z. Palak, A. Bujnowska, Wydawnictwo Uniwersytetu Marii Curie-Skłodowskiej, Lublin 2008, pp. 79–88.

teachers: the ability to recognise and satisfy diverse education needs of pupils; the attitude of openness to cooperation with pupils' parents and families; the ability to work in a team facilitating efficient cooperation with other teachers and specialists both at the school as well as outside of it.¹⁶ Diagnostic studies concerning the feeling of professional competences to work with a disabled pupil among early school education teachers were conducted by Marta Uberman and Aleksandra Mach. The authors adopted the qualification of professional competences suggested by Aniela Korzon (praxeological competences, communication competences, creative competences), taking into account material and methodical preparation of teachers to work with disabled pupils, as stressed by the Polish Ministry of Education in the professional competence standards. The study was conducted in 2015 at 19 public schools from the subcarpathian voivodeship region. The researchers used an original tool – the scale of assessment of own competences in didactic and education work with a disabled pupil and a survey questionnaire, which is also proprietary. The results acquired by the study authors indicated that 75% of those surveyed consider their own professional competences and the preparation for work with a disabled child as being average. Similar results were obtained for all three distinguished competences. As it turns out, teachers were fully aware that their knowledge and skills are insufficient to efficiently work with disabled pupils.¹⁷

¹⁶ D. Al-Khamisy, *Kształcenie uczniów ze specjalnymi potrzebami edukacyjnymi w powszechnym systemie oświatowym*, [in:] *Dydaktyka specjalna w przygotowaniu do kształcenia uczniów ze specjalnymi potrzebami edukacyjnymi. Podręcznik akademicki*, ed. by J. Głodkowska, Wydawnictwo Akademii Pedagogiki Specjalnej, Warszawa 2012, pp. 113–139.

¹⁷ M. Uberman, A. Mach, *Kompetencje nauczyciela edukacji wczesnoszkolnej w szkole ogólnodostępnej w pracy z dzieckiem z niepełnosprawnością*, „Lubelski Rocznik Pedagogiczny” 2016, vol. XXXV, issue 3, pp. 165–185; Conf. also studies by Krystyna Barłóg (e.g. quoted in papers by M. Uberman and A. Mach), the subject of which is support the development of children with minor intellectual disabilities in diverse early education forms. These studies also applied to the area of competences. The results acquired by this researcher disclosed that public school teachers assessed their

The success of the idea of inclusive education is doubtless based on good cooperation of support teachers with teachers of the specific course. In this regard, of significant importance are attitudes towards pupils with individual needs, the conviction concerning the justification of joint teaching of all pupils, relevant knowledge and professional preparation of this second group of teachers as well. The particular situation that teachers of public schools who are not special paedagogues are in, is described by Dorota Krzemińska and Krystyna D. Rzedzicka in the article entitled, *On vocational schooling of special educators' – the (un)changed landscape?* In course of a thorough analysis of object literature (including an analysis of published empirical studies) the authors conclude that public school teachers who are not special educators are not enthusiastic towards inclusive education, that in course of their own vocational preparation they did not acquire knowledge and competences to work with disabled pupils, that they express ignorance of basic concept systems related to the classification of the disabled, their integration, diagnosis, preventive care, focusing mainly on deficiencies related to the limited abilities of pupils, are characterised by ambiguity in terms of evaluation of pupils with special education needs and lack of creativity in the activities undertaken with respect to them.¹⁸

Assumptions and analysis of own research

The own research presented in this study are a fragment of a larger empirical undertaking, the subject of which were made broadly understood issues of the work of the teacher co-organising the process of education of pupils with special education needs in

competences decidedly lower than special and integration school teachers – see K. Barłóg, *Wspomaganie rozwoju dzieci z niepełnosprawnością intelektualną w stopniu lekkim w różnych formach edukacji wczesnoszkolnej*, Wydawnictwo Uniwersytetu Rzeszowskiego, Rzeszów 2008.

¹⁸ D. Krzemińska, K.D. Rzedzicka, *O przygotowaniu zawodowym pedagogów specjalnych – krajobraz (bez)zmian?*, „Niepełnosprawność” 2009, no. 1, pp. 113–124.

public education. The mentioned research project was planned on the basis of a quantitative and qualitative research strategy – “(...) *consideration in social (education) research of diverse points of view, expressed mainly by the fusion of quantitative and qualitative methods (as being complementary with respect to each other), as recommended by Polish paedagogues and specialists in the area of education methodology*”.¹⁹ The study presented here are a pilot study, introductory research, the fundamental objective of which – as it was assumed to be in the form of a diagnostic study – was to get to know only a certain section of the research reality, meaning, the opinion of special educators and other public school teachers (early school education teachers and course-specific teachers) on the work (roles, tasks, properties and personal dispositions) of teachers co-organising the process of education of pupils holding certificates on the need of special education. The own research uses a proprietary survey questionnaire, constructed mainly on the basis of closed and semi-open question and answer systems. During the planning and construction stage of the tool, attention was given to include criteria of psychometric quality, e.g. objectivity, standardisation, aptness.²⁰ The questions of the survey, aimed at the studied teachers, are focused on such areas as: I. Professional qualifications of the analysed teachers; II. Working with pupils with special education needs; III. Skills, personal dispositions.

The research problems took the form of the following questions:

1. *What are the properties of the work (the role and tasks) of a teacher co-organising the process of education of pupils with certificates on the need for special education at the studied public schools?*
2. *What aspects in particular are related to the role and tasks of a support teacher that are the most important success factors of didactic and education work with pupils with special education needs as*

¹⁹ W. Dróżka, *Triangulacja badań. Badania empiryczne ilościowo – jakościowe*, [in:] *Podstawy metodologii badań w pedagogice*, ed. by S. Palka, Gdańskie Wydawnictwo Psychologiczne, Gdańsk 2010, p. 134.

²⁰ Conf. E. Hornowska, *Testy psychologiczne – teoria i praktyka*, Wydawnictwo Scholar, Warszawa 2007, pp. 25–32.

evaluated by teachers conducting classes, including from the point of view of support teachers themselves?

3. *In the opinion of the analysed teacher groups, which competences, skills, personal properties should a support teacher have?*

Table 1. Professional qualifications of surveyed support teachers

Main education	Support teachers		Post-diploma studies, qualification courses, others	Support teachers
	N	%		N
Early education	12	25	Oligophrenic paedagogy	28
Early education with oligophrenic paedagogy	3	6	Surdopedagogy	27
Care and education paedagogy	3	6	Tyfopedagogy	19
Resocialisation paedagogy	1	2	Speech therapy	10
Education in the subject being taught	21	44	Post-diploma studies on working with pupils with ASD	26
Oligophrenic paedagogy	7	15	Resocialisation and sociotherapy	11
Special paedagogy within resocialisation	1	2	Others	40
Total:	48	100	-	161 *most teachers have more than one additional education unit.

Source: Own work.

The study was conducted between February and April of 2019. Initially, 205 surveys were distributed among teachers and special educators working at public schools in the regions of Silesia and Dąbrowa Basin of Poland. As a result, 102 returned and completed surveys were analysed. The study covered 48 support teachers and 54 teachers not being support teachers (early school education teachers and 2nd education stage teachers) from 10 public primary schools (entities from the localities of Katowice, Siemianowice Śląskie,

Sosnowiec, Będzin and Czeladź). Among support teachers, women made up 92% of those surveyed, the remaining 8% being men. Among the studied teachers not being support teachers, 76% were women and 24% men. The highest share in both groups were nominated and certified teachers, there were almost 74% of all teachers participating in the study, whereby in the group of support educators – there were slightly more nominated teachers – 21 (44%) than certified teachers (17, or 35%). The opposite tendency was found in the group not being support teachers, with the most being certified teachers, at 36%, followed by nominated teachers, 33%.

In terms of preparation for working in the profession, the studied support teachers acquired their qualifications in the area of special education mainly during post-diploma studies and additional qualification courses. The main education of the majority of support teachers is related to the course or subject they teach, at 44% and in the area of early education, at 25%, totalling at approx. 70% of the studied group. A much lower percentage (25% in all) are special educators “from the outside”, the main field of whom is special paedagogy or one of its subfields. In terms of additional education in the form of post-diploma studies, qualification courses, the studied support teachers frequently have more than one specialisation. The conducted study also shows that the majority of the analysed teachers presently only work with a single pupil certified to be in need of special education. There were 12 teachers who indicated working with more than one pupil needing support, which made up 25% of all those surveyed in this group. The majority of teachers work with pupils with autism spectrum disorders – 22 persons, the least work with pupils with multiple disabilities – four teachers. In addition, 34 of the surveyed teachers offer re-evaluation classes and 16 teachers hold socio-therapeutic and resocialisation classes.

In the area of questions related to the work of teachers with pupils with special education needs, these were categorised. Such aspects were distinguished as: 1.) Execution of general tasks; 2.) Cooperation with the course teacher; 3.) Cooperation with the pupil’s parents; 4.) Most common barriers and difficulties in the work of

a support teacher. The studied teachers chose one of many suggested responses concerning the individual aspects related to the role and the tasks of a support teacher. They were to indicate that particular response that they believed to be most significant from the point of view of inclusivity of their work and the success of inclusive education.

Table 2. Execution of tasks of a support teacher – most common responses by the studied teachers

Task execution aspects	Responses of support teachers	%	Responses by teachers not being support teachers	%
Within general tasks	Correct selection of methods, forms and resources to work with the pupil.	73	Supporting the teachers with professional knowledge	79
Within cooperation with the course teacher	Cooperation in terms of determining the scope of education adaptations for the pupil.	76	In cooperation with the course teacher – determination of work during the class	74
Within cooperation with the pupil's parents	Inclusion of parents to cooperate with the school, the special education facility	61	Supporting the parents with professional knowledge	63
Barriers, difficulties encountered in work	Contact with the parents	53	Lack of support teacher skills to cope with undesirable behaviour, aggression of the pupil.	56

Source: Own work.

As table 2 shows, teacher responses indicate various choices. It seems that for public school teachers, specific activities undertaken by support teachers are the most important. They expect aid, knowledge and specific solutions to difficulties or problems that emerge in course of work with a pupil requiring particular support. They also indicate that they are the leaders when it comes to the class education process conducted together with the support teacher. Support teachers, in turn, in their most frequent responses focused

mainly on the needs of pupils, mainly stressing the adaptation of all those components of the education process that are able to satisfy the needs of pupils and their capacities as optimally as they can. Within the scope of activities in concert with the course teacher, they appreciate the cooperation component, hence, common engagement in the process of requirement adaptation.

The ultimate area of the study applied to personal skills and traits that should characterise a support teacher. In the view of support teachers, the key skill should be *identification and accentuation of a pupil's strong suits* – 62% of those surveyed; course teachers considered the most desired skill to be the *ability to motivate the pupil* – 59% of those surveyed. Among personal traits, support teachers most frequently indicated: *understanding the pupil's needs* 51%, *empathy* 31%, and teachers from the second surveyed group indicated such properties as *communication ability* 42% and *patience* 38%.

Discussion of the own survey results and conclusions

The key conclusions from the conducted studies, at the same time forming responses to the formulated research problems, can be summarised as follows: 1. Only 25% of the analysed support teachers have special paedagogy as their leading field of education. In most cases these are early education teachers or course teachers who acquired their special education licences during post-diploma studies and in course of post-diploma and additional qualification courses. 2. Considering the execution of roles and tasks that are of significant importance for inclusive education, support teachers considered the following to be the most important: correct choice, preparation and adaptation of education material for pupils, cooperation with course teachers in terms of determination of the education adaptations for pupils, inclusion of parents to cooperate with the school; however, in terms of the encountered barriers and difficulties, it was specifically contact with teachers that turned out to be the most difficult for the educators who were surveyed. At the same

time, the group of teachers not being support teachers declared the following choices: professional knowledge aid provided to them by support teachers, joint determination of activities during classes (one should consider the motivation for this choice; perhaps the case concerns the will to maintain a “dominant” position of teachers holding classes, for whom it is important that the course of the class be consulted), support for teachers with the professional knowledge of support teachers (this selection would suggest the will to transfer responsibility for contacts with parents of “difficult” pupils to support teachers; this would require further study), in the aspect of the encountered barriers and difficulties in the work of the support teacher; the second group of respondents indicated lack of ability of special educators to cope with undesirable behaviour, with pupil aggression (this may suggest the need to take „a closer look” and more thoroughly analyse curricula for special educators – how are special educators prepared to handle difficult situations, what is their actual knowledge on the diverse signs of behaviour disturbances, etc.; are there courses on this topic in their study curriculum and what is their volume?). 3. The studied teachers considered considered diagnostic skills concerning the recognition of strong suits of pupils to be the most significant skill that should characterise a support teacher; course teachers indicated the ability to motivate pupils as such a skill. In both groups, the studied teachers considered properties such as empathy, communication, patience, understanding pupil needs to be important in the work of a support teacher. Within the context of the acquired results of own studies, quoted should be here the study by Maria Flanczewska-Wolny and Jerzy Wolny of 2017. Using their survey questionnaire, the researchers studied a group of 51 teachers in public education (the study spanned teachers from one primary school and two lower secondary schools), also from the territory of the Silesian Voivodeship. The survey asked public school teachers to express their attitude towards tasks to be executed by special paedagogues. The acquired results showed that the activity forms of support teachers considered most important by the respondents should include those that

are to reduce as strongly as possible difficulties related to the fact of a disabled pupil being a member of the class, so as to ensure that they are able to conduct their class without excess disturbances, which would align with the results of own research presented above. However, further findings of the researchers fail to align with the results of the study acquired by the author of the present paper. The studied teachers largely failed to notice the value related to professional support by special educators, the ability to “make use” of their competence resources or special knowledge about the details of diverse disturbances, even for the purpose of expansion of their own skills and professional development.²¹

The presented own research absolutely does not exhaust the issues at hand. It only applies to a minor aspect of the important issue that currently is the role of special educators in the inclusive education system. They do not allow any overly general conclusions, even for the reason of the relatively minor research group. They certainly require further, more detailed exploration and analyses expanded also to include parents and pupils, as well as the usage of methods, techniques and tools characteristic for quality strategies in the study.²² They can constitute a contribution to the ever open scientific discourse in the mentioned field, e.g.:

- with respect to issues of elevation of the status of support teacher and of their work in public education²³;

²¹ M. Flanczewska-Wolny, J. Wolny, *Pedagog specjalny-asystent ucznia z niepełnosprawnością w szkole ogólnodostępnej w opiniach nauczycieli*, [in:] *Wybrane konteksty i wyzwania współczesnej pedagogiki specjalnej*, ed. by K. Barłóg, Wydawnictwo Uniwersytetu Rzeszowskiego, Rzeszów 2017, pp. 228–241.

²² As noted in the chapter on assumptions to the own work – the author of the present study continues work in the discussed scope.

²³ A reference may be provided among Scandinavian countries, such as e.g. Finland, considered to be a country with one of the best education systems and showing great success in education of disabled pupils, where teaching is a profession held in high esteem. Only 10% of candidates are accepted to study to become teachers, and the recruitment procedure ahead of studies is bi-level, checking dispositions of the study candidates in many areas – see D. Mitchell, *Sprawdzone metody w edukacji specjalnej i włączającej. Strategie nauczania poparte badaniami*, Wydawnictwo Harmonia Universalis, Gdańsk 2016, pp. 371–379.

- issues related to vocational preparation of future special educators, the standards of their teaching²⁴, the quality of curricula, also during post-diploma studies;
- issues related to paedagogical preparation of public school teachers (in particular course teachers), the number of modules and the duration of classes in special education;
- as part of the working methods of teachers co-organising education, issues related to the introduction of new content expanding upon the skill of broadly understood cooperation; beside methodical competences the development of social, emotional, education skills that would permit differentiation between the functions of re-validator and educator.

Bibliography

- [1] Al-Khamisy D., *Kształcenie uczniów ze specjalnymi potrzebami edukacyjnymi w powszechnym systemie oświatowym*, [in:] *Dydaktyka specjalna w przygotowaniu do kształcenia uczniów ze specjalnymi potrzebami edukacyjnymi. Podręcznik akademicki*, ed. by J. Głodkowska, Wydawnictwo Akademii Pedagogiki Specjalnej, Warszawa 2012, pp. 113–139.
- [2] Barłóg K., *Wspomaganie rozwoju dzieci z niepełnosprawnością intelektualną w stopniu lekkim w różnych formach edukacji wczesnoszkolnej*, Wydawnictwo Uniwersytetu Rzeszowskiego, Rzeszów 2008.
- [3] Crispiani P., *System rehabilitacji i edukacji osób niepełnosprawnych we Włoszech*, [in:] *Společno-pedagogiczne konteksty niepełnosprawności*, ed. by T. Żółkowska, wolumina@pl, Szczecin 2011, p. 123.
- [4] Chrzanowska I., *Nauczanie inkluzyjne w doświadczeniach polskich – podstawy prawne i społeczne uwarunkowania*, „*Studia Edukacyjne*” 2014, no. 30, pp. 109–117.
- [5] Cybulska R., Derewlana H., Kacprzak A., Pęczek K., *Uczeń ze specjalnymi potrzebami edukacyjnymi w świetle nowych przepisów prawa oświatowego*, Ośrodek Rozwoju Edukacji, Warszawa 2017.
- [6] Cytowska B., *Przegląd badań empirycznych nad inkluzją w edukacji*, „*Problemy Edukacji, Rehabilitacji i Socjalizacji Osób Niepełnosprawnych*” 2016, no. 22/1, pp. 189–213.

²⁴ Information on the guidelines for the new teacher education standards can be found in the work by M. Sekułowicz, *Nowe standardy kształcenia nauczycieli – ich cel, rola, zadania i dylematy realizacyjne*, <https://www.kul.pl/files/581/Wydzial/KRK/dobre_praktyki/FREiSW/Sekułowicz.pdf> [access: 19.05.2019].

- [7] Dróżka W., *Triangulacja badań. Badania empiryczne ilościowo-jakościowe*, [in:] *Podstawy metodologii badań w pedagogice*, ed. by S. Palka, Gdańskie Wydawnictwo Psychologiczne, Gdańsk 2010, pp. 124–135.
- [8] European Agency for Development In Special Needs Education, *Key principles for promoting quality in inclusive education – Recommendations for Policy Makers*, Odense, Denmark 2009, pp. 14–19.
- [9] Firkowska-Mankiewicz A., Szumski G., *Idea integracyjnego kształcenia i edukacji włączającej w polskiej pedagogice* [in:] *„Pedagogika specjalna, podręcznik akademicki”* vol. 2, ed. by D.D. Smith, A. Firkowska-Mankiewicz, G. Szumski, Wydawnictwo Akademii Pedagogiki Specjalnej, Wydawnictwo Naukowe PWN, Warszawa 2008, pp. 319–346.
- [10] Flanczewska-Wolny M., Wolny J., *Pedagog specjalny-asystent ucznia z niepełnosprawnością w szkole ogólnodostępnej w opiniach nauczycieli*, [in:] *Wybrane konteksty i wyzwania współczesnej pedagogiki specjalnej*, ed. by K. Barłóg, Wydawnictwo Uniwersytetu Rzeszowskiego, Rzeszów 2017, pp. 228–241.
- [11] Gajdzica Z., *Opinie nauczycieli szkół ogólnodostępnych na temat edukacji włączającej uczniów z lekkim upośledzeniem umysłowym w kontekście toczącej się reformy kształcenia specjalnego*, [in:] *Uczeń z niepełnosprawnością w szkole ogólnodostępnej*, ed. by Z. Gajdzica, Wydawnictwo Wyższej Szkoły Humanitas, Sosnowiec 2011, pp. 56–79.
- [12] Głodkowska J., *W poszukiwaniu modelu edukacji włączającej*, „*Meritum*” 2009, no. 2, pp. 5–8.
- [13] Hornowska E., *Testy psychologiczne – teoria i praktyka*, Wydawnictwo Scholar, Warszawa 2007, pp. 25–32.
- [14] Janiszewska-Nieścioruk Z., *(Nie)dojrzałość proinkluzyjnych zmian w kształceniu osób z niepełnosprawnością*, „*Niepełnosprawność. Dyskursy pedagogiki specjalnej*” 2016, no. 22, pp. 47–59.
- [15] Korneluk M., Nazarczuk M., *Zakładane i realizowane funkcje nauczycieli wspomagających w klasie integracyjnej*, „*Student Niepełnosprawny. Szkice i Rozprawy*” 2008, no. 8(1), pp. 189–215.
- [16] Krause A., *Współczesne paradygmaty pedagogiki specjalnej*, Oficyna Wydawnicza „Impuls”, Kraków 2011.
- [17] Kruk-Lasocka J., *Dostrzec dziecko z perspektywy edukacji włączającej*. Wydawnictwo Naukowe Dolnośląskiej Szkoły Wyższej, Wrocław 2012.
- [18] Krzemińska D., Rzedzicka K.D., *O przygotowaniu zawodowym pedagogów specjalnych – krajobraz (bez)zmian?*, „*Niepełnosprawność*” 2009, no. 1, pp. 113–124.
- [19] Lechta V., *Pedagogika inkluzyjna*, [in:] *Pedagogika. T. 4, Subdyscypliny i dziedziny wiedzy o edukacji*, ed. by B. Śliwerski, Gdańskie Wydawnictwo Pedagogiczne, Gdańsk 2010, pp. 321–335.
- [20] Lipkowski O., *Pedagogika specjalna*, Wydawnictwo PWN, Warszawa 1981.

- [21] Mitchell D., *Sprawdzone metody w edukacji specjalnej i włączającej. Strategie nauczania poparte badaniami*, Wydawnictwo Harmonia Universlis, Gdańsk 2016.
- [22] Regulation of the Polish Minister of National Education of August 9th, 2017 on the conditions of organisation of education, upbringing and care for children and youths who are disabled, socially unadapted and threatened by lack of social adaptation, § 5 p. 4, § 6, § 7 Polish Journal of Laws of 2017, item no. 1578.
- [23] Regulation of the Polish Minister of National Education of August 25th, 2017 on the mode of keeping of documentation of teaching, education and care work by public preschools, schools and institutions, as well as the types of such documentation, § 18, § 19 Polish Journal of Laws of 2017, item no. 1646.
- [24] Rutkowski M., Bidziński K., *Szkoła ogólnodostępna przestrzenią spotkania nauczycieli i pedagogów specjalnych – realizatorów idei edukacji włączającej*, „Niepełnosprawność. Dyskursy pedagogiki specjalnej” 2018, no. 29, pp. 43–65.
- [25] Sekulowicz M., *Nowe standardy kształcenia nauczycieli – ich cel, rola, zadania i dylematy realizacyjne*, <https://www.kul.pl/files/581/Wydzial/KRK/dobre_praktyki/FREiSW/Sekulowicz.pdf> [access: 19.05.2019].
- [26] Szumski G., współ. Firkowska-Mankiewicz A., *Wokół edukacji włączającej. Efekty kształcenia uczniów z niepełnosprawnością intelektualną w stopniu lekkim w klasach specjalnych, integracyjnych i ogólnodostępnych*, Wydawnictwo Akademii Pedagogiki Specjalnej, Warszawa 2010.
- [27] Szumski G., *Edukacja włączająca – niedokończony projekt*, „Ruch Pedagogiczny” 2014, no. 4, pp. 127–139.
- [28] Uberman M., Mach A., *Kompetencje nauczyciela edukacji wczesnoszkolnej w szkole ogólnodostępnej w pracy z dzieckiem z niepełnosprawnością*, „Lubelski Rocznik Pedagogiczny” 2016, vol. XXXV, issue 3, pp. 165–185.
- [29] UNESCO, *Policy Guidelines on Inclusion In Education*, UNESCO, Paris 2009, pp. 7–9.
- [30] Zacharuk T., *Włączająca edukacja*, [w:] *Encyklopedia Pedagogiczna XXI w.*, vol. VII, ed. by T. Pilch, Wydawnictwo Akademickie „Żak”, Warszawa 2008, pp. 167–173.
- [31] Zamkowska A., *Kompetencje nauczyciela wymagane w pracy z uczniem z niepełnosprawnością umysłową w procesie edukacji inkluzyjnej*, [in:] *Kompetencje pedagoga specjalnego. Aktualne wyzwania teorii i praktyki*, ed. by Z. Palak, A. Bujnowska, Wydawnictwo Uniwersytetu Marii Curie-Skłodowskiej, Lublin 2008, pp. 79–88.



Apparent Activities in Special Education. A Critical Analysis of Core Curriculum

ABSTRACT: Maciej Jabłoński, *Apparent Activities in Special Education. A Critical Analysis of Core Curriculum*. Interdisciplinary Contexts of Special Pedagogy, no. 26, Poznań 2019. Pp. 103–124. Adam Mickiewicz University Press. ISSN 2300-391X. DOI: <https://doi.org/10.14746/ikps.2019.26.05>

The topic discussed herein concerns a particular deconstruction of the core curriculum in primary special schools carried out by means of a critical analysis of this document. On the grounds of this analysis, the article shows the consequences of apparent actions that are taking place in special schools, which in consequence lead to violence, perpetuating negative stereotypes and stigmatisation of students with intellectual disabilities.

KEY WORDS: Apparent actions, violence, intellectual disability, social competences, civic competences

Introduction

In order to educate students in the belief that everyone has the right to freedom, it is necessary to get acquainted with the principles of democracy and the processes of democratisation of the system of education as well as with the close links between educational and political systems. While democratic education should prepare for the actual application of democracy, educational activity should

be linked to fair, effective and democratic practice.¹ However, one should bear in mind that "(...) teaching students about democracy does not necessarily make democrats out of them; this can be achieved through practical experience derived from a democratically established school".² That is why, in a democratic state, the school has (or rather should have, as I believe it has lost this ability) the fundamental role in building foundations for the universal awareness of these ideals, without which there can be no democracy. It is precisely here that teachers should contribute to the acquisition of social and civic competences by students, among other things, by implementing the objectives set out in the curriculum.

Knowledge of these competences and understanding their role in building the identity of people with disabilities in a democratic state constitutes nowadays a particularly important issue. The problem regarding education of students with disabilities,³ regardless of the place of education – be it is a special school, integrated school, state school or family home – is of great importance or even seriousness. The aim of this education is, inter alia, to "build the student's identity, develop their autonomy and dignity, adjust them to

¹ E. Faure, *Uczyć się, aby być (Learning to Be. The World of Education Today on Tomorrow)*, PWN, Warsaw 1975 p. 209.

² B. Śliwerski, *Meblowanie szkolnej demokracji (Furnishing School Democracy)*, Wolters Kluwer, Warsaw 2017, p. 166.

³ See, inter alia: I. Chrzanowska, *Problemy edukacji dzieci i młodzieży z niepełnosprawnością: regionalna specyfika czy ogólnopolska tendencja (Educational Problems of Children and Young People with Disabilities: Regional Specificity or National Tendency)*, Oficyna Wydawnicza „Impuls”, 2010; *Rozwój i funkcjonowanie osób niepełnosprawnych. Konteksty edukacyjne i prawne (Development and Functioning of People with Disabilities. Educational and Legal Contexts)*, ed. Z. Gajdzica, Oficyna Wydawnicza „Impuls”, Kraków 2007; B. Jachimczak, *Gotowość nauczycieli szkół ogólnodostępnych do pracy z uczniem o specjalnych potrzebach edukacyjnych (Willingness of teachers at public schools to work with students with special educational needs)*, [in:] *Miejsce Innego we współczesnych naukach o wychowaniu – wyzwania praktyki (The Place of Other in Modern Educational Sciences. The Challenges of Practice)*, ed. I. Chrzanowska, B. Jachimczak, Wydawnictwo Satori, Łódź 2008; A. Krauze, *Współczesne paradygmaty pedagogiki specjalnej (Contemporary Paradigms of Special Needs Education)*, Oficyna Wydawnicza „Impuls”, Kraków 2010.

the functioning of society and to the understanding and observance of social norms, and in particular to equip them with such skills and knowledge that will enable them to exercise their freedom and human rights to the best of their ability and to perceive themselves as independent people".⁴ Here, we have to pose a vital question. Namely: do the contents of the core curriculum, which in their formal and legal assumptions serve the development of students with disabilities, really compensate and equalize development opportunities for them, at least in terms of acquiring social and civic competences? Or maybe, the activities that can be found in the proceedings of both institutions co-organising the special needs education system and individual persons participation in this system directly or indirectly (teachers, therapists, directors, clerks, students, parents) are of an apparent nature thus rendering these opportunities equalized only ostensibly?⁵

I subjected the analysis of the core curriculum to critical "deconstruction" by means of analytical categories created by Violetta Kopinska,⁶ which are the result of a three-step process, i.e.:

- firstly, it is based on documents that should be taken into account when establishing the core curriculum for general education at European and national level;
- secondly, it is created on the basis of literature on the subject, which makes it possible to avoid the mistake of constructing a catalogue that is too narrow, one-sided, specific or perhaps "politicized";

⁴ Appendix No. 3 to the Regulation of the Minister of National Education of 14 February 2017, item 356. p. 211, i.e. the Primary School Curriculum for students with moderate or severe intellectual disabilities.

⁵ Cf. K. Parys, *Zjawisko pozoru w systemie kształcenia uczniów niepełnosprawnych – próba identyfikacji i propozycje rozwiązań* (An Attempt at Identifying the Phenomenon of Pretense in the Education of Students with Disabilities and Proposals for Solutions). *Interdyscyplinarne Konteksty Pedagogiki Specjalnej* no. 4/2014, 2014, pp. 29–30.

⁶ See: *Kompetencje społeczne i obywatelskie. W podstawach programowych kształcenia ogólnego. Analiza krytyczna* (Social and Civic Competences. In the Core Curriculum of General Education. A Critical Analysis), ed. V. Kopińska, H. Solarczyk-Szwec, Wydawnictwo Naukowe Uniwersytetu Mikołaja Kopernika, Toruń 2017.

– thirdly, by using open encoding, it is adapted to the tested sample and at the same time is not limited to the codes resulting from the core curriculum, which in turn makes it possible to identify those learning outcomes which are not included in the core curriculum and which are part of social and civic competences.⁷

This shall give the possibility to see if the actions of the message provider (teachers, tutors) as the implementer of the core curriculum are doomed to failure. The question remains, however, of whether the contents of the message have a chance to equip the student with the necessary social and civic competences.

Apparent actions as systemic violence

Jan Amos Comenius wrote: “(...) Since we are all born, this must be accomplished that at the end of the day no one shall regret the fact of coming to this world. And how can that be done? (...) First of all, by making no one live like a dull creature but heed the dictate of reason: everyone is endowed with its light, but to use what everyone has, not everyone knows how – unless he learns it. Therefore, he must be taught. Otherwise, it shall be a testament of stupidity (...). And one should not only wish that people would not become dull, but also that they should become as witty as possible. (...) because we must not wish to deprive any human being of his humanity through degradation, we must wish that no human being should be left without education: since for people without education, the easiest thing to do – which is inherent in human nature – is to de-

⁷ There may be doubts whether the analytical categories proposed by Violetta Kopińska are adequate for the analysis of the core curriculum of a special needs school. I still have them myself. However, the general and special curriculum basis was developed on the grounds of the same materials as the MEN documentation, and social and civic competences are universal competences, i.e. they are independent of whether we have or do not have any disabilities.

grade”.⁸ The words of the classic become more and more up-to-date for me, when I undertake to continue his discussion asking – following in Maria Dudzikowa’s footsteps – the following questions about the essence of apparent actions:

“1) What terms can/should we examine the categories of apparent actions? In what theories or conceptions can we place the term of apparent actions? Who/what can/should be the object of studies so as to identify apparent actions? With what indices, measured in what way? Using what techniques? 2) Are the practices connected with widely understood education apparent? Which of them? To what degree? What is the scale and dominant form of apparent actions at the level of macro- and micro-phenomena? What are the grounds and consequences? What institutional/awareness/cultural terms occur? 3) Which of the symptoms and mechanisms of apparent actions described by Jan Lutyński and regarding the past system were subject to weakening in the area of education and which survived despite the systemic change? Can we see – and if yes in which areas connected with education as a system and a process – the occurrence of new examples of apparent actions and what is the mechanism of their formation? In what situations can we find alternation of the perpetrators and the victims? 4) What direct social results (in particular economic, organizational outcomes) and indirect social outcomes (in particular in the area of attitudes, with further negative consequences) can be noted? What are the barriers hindering fighting against apparent actions and what do they consist in? Is it possible to fight apparent actions and in what conditions?”⁹

⁸ J.A. Komeński (Comenius), *Pampaedia*, Zakład Narodowy im. Ossolińskich, Wydawnictwo Państwowe Wydawnictwo naukowe, Wrocław – Warsaw – Kraków – Gdańsk 1973, pp. 16–17.

⁹ M. Dudzikowa, *Działania pozorne w edukacji jako palący problem. Wprowadzenie do książki (Apparent activities in education as a burning problem. Introduction to the book)*, [in:] *Sprawcy i/lub ofiary działań pozornych w edukacji szkolnej (Perpetrators and/or Victims of Apparent Activity in School Education)*, ed. M. Dudzikowa, K. Knasiecka, Oficyna Wydawnicza „Impuls”, Kraków 2014, p. 24.

The risk of an apparent action is such that it lures like a drug with the fact that the area of freedom is large and that I can use it whenever I want. "In the meantime a significant part of our choices and actions is not a result of free decisions, but of this or that addiction. We act in our lives as puppets pulled by the strings by various habits. At the same time we are not aware of it, so we are even more exposed to them".¹⁰ We are exposed to apparent actions, playing with them, getting tangled in more and more dependencies. According to Lutyński apparent actions have six basic features: "1. They are officially deemed to be significant for the performance of some socially important objective; 2. They fail to meet this objective in reality; 3. The given community commonly knows of their worthlessness; 4. It is private knowledge, not expressed officially; 5. Their real function consists in their existence only; 6. They always contain some element of fiction, referring to their course or objective".¹¹

Lutyński also distinguished four mechanisms that foster the occurrence of apparent actions in a centrally controlled system. They constitute: "1) an organizational and decision-making mechanism inherent in the organizational and institutional structure and at the same time in the decision-making system; 2) axiological mechanism, i.e. regarding the sphere of values, referring to values that are recognized but unrealized for various reasons (for example, they usually stem from other social systems or from earlier historical periods, and are adopted by acclamation and planned / controlled occurrences); 3) the mechanism of compulsory enforcement of unrealistic provisions, which is triggered by an increase in regulations and provisions associated with the expansion and bureaucracy of

¹⁰ A. Dodziuk, *Nałogowy człowiek w nałogowym społeczeństwie (An Addictive Person in an Addictive Society)*, [in:] A. Dodziuk, L. Kapler, *Nałogowy człowiek (An Addictive Person)*, Instytut Psychologii Zdrowia, Polskie Towarzystwo Psychologiczne, Warsaw 2007, p. 9.

¹¹ J. Lutyński, *Działania pozorne (Apparent actions)*, [in:] J. Lutyński *Nauka i polskie problemy. Komentarz socjologa (Science and Polish Issues. A Sociologist's Commentary)*, Państwowy Instytut Wydawniczy, Warsaw 1990, p. 105.

various divisions of the system and all activities of the authorities; 4) a supposedly pragmatic mechanism, causing apparent actions organized by the authorities, aimed at solving a swollen social problem".¹²

In my opinion, this typology reveals (uncovers, exposes) something very important. Namely, violence hidden behind an appearance. Violence, which – as Andrzej Zybertowicz claims – “plays a constructive role in the process of creating, disseminating and functioning of knowledge in society and it is impossible to explain knowledge without placing it in the centre of attention”.¹³ Slavoj Žižek draws attention to two types of violence: subjective and objective. “The first one is what we used to associate with violence – it comes down to aggression, cruelty, it is expressed in “crimes, social unrest or international conflicts”.¹⁴ These spectacular manifestations of brutality are accompanied by the second type of violence that very often goes unnoticed, i.e. objective violence. It can be present in perfectly organised communities that is where (paradoxically) “there seems to be order”.¹⁵ It is a form of oppression that results from the operation of various types of systems, ranging from the language system to economic and political systems. Žižek distinguishes two types of objective violence: “The first one is symbolic violence, inscribed in language and its forms, which is called by Heidegger “the human house of being”.¹⁶ Žižek calls the other type of objective violence a *systemic violence*. It is the characteristic feature of all systems whose task is to maintain the level of normality in a society. We do not see it because it organizes reality (it is con-

¹² J. Lutyński, *ibidem* 1990, p. 106.

¹³ A. Zybertowicz, *Przemoc i poznanie, Studium z nie-klasycznej socjologii wiedzy (Violence and Cognition: A Study in Non-classical Sociology of Knowledge)*, Wydawnictwo Uniwersytetu Mikołaja Kopernika, Toruń 1995, p. 14.

¹⁴ S. Žižek, *Przemoc. Sześć spojrzeń z ukosa (Violence: Six Sideways Reflections)*, Muza, Warsaw 2010, p. 5.

¹⁵ S. Žižek, *ibidem* 2010, p. 6.

¹⁶ *Ibidem*, p. 6.

tained in social, economic and political systems).¹⁷ The last sentence fits perfectly with the concept of “bad faith,” which consists “(...) in creating the appearance that something is necessary while in reality it is voluntary. (...) Anyone who says: “I have no choice” in relation to what their social role requires of them, persists in “bad faith.” We can easily imagine the circumstances in which this statement will be true to the extent that there is no choice in this particular role. Nevertheless, an individual has a choice – to abandon this role.¹⁸ It is violence in our world that is a more primitive reality than the false and true or good and evil. Violence in its various forms – physical and mental. A stronger personality subordinates the weaker one and *de facto* sets the values according to which social communication takes place.¹⁹

Violence is also a part of the educational system. As Pierre Bourdieu pointed out, that is one of the most spectacular expressions of symbolic violence. For, as this thinker claims, **the principle of all violence is its ability to hide under the appearance of objectivity or obviousness** (emphasis added by M. Jabłoński). In pedagogical activity, which seems to be treated as a prototype of any social activity that enforces spontaneity, Bourdieu claims, there is a double arbitrariness: not only is the enforcing authority, but the enforced content of teaching is equally arbitrary.²⁰ Appearance covers the homology between the school monopoly on legitimate symbolic violence and the state monopoly on legitimate physical violence.²¹ Appearance unfortunately justifies systemic violence under the cover of the slogan: There is nothing I can do, this is the system that we have!!! (sic!).

¹⁷ This is what Jan Lutyński showed in his typology in points 3 and 4.

¹⁸ P.L. Berger, *Zaproszenie do socjologii (Invitation to Sociology)*, Państwowe Wydawnictwo Naukowe, Warsaw 1988, pp. 149–150.

¹⁹ Jasiński, *Zagubiony etos (The Lost Ethos)*, *Miesięcznik Literacki*, nos. 7–8, 1987, p. 131.

²⁰ E. Zakrzewska-Manterys, *Upośledzeni umysłowo. Poza granicami człowieczeństwa (Mentally Handicapped. Beyond the Borders of Humanity)*, Wydawnictwo Uniwersytetu Warszawskiego, Warsaw 2010, p. 161.

²¹ See: P. Bourdieu, J.-C. Passeron, *Reprodukcja. Elementy teorii systemu nauczania (Reproduction. Elements of the Educational System Theory)*, PWN, Warsaw 2006, p. 69.

On systemic violence in the approach to disability

In relation to people with disabilities, appearances can be seen as systemic violence. "Because a development matrix is applied to the lives of people with disabilities, as proposed by the great theoreticians of developmental psychology (...) I consider this way of using the development approach to study the adulthood of people with disabilities to be a waste of opportunity to create a new paradigm in studying disability issues, as well as such a theoretical procedure which cannot contribute to progress in providing effective assistance to the development of persons".²² And it is "(...) the pathology that fulfils the adjustment function, is the reaction to factors harmful to the system and a way to deal with it in order to keep the system alive".²³ This raises the question of how do we actually perceive people with disabilities. Who or what do we see first seeing them in the street, in a shop or at school? Is it an individual first or their disability? Is it possible that this "defectological" point of view sends us the whole picture of a given reality? Or maybe the disabled are perceived as a minority group, and the disability as a difference / otherness, rather than lack of something. Therefore, all members of a given society have the right to live independently in a community, with mutual recognition of differences and the development of coexistence skills for all members of the society?²⁴

²² S. Kowalik, *Pomoc w dochodzeniu i utrzymaniu własnej dorosłości przez osoby niepełnosprawne (Helping disabled people to discover and retain their own adulthood)*, [in:] *Niepełnosprawność w zwierciadle dorosłości (Disability in the Mirror of Adulthood)*, ed. R. Kijak, Oficyna Wydawnicza „Impuls”, Kraków 2012, p. 39.

²³ M. Kościelska, *Oblicza upośledzenia (The Faces of Impairment)*, PWN, Warsaw 1995, p. 197.

²⁴ See: G. Szumski, *Edukacja inkluzyjna – geneza, istota, perspektywy (Inclusive Education – Genesis, Essence, Perspectives)*, *Kwartalnik Pedagogiczny* 2006, no. 1, pp. 96–100; cf. J. Skibska, M. Warchał, *Edukacja inkluzyjna dziecka niepełnosprawnego w szkole ogólnodostępnej a integracja społeczna Edukacja jutra w kontekście wyzwań współczesności (Inclusive education of disabled children in public school and social integration. Education of tomorrow in the context of challenges in contemporary times)*, [in:] *Edukacja jutra w kontekście wyzwań współczesności dostępnej a integracja społeczna (Education of Tomorrow in the Context of Challenges of the Accessible Modernity and Social Integration)*, eds. K. Denek,

Clashing with this multitude of opinions, another question arises of whether we have to define everything and everyone. Seeing that often by playing with concepts we miss the sense of an individual, the meaning of life. Is this peculiar “game” of detailed specification and continuous redefinition not an apparent action? On the other hand, an attempt to clarify the terminology may serve as a tool for explaining sources and becomes a means enabling theoretical justification and at the same time practical exposition of actual social practices used for oppressive purposes towards people with disabilities by pushing them into various apparent activities.²⁵

When examining the legal provisions relating to special education and students with disabilities, Agnieszka Olechowska argues that based on the conducted critical analysis of the provisions of selected legal acts, the provisions dominate that are characteristic of the paradigm of biological perception of disability, which may establish negative stereotypes and stigmatization of students with special needs.²⁶ If the provisions in legal acts are “closer” to the biological paradigm than to the social one, then the question is whether and to what extent the program basis described and analysed by me was subject to public consultation? If it was, what entities commented on it and what resulted from their commentaries in favour of changing the quality of education for students with intellectual disabilities in terms of the competences studied, i.e. social and civic? I sent my query to the Ministry of National Education and on 1 March 2019 I received a reply saying that the basis had been sent to 96 entities²⁷ including the Polish Ombudsman, the Ombudsman

A. Kamińska, W. Kojs, P. Oleśniewicz, Oficyna Wydawnicza „HUMANITAS”, Sosnowiec 2012, pp. 369–386.

²⁵ See: *Człowiek z niepełnosprawnością w rezerwacie przestrzeni publicznej (People with Disabilities in the Reserve of Public Space)*, ed. Z. Gajdzica, Oficyna Wydawnicza „Impuls”, Kraków 2013; Zakrzewska-Manterys, *ibidem* 2010; Krause, *ibidem*, 2010.

²⁶ A. Olechowska, *Paradygmaty pedagogiki w oficjalnym dyskursie pedagogicznym jako narzędziu polityki edukacyjnej (Paradigms of Pedagogy in the Official Pedagogical Discourse as a Tool of Educational Policy)*, „Zarządzanie Publiczne” 1(41), 2018, p. 59.

²⁷ Full list of entities to which the project has been sent <<https://legislacja.rcl.gov.pl/docs//501/12293659/12403175/12403176/dokument265873.pdf>> (added on 30.03.2019).

for Children, Committee on Education studies of the Polish Academy of Sciences, Civic Education Association, Polish Association for Persons with Mental Disabilities (currently Polish Association for Persons with Intellectual Disability), Foundation for Social Diversity, Foundation in Support of Local Democracy, or Polish Teachers' Union. An interesting, and, in my opinion, sad thing is that out of the above-mentioned institutions it was only the Polish Teachers' Union that sent their comments and proposed changes.²⁸

Following this lead, the question should be asked who falls victim to the systemic violence Žižek is writing about? Who does not even try to change reality – in this case the formal and legal reality? Thanks to observing the reality associated with the system of education of students with disabilities, analysis of academic literature as well as laws and ordinances, I shall try to present an example of apparent activities at the macro (national) level in the area of special education of students with moderate and severe intellectual disability on the basis of a critical analysis of the core curriculum.

Critical analysis of the core curriculum

The purpose of the analysis of the core curriculum was to identify the content pertaining to social and civic competences as well as its potential educational outcomes. "There is no sharp distinction between social and civic competences. As it is, their meanings often overlap".²⁹ Social competences are a broader category, while civic competences constitute a subset thereof. If we refer to the metaphor of base and superstructure, we can say that social competences are

²⁸ See: <<https://legislacja.rcl.gov.pl/docs//501/12293659/12403175/12403178/dokument272179.pdf>> (added on 30.03.2019).

²⁹ *Kompetencje społeczne i obywatelskie. W podstawach programowych kształcenia ogólnego. Analiza krytyczna (Social and Civic Competences. In the Core Curriculum of General Education. A Critical Analysis)*, eds V. Kopińska, H. Solarczyk-Szwec, Wydawnictwo Naukowe Uniwersytetu Mikołaja Kopernika, Toruń 2017, p. 11.

a base, while civic competences are a superstructure. This is yet another reason to analyse them together.³⁰

The method employed to collect data for this study was a review of secondary sources.³¹ The study sample was the primary school core curriculum – for pupils with moderate or severe intellectual disability.³²

The following question was posed: What learning outcomes are observed in special education core curricula as regards social and civic competences? For my research I selected primary school core curriculum, designed for pupils with moderate or severe intellectual disability, which constituted Appendix no. 3 to the Regulation of 24th February 2017, item 356. In this kind of school there are: 1) educational classes, including: a) individual and social functioning, b) classes focused on communication, c) classes focused on creativity, d) physical education, e) ethics, 2) remedial classes. The type of remedial classes is defined in the individual educational and therapeutic programme for a specific pupil, designed on the basis of recommendations included in the document confirming the need for special education and on the outcome of the multifaceted specialist functioning assessment.³³ What we read in the core curriculum is: “the teaching content has been designed as an open set of social situations and roles the pupil might be faced with. The teaching content may exceed the abovementioned areas, depending on the pupils’ needs. The teacher has a right to choose (also narrow down or expand) the teaching content, which is beneficial for the pupil’s development, with special attention paid to the pupil’s autonomy and dignity”.³⁴ This is why the analysed core curriculum was treated holistically, without dividing the content into individual classes.

³⁰ Cf. V. Kopińska, H. Solarczyk-Szwec, *ibidem* 2017.

³¹ K. Rubacha, *Metodologia badań nad edukacją (Methodology of Research on Education)*, Wydawnictwa Akademickie i Profesjonalne, Warsaw 2008, pp. 157–164

³² Appendix no. to the Regulation of the Minister of National Education of 14 February 2017, item 356, on the core curriculum for primary schools for students with moderate or severe intellectual disabilities.

³³ *Ibidem*.

³⁴ *Ibidem*.

What became the starting point for the search for main analytical categories related to social and civic competences was Appendix to the Recommendation of the European Parliament and the Council of 18th December 2006 on key competences for lifelong learning – Key competences in lifelong learning – European Frame of Reference (L/394).³⁵ According to the Frame, the goal of civic education is to make sure the citizens:

- know their civic rights and obligations, know what a citizen may demand from public institutions, but also what our obligations are towards our fellow citizens;
- know such notions as human rights, are able to recognise signs of human right infringement, but also actively oppose such breaches and sympathize with victims of such infringements.

Key social competences in three areas include:

Knowledge: understanding the rules and principles of behaviour generally accepted in various societies and circles (e.g. at work, school, in the office); knowledge of the basic notions related to people, groups, professional organizations; understanding the principles of gender equality and non-discrimination; knowledge and understanding of multicultural, social and economic dimensions of European societies. Competences: constructive communication in various environments, with people of different origin, with various interests, views; showing tolerance; expressing and understanding various points of view; negotiating combined with the ability to create the climate of trust; coping with stress and frustration and expressing them in a constructive manner. Attitudes: being open to cooperation, assertiveness, righteousness; being interested in social and economic development; appreciating diversity and respecting others, as well as being prepared to overcome prejudice and reaching compromise.³⁶

³⁵ Given the limited length of the text, I will only mention the main objectives concerning social and civic competences.

³⁶ See: M. Jabłoński, *Edukacja obywatelska. Krytyczna analiza statutów podmiotów prowadzących Warsztaty Terapii Zajęciowej (Civic Education. Critical analysis of the statutes of entities running Occupational Therapy Workshops)*. „Niepełnosprawność. Dyskursy pedagogiki specjalnej” no. 32/2018, pp. 276–292.

Social and civic competences in the document under analysis are understood in a very broad sense, both from the perspective of national citizenship and the sum of values such as responsibility, awareness, caring for others and the immediate environment. They constitute a kind of clasp connecting a certain set of attitudes and values created as desirable for a given society. What I present below is a table containing results of the analysis of the base content.

Table 1. Most numerous analytical categories (learning outcomes) in the core curriculum for primary schools for students with moderate to severe intellectual disabilities

Area of knowledge		
Analytical category/learning outcome	N = 44	
	occurs	does not occur
Knowledge regarding forms of communication	3	41
Knowledge regarding assertiveness and its meaning in interpersonal contacts	3	41
Understanding of codes of conduct and rules of conduct generally accepted in various communities and environments	2	42
Knowledge regarding assertiveness and its meaning in interpersonal contacts	1	43
Knowledge regarding empathy and its meaning in interpersonal contacts	1	43
Knowledge regarding non-governmental organizations and volunteering work	1	43
Knowledge regarding environmental protection	1	43
Knowledge regarding behaviour in crisis situations (life- and health-threatening)	1	43
Knowledge regarding how to ensure one's physical and mental health (including how a healthy lifestyle can contribute to this)	1	43
Knowledge regarding human rights	1	43
Knowledge regarding human rights protection	1	43

Area of knowledge		
Analytical category/learning outcome	N = 44	
	occurs	does not occur
Knowledge regarding (other than elections) ways/forms of participation in decision-making processes at local level	1	43
Area of competence		
Communication skills	5	39
Ability to act in accordance with the procedures and policies prevailing in different environments	4	40
Ability to express one's own opinion, to present one's own ideas in writing and/or in speech	3	41
Ability to act in accordance with the procedures in force in various institutions and organisations	2	42
Ability to cope with stress and frustration and with expressing them in a constructive way	2	42
Ability to express emotions	1	43
Ability to distinguish between fact and opinion	1	43
Ability to make public appearances	1	43
Ability to understand different points of view	1	43
Ability to identify and discuss one's own problems	1	43
Ability to act in accordance with the procedures in force in various institutions and organisations	1	43
Area of attitude		
Willingness to act autonomously	3	41
Sense of belonging to the environment	1	43
Willingness to take responsibility for the consequences of its own actions	1	43

The table lists the most common analytical categories related to social and civic competences included in the core curriculum. The most represented are the outcomes in the area of competence (22³⁷), where the most common analytical categories are: communication

³⁷ The total number of outcomes in a given area.

skills (5), the ability to act in accordance with the procedures and policies prevailing in different environments (4) and the ability to express one's own opinion, to present one's own ideas in speech and/or writing (3). What follows in terms of the number of outcomes is the area of knowledge (17) in which the categories of knowledge regarding forms of communication and of knowledge regarding assertiveness and its meaning in interpersonal contacts occurred with the same frequency (3), while the category of understanding of codes of conduct and rules of conduct generally accepted in various communities and environments occurred (2) times. In the attitude area (4), the willingness to act autonomously occurs (3) times. As one can see, communication is the category that dominates in the areas of knowledge and competence.

Conclusions instead of summary

Approaching the analysis of the core curriculum of primary school – for pupils with intellectual disability at a moderate or significant degree that constitutes Appendix No. 3 to the Regulation, at the beginning I compared: first of all the core curriculum of general education primary school, which consists of 200 pages, and for primary education of special needs school, which consists of 15 pages. Both the disproportion and the number of the identified requirements referring to the social and civil competences are puzzling. The core curriculum of general education contains 569 identified analytical categories.³⁸ My analysis contains 44.

I am aware that such a comparison is not entirely valid as the curricula were studied in a different way. However the basis for both were the Guidelines of the European Parliament and of the Council of 18th December 2006 on key competences in the process of life-long learning. I know that the method of analysis itself as well as interpretation of the results may be in a way subject to a discus-

³⁸ After: V. Kopińska, H. Solarczyk-Szwec, *ibidem*, 2017, p. 216.

sion. However the quantitative difference is huge. If I were to recommend the most significant, though **absent**, competences in the areas of knowledge, competences and attitudes in the analysed curriculum, they would certainly be in the area of knowledge: **knowledge on the forms of citizens' objection; knowledge and application of the term "democracy"; knowledge and application of the term "justice"; knowledge and application of equality.**³⁹ In the second area, competences, I consider the following missing: **skills to define own problems and talking about them; the skill to solve conflicts; the skill to assess own actions; the skill to assess the actions of other persons; the skill to undertake actions to guarantee physical and mental health, to protect environment.** Whereas in the area of attitudes, we fail to find such competences as: **respecting values and privacy of other persons; respecting human rights (freedom, equality, dignity); conviction about the meaning of mental and physical health and about the necessity to guarantee oneself the optimum level of physical and mental health.**

The feeling of deficiency and peculiar "bleakness" is additionally strengthened by one significant fact that the process of acquiring social and civic competences by the pupils in general education schools is supported by their participation in the student government. In the case of special needs school for pupils with moderate and significant intellectual disability the student government under the Regulation of the Ministry of National Education of 23rd February 2007 is not established.⁴⁰ There arises a question whether such actions are not apparent. I believe that they are apparent actions that also infringe e.g. Article 32 of the Constitution of the Republic of Poland of 2nd April 1997, which states in item 1. "All people are equal. All people have the right to equal treatment by public authorities;" whereas in item 2. "Nobody can be discriminated against in the political, social or economic life for any reason".⁴¹

³⁹ Ibidem p. 98.

⁴⁰ See: Journal of Laws of 23 March 2007. No. 52, item 347.

⁴¹ There are studies on students government in special institutions conducted within the framework of NCN Miniature 2 Students government and social inclu-

“This causes that the group of people often (...) have no competences for any participation in these spheres of public and cultural life that require communication with the aid of symbols”.⁴² The beautiful and momentous slogans like those included in the core curriculum and regarding the UN Convention on the Rights of the Disabled Persons, where Article 19 talks of teaching independent life “(...) the society of the State of a Party to this Convention deems equal the right of all the disabled persons to live in a society and the right to make choices equally with other persons and shall undertake efficient and proper means to facilitate full use of such right by the disabled and their full inclusion and participation in the society”.⁴³ There arises a question of how the pupils acquire social and civic rights if they have no possibility to exercise the right to create student governments in their schools. I also believe that the Convention is not respected. Is not speaking of equality just apparent? The State allowed for creation and functioning of the student governments only in the selected schools and only the capable pupils and lightly disabled pupils. It is still the cultural reproduction that strengthens social inequality.⁴⁴

On the other hand, we can see that just the legal regulations, the top-down paradigm character of the areas of knowledge actually fail to work. At the utmost, they make everyone the slaves of the system, the system of areas colonised by healthy, strong persons throwing from time to time “the sops of freedom” to the disabled, not necessarily according to their needs. As a result of the analysis of the above study issue there arise five questions on the apparent actions of “authorities” (parents, teachers, head masters, politicians,

sion in special education, the results of which I plan to publish at the end of year 2019.

⁴² Z. Kwieciński, *Tropy – ślady – próby. Studia i szkice z pedagogiki pogranicza (Clues – Traces – Trials. Studies and sketches of borderline pedagogy)*, Edytor, Toruń 2000, p. 164.

⁴³ See: <<http://konwencja.org/konwencja/>> [date of access: 31 Jan. 2019 (added on 30.03.2019)].

⁴⁴ See: P. Bourdieu, J.-C. Passeron, *Reprodukacja. Elementy teorii systemu nauczania (Reproduction. Elements of the Educational System Theory)*, PWN, Warsaw 2006.

society). 1) Initiation – which regards how the study process starts and whose interests and methods determine and define their results. The capable persons or the disabled? 2) Benefits – the question who will take direct advantages from the studies and will by any chance no one suffer? 3) Authorization – it is the question about power that we give to our texts. Is it not so that the knowledge of the disabled is diminished so as to strengthen the knowledge, practice and processes of the capable persons? 4) Responsibility – who takes responsibility for the processes in education: the authorities, the researchers, the teachers or perhaps the pupils? Who exercises control over initiation, procedures, assessments, building texts and distribution of newly-built knowledge? 5) Representation – whose tests deliver the right picture of reality?⁴⁵

Perhaps it is still so that in the name of some indeterminate good the still “authoritative” voice of an “expert” displaces the experience of the disabled persons expressing it in terms defined by such an “expert”? In the afore-discussed example of apparent actions occurring in the area of special education, I can see marginalization of cognitive values, one-sidedness of perceiving the problems of special needs education, chaos and lack of reflectivity.

Bibliography

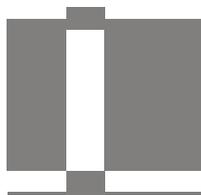
- [1] Berger P.L., *Zaproszenie do socjologii (Invitation to Sociology)*. PWN, Warszawa 1988.
- [2] Bishop R., Maori K., *Przewyciężyć neokolonializm w badaniach społecznych (Freeing ourselves from neocolonial domination in research)*, [in:] *Metody badań jakościowych (Qualitative Research Methods)* Vol. 1 and Vol. 2, eds. Norman K. Denzin, Yvonna S. Lincoln, PWN, Warszawa 2010.
- [3] Bourdieu P., Passeron J.-C., *Reprodukcja. Elementy teorii systemu nauczania (Reproduction. Elements of the Educational System Theory)*, PWN, Warszawa 2006.

⁴⁵ R. Bishop, K. Maori, *Przewyciężyć neokolonializm w badaniach społecznych (Freeing ourselves from neocolonial domination in research)*, [in:] *Metody badań jakościowych (Qualitative Research Methods)* Vol. 1 and Vol. 2, eds. Norman K. Denzin, Yvonna S. Lincoln, Warsaw, PWN, 2010, pp. 167–205.

- [4] Chrzanowska I., *Problemy edukacji dzieci i młodzieży z niepełnosprawnościami: regionalna specyfika czy ogólnopolska tendencja (Educational Problems of Children and Young People with Disabilities: Regional Specificity or National Tendency)*, Oficyna Wydawnicza „Impuls”, Kraków 2010.
- [5] Dodziuk A., *Natógowy człowiek w natógowym społeczeństwie (An Addictive Person in an Addictive Society)*, [in:] eds. A. Dodziuk, L. Kapler *Natógowy człowiek (An Addictive Person)*. Warszawa: Instytut Psychologii Zdrowia, Polskie Towarzystwo Psychologiczne, Warszawa 2007.
- [6] Dudzikowa M., *Działania pozorne w edukacji jako palący problem. Wprowadzenie do książki (Apparent activities in education as a burning problem. Introduction to the book)*, [in:] *Sprawcy i/lub ofiary działań pozornych w edukacji szkolnej (Perpetrators and/or Victims of Apparent Activity in School Education)*, ed. M. Dudzikowa, K. Knasiecka-Flabierska, Oficyna Wydawnicza „Impuls”, Kraków 2014.
- [7] Faure E., *Uczyć się, aby być (Learning to Be. The World of Education Today on Tomorrow)*, PWN, Warszawa 1975.
- [8] *Rozwój i funkcjonowanie osób niepełnosprawnych. Konteksty edukacyjne i prawne (Development and Functioning of People with Disabilities. Educational and Legal Contexts)*, ed. Z. Gajdzica, Oficyna Wydawnicza „Impuls”, Kraków 2007.
- [9] *Człowiek z niepełnosprawnością w rezerwacie przestrzeni publicznej (People with Disabilities in the Reserve of Public Space)*, ed. Z. Gajdzica, Oficyna Wydawnicza „Impuls”, Kraków 2013.
- [10] Jabłoński, M., *Edukacja obywatelska. Krytyczna analiza statutów podmiotów prowadzących Warsztaty Terapii Zajęciowej (Civic Education. Critical analysis of the statutes of entities running Occupational Therapy Workshops)*. „Niepełnosprawność. Dyskursy pedagogiki specjalnej” no. 32/2018, pp. 276–292.
- [11] Jachimczak B., *Gotowość nauczycieli szkół ogólnodostępnych do pracy z uczniem o specjalnych potrzebach edukacyjnych (Willingness of teachers at public schools to work with students with special educational needs)*, [in:] *Miejsce Innego we współczesnych naukach o wychowaniu – wyzwania praktyki (The Place of Other in Modern Educational Sciences. The Challenges of Practice)*, ed. I. Chrzanowska, B. Jachimczak, Wydawnictwo Satori, Łódź 2008.
- [12] Jasiński B., *Zagubiony etos (The Lost Ethos)*, Miesięcznik Literacki, nos. 7–8, 1987, pp. 125–134.
- [13] Komeński (Comenius) J.A., *Pampaedia*, Zakład Narodowy im. Ossolińskich, Wydawnictwo Państwowe Wydawnictwo naukowe, Wrocław – Warszawa – Kraków – Gdańsk 1973.
- [14] *Constitution of the Republic of Poland of 2 April 1997*, Wydawnictwo Sejmowe, Warsaw 2003.
- [15] *The UN Convention on the Rights of Persons with Disabilities was adopted by the General Assembly of the United Nations (UN) on 13 December 2006.*
- [16] *Kompetencje społeczne i obywatelskie. W podstawach programowych kształcenia ogólnego. Analiza krytyczna (Social and Civic Competences. In the Core Curriculum of*

- General Education. A Critical Analysis*), ed. V. Kopińska, H. Solarczyk-Szwec, Wydawnictwo Naukowe Uniwersytetu Mikołaja Kopernika, Toruń 2017.
- [17] Kościelska M., *Oblicza upośledzenia (The Faces of Impairment)*, PWN, Warszawa 1995.
- [18] Kowalik S., *Pomoc w dochodzeniu i utrzymaniu własnej dorosłości przez osoby niepełnosprawne (Helping disabled people to discover and retain their own adulthood)*, [in:] *Niepełnosprawność w zwierciadle dorosłości (Disability in the Mirror of Adulthood)*, ed. R. Kijak, Oficyna Wydawnicza „Impuls”, Kraków 2012.
- [19] Krause A., *Współczesne paradygmaty pedagogiki specjalnej (Contemporary Paradigms of Special Needs Education)*, Oficyna Wydawnicza „Impuls”, Kraków 2010.
- [20] Kwieciński Z., *Tropy-ślady-próby. Studia i szkice z pedagogiki pogranicza (Clues – Traces – Trials. Studies and sketches of borderline pedagogy)*, „Edytor”, Toruń 2000.
- [21] Lutyński J., *Działania pozorne (Apparent actions)*, [in:] *Nauka i polskie problemy. Komentarz socjologa (Science and Polish Issues. A Sociologist’s Commentary)*, J. Lutyński, Państwowy Instytut Wydawniczy, Warszawa 1990.
- [22] Olechowska A., *Paradygmaty pedagogiki w oficjalnym dyskursie pedagogicznym jako narzędziu polityki edukacyjnej (Paradigms of Pedagogy in the Official Pedagogical Discourse as a Tool of Educational Policy)*, „Zarządzanie Publiczne” 2018, 1(41) pp. 59–74.
- [23] Pawelczak K., *Niepełnosprawność – Inna jakość, która ma prawo taką pozostać (Disability. Another quality that has the right to remain as it is)*, „Studia Edukacyjne” 2012, no. 25/2012, pp. 150–157.
- [24] Parys K., *Zjawisko pozorów w systemie kształcenia uczniów niepełnosprawnych – próba identyfikacji i propozycje rozwiązań (An Attempt at Identifying the Phenomenon of Pretense in the Education of Students with Disabilities and Proposals for Solutions)*, „Interdyscyplinarne Konteksty Pedagogiki Specjalnej” 2014, no. 4/2014, pp. 29–55
- [25] Regulation of the Ministry of Education of 23 February 2007, No. 53, item 347, on the types of schools and institutions in which no student self-government is established.
- [26] Rubacha K., *Metodologia badań nad edukacją (Methodology of Research on Education)*. Wydawnictwa Akademickie i Profesjonalne, Warszawa, 2008, pp. 157–164
- [27] Skibska J., Warchał M., *Edukacja inkluzyjna dziecka niepełnosprawnego w szkole ogólnodostępnej a integracja społeczna Edukacja jutra w kontekście wyzwań współczesności (Inclusive education of disabled children in public school and social integration. Education of tomorrow in the context of challenges in contemporary times)*, [in:] *Edukacja jutra w kontekście wyzwań współczesności dostępnej a integracja społeczna (Education of Tomorrow in the Context of Challenges of the Accessible Modernity and Social Integration)*, eds. K. Denek, A. Kamieńska, W. Kojs, P. Oleśniewicz, Oficyna Wydawnicza „HUMANITAS”, Sosnowiec 2012.

- [28] Songin M.Z., *porządkowanego punktu widzenia (From an Orderly Point of View)*, [in:] *Humanistyka i dominacja. Oddolne doświadczenia społeczne w perspektywie zewnętrznych rozpoznań (Humanities and Dominance. Bottom-up social experiences in the perspective of external diagnoses)*, eds. T. Rakowski, A. Malewska-Szałygin, Colloquia Humaniorum, Warszawa 2011.
- [29] Szumski G., *Edukacja inkluzyjna – geneza, istota, perspektywy (Inclusive Education – Genesis, Essence, Perspectives)*, „Kwartalnik Pedagogiczny” 2006, no. 1, pp. 96–100.
- [30] Śliwerski B., *Meblowanie szkolnej demokracji (Furnishing School Democracy)*, Wolters Kluwer, Warszawa 2017.
- [31] Recommendation of the European Parliament and of the Council of 18 December 2006 on key competences for lifelong learning, published in the Official Journal of the European Union of 30 December 2006.
- [32] Appendix no. to the Regulation of the Minister of National Education of 14 February 2017, item 356, on the core curriculum for primary schools for students with moderate or severe intellectual disabilities.
- [33] Zakrzewska-Manterys E., *Upośledzeni umysłowo. Poza granicami człowieczeństwa (Mentally Handicapped. Beyond the Borders of Humanity)*, Wydawnictwo Uniwersytetu Warszawskiego, Warsaw 2010.
- [34] Zybertowicz A., *Przemoc i poznanie, Studium z nie-klasycznej socjologii wiedzy (Violence and Cognition: A Study in Non-classical Sociology of Knowledge)*, Wydawnictwo Uniwersytetu Mikołaja Kopernika Toruń 1995.
- [35] Žižek S., *Przemoc. Sześć spojrzeń z ukosa (Violence: Six Sideways Reflections)*, Muza, Warszawa 2010.



The context of special pedagogy: practical inclusive education or simulated inclusive education?

ABSTRACT: Krystyna Barłóg, *The context of special pedagogy: implemented inclusive education or simulated inclusive education?* Interdisciplinary Contexts of Special Pedagogy, no. 26, Poznań 2019. Pp. 125–142. Adam Mickiewicz University Press. ISSN 2300-391X. DOI: <https://doi.org/10.14746/ikps.2019.26.06>

In many contexts of contemporary special education, its main present and future challenges are the implementation of effective inclusive education, the preparation of the required conditions, space and relations of safe functioning of a child with disabilities or special education needs together with healthy, able-bodied peers. Are the long-standing dreams of parents and many special educators regarding the equal rights of all people with disabilities, and in particular the right to education closest to the child's place of residence, genuinely achieved nowadays? The diagnosis of selected municipal schools shows the real situation of the implementation of inclusive education. Are these successes already being achieved today? Or is it still a educational reality?

KEY WORDS: special pedagogy, inclusive education, context, children with disabilities

Introduction

Irrespective of the development of special pedagogy, one can still see the need for many changes that are supposed to bring disabled persons, in particular children and youths, closer to normalisa-

tion situations, in particular those securing full access to schools and to life within a specific community. One needs to conclude today already that in many aspects of life, changes for the better are occurring that are improving on the difficulties in the lives of disabled people and their families.¹ One can see, however, that in certain situations, disabled people may be excluded, isolated or rejected. Some of them may still experience many negative things only because that certain communities uphold the tendency of exclusion and marginalisation.² However, the basis of inclusive education encompasses the belief of the necessity to counteract the discrimination of the disabled, as is expressed in the opposition against the treatment of disabled persons less favourably. Many activities are undertaken to equalise chances and participation.³ Speaking from the historic point of view, the entire philosophy of inclusive education was implemented in practice over forty years ago in Scandinavia as the need to provide so-called normalisation. In the 1960s and 1970s, it was popular in the United States, with the assumption that disabled children should be taught in an environment, in which there are as few limitations as possible.^{4,5} In June of 1994 in Salamanca, a statement was signed on inclusive education on the international scene, whereby it was assumed that persons with special

¹ I. Chrzanowska, *Pedagogika specjalna* Oficyna Wydawnicza „Impuls”, Kraków, 2015, p. 120.

² D.D. Smith, *Pedagogika specjalna*, sc. ed. by A. Firkowska-Mankiewicz, G. Szumski, Wydawnictwo APS, Warszawa 2009, pp. 31-71.

³ P. Bayliss, *Edukacja włączająca*, [in:] *Od nauczania integracyjnego do szkoły równych szans*, J. Bogucka, D. Żyro (ed.), Wydawnictwo CMPPP MEN, Warszawa 2002, p. 21.

⁴ G. Szumski, *Wokół edukacji włączającej. Efekty kształcenia uczniów z niepełnosprawnością intelektualną w stopniu lekkim w klasach specjalnych, integracyjnych i ogólnodostępnych*, Wydawnictwo Akademii Pedagogiki Specjalnej im. Marii Grzegorzewskiej, Warszawa 2010.

⁵ A. Zamkowska, *Wsparcie edukacyjne uczniów z upośledzeniem umysłowym w stopniu lekkim w różnych formach kształcenia na pierwszym etapie edukacji*, Wydawnictwo Politechniki Radomskiej, Radom 2009.

needs have to have access to typical schools, which are the best resource for counteracting discrimination and the establishment of an integrated society.^{6,7}

In the opinion of Iwona Chrzanowska, the consideration of issues of disability in the context of the risk of exclusion, or exclusion itself, is nothing new in the area of special education or sociology.⁸ For centuries, disabled people have seen oppressive behaviour by fully able people. They were accompanied, among others, by terror, fear, distrust, mercy and others. Oppression against them took the forms of: extortion, marginalisation, powerlessness, cultural imperialism or violence.⁹ As Amadeusz Krause writes, “despite ideological, theoretical, methodical and political declarations in Poland concerning the assurance for disabled persons of conditions for normal functioning, we are dealing with a systemic and social *disability* of adulthood of disabled persons”.¹⁰ Over the course of centuries, the attitude of societies towards disabled persons and their families has changed. One may conclude that this process evolved from complete segregation and exclusion towards normalisation and respect for laws through the start-up of activity spanning integration and inclusion.¹¹ Aleksander Hulek wrote many times that the best sys-

⁶ *The Salamanca Statement and Framework for Action on Special Needs Education adopted by the World Conference on Special Needs Education: Access and Quality*, UNESCO, Salamanca 1994.

⁷ D. Mitel, *Sprawdzone metody edukacji specjalnej i włączającej*, transl. by J. Okuniewski, Wydawnictwo Harmonia, Gdańsk 2016, pp. 352–353.

⁸ I. Chrzanowska, *Pedagogika specjalna*, Oficyna Wydawnicza „Impuls”, Kraków 2015, p. 120.

⁹ A. Twardowski, *Spółeczny model niepełnosprawności – geneza, istota, kontrowersje*, [in:] K. Barłóg (ed.), *Wybrane konteksty i wyzwania współczesnej pedagogiki specjalnej*, Wydawnictwo UR, Rzeszów 2017, pp. 18–19.

¹⁰ A. Krause, *Dorosłość w niepełnosprawności intelektualnej*, [in:] „NIEPEŁNOSPRAWNOŚĆ. Dyskursy pedagogiki specjalnej. Dorosłość osób z niepełnosprawnością. Różne oblicza”, Wydawnictwo UG, Gdańsk 2016, p. 12.

¹¹ K. Barłóg, *Empathic Sensitivity of Children with Special Educational Needs in Inclusive Learning Environment in Poland*, [in:] “*The New Educational Review*”, Vol. 53, No. 3, 2018, pp. 273–282.

tem of education and upbringing for disabled children and youths is one that allows for the satisfaction of various needs. He reminded that historically, the problem of disability was solved through exhaustion, exploitation, isolation and segregation of the disabled from the rest of society. Such persons did not have the right to remain among healthy people. Everything is changing, and the concept of "normalisation" emerges, which means that the duty exists to include disabled persons into normal life, and to ensure such conditions [for them], as fully able people have. This will allow them to develop normally and to have similar achievements just like their healthy colleagues – their peers.¹² Nowadays, we observe the changes that are taking place not only in the perception of disabled people, their families, but also the respect for many rights, including the right to education, with the assurance of required conditions and with processional support. Is it thus a situation, in which the child with special education needs is just accepted into a school in a typical school environment, or is the expected aid and support secured as well? The objective of the article is an attempt at responding to the question, whether the current image of inclusive education corresponds to its assumptions, or does it rather boil down to simulated actions? Assumptions of integration and inclusion proposed even in the 1970s by Aleksander Hulek do not seem to be fully implemented in the process of inclusion of children with special education needs at mass schools. One also needs to look at the frequently repeated question: Is inclusive education is the most advantageous form of education for every child with special education needs? Is inclusive education and the expectation of changes and successes in children with special education needs is a "fad" today to hide the real needs and all circumstances surrounding this complex, very difficult process of changes and of inclusion?

¹² A. Hulek, *Integracyjny system kształcenia osób niepełnosprawnych*, [in:] A. Hulek (ed.), *Pedagogika rewalidacyjna*, Państwowe Wydawnictwo Naukowe, Warszawa 1977, pp. 493–494.

Assumptions of inclusive education as a category opposing exclusion

Education is not just a form of influence to “*know, be able to, live together and be*” as we know from the report by J. Delors.¹³ In contemporary understanding, education is preparation to become a subject, to tolerance, democratisation, personal and collective safety and security, but also to the protection of life and the natural environment, while maintaining a worthy, decent existence. It is also a path to individual development and self-creation, but also to the creation of preliminary conditions of respect for the rights and dignity as well as equality of *chances for everyone*. It is thus supposed to be a relatively just *equality of chances and opportunities* in the struggle for everyone’s social status.¹⁴ Assuming that education is a particular value against social exclusion and that it facilitates processes of establishment of readiness ahead of changes, one needs to conclude that contemporary education, embedded in the context of dynamic, progressing civilisational changes is and should be a factor of establishment of positive changes and transformations for everyone. Already the “inclusion of an excluded person [itself] into the educational process is a symptom of an advantageous change, and constitutes a significant factor of protection”. Objectives of education should assume the start-up of behaviour that is advantageous for the health and development of a person”.¹⁵ For children and youths with diverse disabilities, education has a particular significance: It is a chance at their normalisation and better quality of life. Inclusion

¹³ J. Delors (ed.), *Edukacja. Jest w niej ukryty skarb. Raport dla UNESCO*. Warszawa 1999.

¹⁴ R. Michalak, *Edukacja szansą dla osób wykluczonych społecznie*, [in:] J. Hoffmann (ed.), *Znaczenie edukacji w procesie readaptacji osób wykluczonych w kontekście doświadczeń projektu KPU-NSD*. Wydawnictwo Wyższa Szkoła Zawodowa „KADRY DLA EUROPY”, Poznań 2008, p. 16.

¹⁵ A. Rosińska, *Znaczenie edukacji osób w procesie budowania ich gotowości do zdrowotnej zmiany*, [in:] J. Hoffmann (ed.), *Znaczenie edukacji w procesie readaptacji osób wykluczonych w kontekście doświadczeń projektu KPU-NSD*, Wydawnictwo Wyższa Szkoła Zawodowa „KADRY DLA EUROPY”, Poznań 2008, p. 37.

as opposition to social exclusion is a process of changes, with the right to education, learning with peers, common relations and participation of all pupils in education.^{16,17} "Inclusive education is a process that encompasses the transformation of schools and other learning facilities in such a way so that they could serve all children: Both boys and girls, children from ethnic and linguistic minorities, rural dwellers, persons with HIV/AIDS and persons with disabilities and learning difficulties".¹⁸ The process of inclusion is opposition against the process of exclusion. Exclusion is coupled with discrimination and stripping of rights and privileges, deprivation, restitution or marginality.¹⁹ One could point to factors taken into account in the social exclusion model in the multidimensional perspective. Anna Brzezińska along with a team of researchers makes such a proposition.

Table no 1. Factors taken into account in the multidimensional model of social exclusion according to Levitas and others (2007). Edited by A.I. Brzezińska, J. Pluta, P. Rycielski²⁰

Resources	Participation	Quality of life
material social access to the sector of public and private services	in the economic sense in social life in the system of education, knowledge and culture in the political system and the civic society	health and happiness environment of life crime safety and conflicts with the law

¹⁶ M. Ainscow, T. Booth, *Przewodnik po edukacji włączającej. Rozwój kształcenia i uczestnictwa w życiu szkoły*, Wydawnictwo Olimpiady Specjalne Polska, Warszawa, 2011.

¹⁷ K. Barłóg, *Inkluzja społeczna, edukacyjna a problemy młodych osób z ograniczeniami sprawności*, [in:] „Lubelski Rocznik Pedagogiczny”, Vol. 36, No. 2, 2017, pp. 171-183.

¹⁸ D. Mitchel, *Sprawdzone metody w edukacji specjalnej i włączającej. Strategie nauczania poparte badaniami*, transl. by Juliusz Okuniewski. Wydawnictwo HARMONIA, Gdańsk 2016, p. 351.

¹⁹ I. Chrzanowska, *Problemy edukacji dzieci i młodzieży z niepełnosprawnością. Regionalna specyfika czy ogólnopolska tendencja*. Oficyna Wydawnicza „Impuls”, Kraków 2009.

²⁰ A. I. Brzezińska, J. Pluta, P. Rycielski (2010) *Wsparcie dla osób z ograniczeniami sprawności i ich otoczenia*, Wydawnictwo Naukowe SCHOLAR, Warszawa 2010, p. 80.

The strategy of inclusive education

In his book *“What Really Works in Special and Inclusive Education: Using evidence-based teaching strategies”*, D. Mitchell distinguishes among twenty-nine strategies, assuming that one of them may be inclusive education, even as a multi-part strategy or megastrategy.²¹ He assumes that if it is implemented correctly, then pupils with special needs should experience advantages both in terms of education as well as in social affairs. Their self-esteem should be improved. Other pupils should also experience educational advantages, but also learn to respect the community, understand ideas of equality and social justice, develop competences, social attitudes and attitudes of caring. Pupils with special education needs have the right to learn together with their fully able colleagues, peers, who do not require particular support, which is in agreement with rules of social equality and justice. Inclusive education is more substantiated for economic reasons, omits costs related to the transport and accommodation of pupils at special facilities, in particular in rural settings.²²

Examples of research conducted on inclusive education

One can already find much scientific research on this topic, mainly showcasing the shortcomings, barriers in terms of securing of conditions for pupils with special education needs. For instance, an English study from the year 2004 confirmed that the presence of a fairly large number of pupils with special education needs at ordinary schools has no negative influence on the results achieved by other pupils. Indicated was the significance of such factors as: the

²¹ D. Mitchel, *Sprawdzone metody w edukacji specjalnej i włączającej. Strategie nauczania poparte badaniami*, transl. by Juliusz Okuniewski, Wydawnictwo HARMONIA, Gdańsk 2016, p. 26.

²² D. Mitchel, *Sprawdzone metody w edukacji specjalnej i włączającej. Strategie nauczania poparte badaniami*, transl. by Juliusz Okuniewski, Wydawnictwo HARMONIA, Gdańsk 2016, p. 352.

socio-economic status, the gender, social origin or language. It was confirmed that pupils with special education needs progress within school education, but also within social and personal development. Joint education can correlate positively with the results of all people, mainly in terms of social competences and understanding. Research has shown that special education needs of children can be related to their isolation as well as their low self-esteem and low self-perception²³.

Other research on factors facilitating or hindering the inclusion of people with disabilities was presented by a research team headed by prof. Anna Brzezińska in the book *„Wsparcie dla osób z ograniczeniami sprawności”* [Support for people with limited physical abilities].²⁴ Research has shown the context of factors that facilitate inclusion or that hinder it, in a group of people with physical limitations. Stressed was the particular role of the environment of support for the studied persons, meaning: a supporting family, the closest people, acquaintances, friends, neighbours, but also the closeness of supporters; the ability to speak about problems and difficulties, or even a specific style of upbringing. It was assumed that these factors influence the level of participation of those analysed in social life, and as a consequence, they influence not only educational activity but also professional activity and the subjectively high perception of the quality of life, satisfaction with one's financial situation and general satisfaction from life.²⁵ The own research conducted together with students as part of projects within the Students' Paedagogues and Special Educators Research Club in the year 2017 encompassed twenty-two public primary schools in the city of Rzeszów. The

²³ D.A. Dyson, P. Farrell, F. Polat, G. Hutchesson, *Inclusion and pupil achievement, Raport z badań RR5778*, London: DIES, 2004, as quoted in: D. Mitel, *Sprawdzone metody w edukacji specjalnej i włączającej. Strategie nauczania poparte badaniami*, transl. by Juliusz Okuniewski, Wydawnictwo HARMONIA, Gdańsk 2016.

²⁴ A.I. Brzezińska, J. Pluta, P. Rycielski (2010) *Wsparcie dla osób z ograniczeniami sprawności. Wyniki badań*, Wydawnictwo Naukowe SCHOLAR Warszawa 2010.

²⁵ A.I. Brzezińska, J. Pluta, P. Rycielski (2010) *Wsparcie dla osób z ograniczeniami sprawności i ich otoczenia, Wyniki badań*, Wydawnictwo Naukowe SCHOLAR, Warszawa 2010, pp. 79–91.

objective of research was a diagnosis of readiness of schools of the city of Rzeszów to take on children with disabilities, but also to satisfy their special needs.²⁶ The selection of the area of research was purposeful, and was based on the assumption that in such a large city, the situation of children with special education needs should be more favourable than in small rural schools. The results achieved following the conducted interviews with the headmasters of the studied schools, however, did not prove optimistic. Pupils with special education and health needs often learn in overcrowded classes, because they number between 21 and 30 pupils, contacts with specialists remain infrequent, mainly in situations of diagnosis of special needs, the determination of the type and scope of support work. The majority of headmasters of the analysed facilities concluded that *“the school is, in general, not adapted to the education of children with mobility disabilities, due to, for instance, architectural barriers, even though children with mobility disabilities learn in the classes”*. In other opinions, one could obtain the information that *“the assurance of relevant conditions depends on the individual case of the pupil. The school always tries to provide aid and support for children with special education needs, but a hindrance are financial limitations, limitations of space or the organisation of work of the school itself”*. Research has confirmed that the decisive majority of teachers concluded post-diploma studies mainly in oligophrenologic pedagogy, but also diverse training courses. There are fewer teachers who have graduated from full master’s studies in special education. There is also a group of teachers that have indicated lack of preparation in the area of special education, having finished studies in early education or care and upbringing pedagogy. Hence, the determined project title of *“A school friendly to disabled children”* was not fully suitable to the presented diagnosis of readiness of schools to provide conditions to satisfy the special needs of disabled pupils at public schools”.

²⁶ K. Barłóg, D. Karcz, J. Kawa, K. Sabat-Zabłotni, *Szkoła przyjazna dla dzieci z niepełnosprawnością. Biuletyn gotowości rzeszowskich szkół podstawowych do przyjęcia dzieci z ze specjalnymi potrzebami edukacyjnymi*. Wydawnictwo Uniwersytetu Rzeszowskiego, Rzeszów 2017.

Own research

A continuation of historic research were own studies conducted in a group of teachers of the Subcarpathian Voivodeship towards the end of 2018 and in the beginning of 2019. The objective of the research was attempt at finding an answer to the question- how do teachers determine and classify difficulties and successes in inclusive education? The study encompassed 65 teachers working at public schools, these were women aged 30 to 54 years. 100.0% of them had higher education, 56.0% of those studied had teaching experience of 25 years or more. The remaining teachers had between five and ten years of teaching experience. The opinions of the teachers on difficulties of working with children with special education needs are presented in table no 1.

Table no 1. Difficulties of inclusive education from the point of view of teachers

No.	Response categories	N	%
1	Overcrowded classes	22	53.0
2	Excess number of children with difficulties	10	24.0
3	No education aids	5	12.0
4	Financial limitations	7	17.0
5	Limited access to support	7	17.0
6	No support by parents	5	12.0
7	Difficulties of children with special needs	9	22.0

Multiple choice questions.

The achieved results confirm that teachers, working with children with special education needs, experience many difficulties: organisational, financial, related to the functioning of the education facility and lack of aid or support. A particular difficulty are overcrowded classes, in which pupils with diverse needs and individual capacities learn, and this is the opinion of half of those studied (53.0%); the high proportion of children with special education and

health needs (24.0% of those studied) as well as the difficulties and individual problems of such children themselves (22.0%). Disturbing is the fact that in many cases the teachers do not get support, be it from the facility or from the outside (17.0%), but also from the parents of the children with special education needs themselves. These problems are often compounded by financial limitations (17.0%) or even the lack of basic aids or tools (12.0%).

Table no. 2. Difficulties in terms of cooperation with parents of children with special education needs

No.	Response categories	N	%
1	Lack of trust in teacher	1	2.4
2	Excess expectations of parents	5	12.0
3	No preparation of teachers to cooperate with the parents	18	43.0
4	Parental overprotectiveness	21	50.0
5	Difficulties of children expecting support	18	43.0
6	No understanding for the child's needs and problems	1	2.4
7	No engagement in cooperation by the parents	6	14.0
8	Difficulties related to cooperation with parents	2	4.8

Multiple choice questions.

The studies confirm unequivocally that teachers working with children with special education needs also experience many difficulties in terms of cooperation with the parents of the children with special education needs themselves; as these parents significantly fail to amend the work through engagement with the child, or are an entity that does not receive the educational and developmental stimuli of the child. Troubling is the fact that teachers do not feel suitably prepared to support parents in their problems and difficulties related to the need to care for a child with special education needs (43.0%), that they see the problems of such families (43.0%) and frequent overprotectiveness represented by half of the parents of children with special education needs (50.0%), or even lack of

trust for the work of teachers by parents (2.4%) or even excess expectations of parents (12.0%). Teachers also sometimes perceive the lack of will and engagement by parents (14.0%). Some of them admit that they have difficulties cooperating with parents of children with special education needs (4.8%).

Table no. 3. Difficulties of teachers left without aid or support

No.	Response categories	N	%
1	Impatience	3	7.2
2	Helplessness	21	50.0
3	Distress	1	2.4
4	Dismay	5	12.0
5	Fatigue	9	22.0
6	No such problems	9	22.0

Multiple choice questions.

The study revealed that some teachers working with children with special education needs who are left without aid and support sometimes experience negative emotions and psychological fatigue, such as helplessness in certain situations (50.0%), fatigue (22.0%) or dismay (12.0) and even impatience (7.2%) or distress (2.4%). Of course, a significant number of teachers does not experience such problems (22.0%), however the achieved study results can be an important information confirming that some teachers are left without the necessary aid and support and can experience many negative feelings and incidents, helplessness in working with children with special education needs.

The tested teachers include regular professional development among their particular professional successes.

One could confirm that a particular success of teachers working with children with special education needs is regular improvement of own professional competences to achieve more efficient work

with children with special education needs, in particular through attending post-diploma studies in special education (48.0%), but other forms of learning as well: participation in trainings, scientific and educational conferences (17.0%), courses and other forms of learning (9.5%) or reading professional literature (81.0%).

Table no. 4. Forms of improvement of own professional qualifications

No.	Response categories	N	%
1	Attending post-diploma studies	20	48.0
2	Participation in trainings, conferences	7	17.0
3	Reading specialist literature	34	81.0
4	Participation in courses and other forms of learning	4	9.5

Multiple choice questions.

Table no. 5. Successes of children with special education needs in teacher statements

No.	Response categories	N	%
1	Visible positive developmental changes	26	52.0
2	Integration with the group	44	88.0
3	Visible intellectual development	26	52.0
4	Successes in learning	28	56.0
5	Visible development of social competences	44	88.0

Multiple choice questions.

The statements by teachers indicate that they appreciate and successes of children with special education needs – this is the opinion of the decisive majority of teachers. These successes apply mostly to changes in terms of integration with the peer group (88.0%), the development of positive attitudes and social behaviour (88.0%), but also visible successes in learning (56.0%), intellectual and general development of the child (52.0%), in general: visible positive developmental changes (52.0%).

Table no. 6. Successes of teachers in work with children with special education needs

No.	Response categories	N	%
1	Diagnosing the needs of children with special education needs	38	76.0
2	Elimination of difficulties experienced by a child with special education needs	24	48.0
3	Motivating to activity and learning	32	64.0
4	Achievement of successes and better grades by a child with special education needs	34	68.0
5	Elimination of barriers and equalisation of chances of children with special education needs	12	24.0
6	Special preparation of the teacher	36	72.0
7	Aid for a child with special education needs	24	48.0
8	Inclusion of the child in the peer group	44	88.0
9	Rewarding the child's successes	18	36.0

Multiple choice questions.

The study shows that teachers of public schools also notice many successes when working with children with special education needs, in particular concerning the inclusion of the child in the peer group (80.0%), diagnosing the needs and capacities of the child (76.0%), achievement of successes and better grades by children with special education needs (68.0%), own preparation for working with children with special education needs (72.0%), aid for children with special needs (48.0%). They are also happy with successes in terms of elimination of difficulties for children with special needs (36.0%) and in general the equalisation of chances, elimination of barriers and hindrances in terms of satisfaction of special needs and inclusion.

The studies confirm that a significant proportion of teachers at public schools perceives many positive values in working with children with special education needs. Despite certain difficulties, a significant share of these perceive, as their professional success, satisfaction due to setting demanding educational requirements and goals that are achievable by children (88.0%), the usage of interest-

ing methods of work (84.0) and individual perception of the child's needs (68.0%). This is also a positive attitude towards the difficulties and special needs of children (64.0%); adaptation of the curriculum and time to the individual capacities and needs of the child (60.0%) and efficient cooperation with parents (52.0%), etc.

Table no. 7. Successes in inclusive education in teacher statements

No.	Response categories	N	%
1	Positive attitude towards the difficulties of children with special education needs	32	64.0
2	A curriculum, pace and time adapted to the needs of pupils with special education needs	30	60.0
3	Interesting methods of work	42	84.0
4	Interesting education strategies	18	35.0
5	Usage of interesting educational and technical resources	22	44.0
6	Positive cooperation with specialists	30	60.0
7	Efficient, partnerly cooperation with parents	26	52.0
8	Individual perception of the child with special needs	34	68.0
9	Faith in the sense of working with children with special needs	20	40.0
10	Setting achievable goals	44	88.0

Multiple choice questions.

Conclusion

The fragmentarily presented results of the scientific research and the theoretical substantiation confirms that the process of inclusive education is a complex one, even though, despite many difficulties, it is already visible, and in certain areas of its execution or educational spaces – efficient. Research confirms that many difficulties remain that the studied teachers have to handle: a high proportion of children with difficulties, overcrowded classes, the needs of the children themselves and of their parents, lack of preparation for

working with parents, helplessness or fatigue. Despite the fact that the studied teachers confirm a certain fatigue or sometimes helplessness in light of the problems, needs of pupils, they also see the first successes. They admit that many of them already have special preparation, graduated from post-diploma studies in special education, study professional literature, utilise interesting methods of education and therapy, diagnose the special needs of children. As Władysław Dykcik writes, contemporary systemic education does not establish the threat of failure of pupils with special education needs, and frequently many of its intentional activities secure individual subjectivity and personal autonomy of these pupils. Referring to guidelines concerning the prevention of discrimination (*Inclusion Europe*), he reminds of rules setting out the efficiency of activity for people with disability. He assumes that a disabled person is able to have certain achievements. One must reject traditional thinking that the problem lies only in the disabled person, and that it is they that must change so that they could be able to emerge within society. One must conclude that disability is a social issue, hence, the rights of disabled persons must be sanctioned politically. One needs to support the establishment of an identity and culture of disabled persons. Persons with disabilities should find at least a shadow of joy in their disability, and these people should be treated as having control of their own lives²⁷. The process of inclusive education, already commenced and already ongoing, requires precise diagnoses, on which positive change and transformation models must be built. Every educational situation should respect the child's dignity and satisfy their individual needs. Particularly important in this regard is the observation of ongoing changes and the offer of systemic support, but also the establishment of a feeling of value of participants²⁸. The encountered dilemmas may only be seeming ones.

²⁷ W. Dykcik, *Problemy osób społecznie naznaczonych i upośledzonych*, [in:] *Znaczenie edukacji w procesie readaptacji osób wykluczonych w kontekście doświadczeń projektu KPU-NSD*, J. Hoffmann (ed.), Wydawnictwo Wyższa Szkoła Zawodowa „KADRY DLA EUROPY”, Poznań 2008, p. 58.

²⁸ A. Rosińska, *Znaczenie edukacji w procesie budowania gotowości do zmiany*, [in:] *Znaczenie edukacji w procesie readaptacji osób wykluczonych w kontekście doświadczeń*

Bibliography

- [1] Ainscow M., Booth T., *Przewodnik po edukacji włączającej. Rozwój kształcenia i uczestnictwa w życiu szkoły*, Wydawnictwo Olimpiady Specjalne Polska, Warszawa 2011.
- [2] Barłóg K., *Empathic Sensitivity of Children with Special Educational Needs in Inclusive Learning Environment in Poland*, [in:] "The New Educational Review", Vol. 53, No. 3, 2018.
- [3] Barłóg K., *Inkluzja społeczna, edukacyjna a problemy młodych osób z ograniczeniami sprawności*, [in:] „Lubelski Rocznik Pedagogiczny”, Vol. 36, No. 2, 2017.
- [4] Barłóg K., Karcz D., Kawa J., Sabat Zabłotni K., *Szkoła przyjazna dla dzieci niepełnosprawności*, Wydawnictwo Uniwersytet Rzeszowski, Rzeszów 2017.
- [5] Bayliss P., *Edukacja włączająca*, [in:] J. Bogucka, D. Żyro (ed.), *Od nauczania integracyjnego do szkoły równych szans*, Wydawnictwo PPP MEN Warszawa 1997.
- [6] Brzezińska A.I., Pluta J., Rycielski P., *Wsparcie dla osób z ograniczeniami sprawności. Wyniki badań*. Wydawnictwo Naukowe SCHOLAR, Warszawa 2010.
- [7] Chrzanowska I., *Pedagogika specjalna. Od tradycji do współczesności*, Oficyna Wydawnicza „Impuls”, Kraków 2015.
- [8] The Salamanca Statement and Framework for Action on Special Needs Education adopted by the World Conference on Special Needs Education: Access and Quality, UNESCO, Salamanca 1994.
- [9] Delors J., *Edukacja. Jest w niej ukryty skarb. Raport dla UNESCO Międzynarodowej Komisji ds. Edukacji dla XXI wieku*, Warszawa 1999.
- [10] Dykik W., *Problemy osób społecznie naznaczonych i upośledzonych*, [in:] J. Hoffmann (ed.), *Znaczenie edukacji w procesie readaptacji osób wykluczonych w kontekście doświadczeń projektu KPU-NSD*, Wydawnictwo WSZ „KADRY DLA EUROPY”, Poznań 2008.
- [11] Hulek A., *Integracyjny system kształcenia osób niepełnosprawnych*, [in:] A. Hulek (ed.), *Pedagogika rewalidacyjna*, Państwowe Wydawnictwo Naukowe, Warszawa.
- [12] Krause A., *Dorobłość w niepełnosprawności intelektualnej*, [in:] „NIEPEŁNOSPRAWNOŚĆ. Dyskursy pedagogiki specjalnej. Różne oblicza”, Wydawnictwo Gdańsk 2016.
- [13] Michalak R., *Edukacja szansą dla osób wykluczonych społecznie*, [in:] J. Hoffmann (ed.), *Znaczenie edukacji w procesie readaptacji osób wykluczonych w kontekście doświadczeń projektu KPU-NSD*, Wydawnictwo WSZ „KADRY DLA EUROPY”, Poznań 2008.

- [14] Mitel D., *Sprawdzone metody w edukacji specjalnej i włączającej. Strategie nauczania poparte badaniami*, transl. by Juliusz Okuniewski, Wydawnictwo HARMINIA, Gdańsk 2016.
- [15] Rosińska A., *Znaczenie edukacji w procesie budowania gotowości do zmiany*, [in:] J. Hoffmann (ed.), *Znaczenie edukacji w procesie readaptacji osób wykluczonych w kontekście doświadczeń projektu KPU-NSD*, Wydawnictwo WSZ KADRY DLA EUROPY, Poznań 2008.
- [16] Smith D.D., *Pedagogika specjalna. Podręcznik akademicki*, sc. ed. A. Firkowska-Mankiewicz, G. Szumski, Wydawnictwo APS Warszawa, No. 1, 2009.
- [17] Szumski G., *Wokół edukacji włączającej. Efekty kształcenia uczniów z niepełnosprawnością intelektualną w stopniu lekkim w klasach specjalnych, integracyjnych i ogólnodostępnych*, Wydawnictwo Akademii Pedagogiki Specjalnej, Warszawa 2010.
- [18] Twardowski A., *Spoleczny model niepełnosprawności – geneza, istota, kontrowersje*, [in:] *Wybrane konteksty i wyzwania współczesnej pedagogiki specjalnej*, [in:] K. Barłóg (ed.), Wydawnictwo Uniwersytetu Rzeszowskiego, Rzeszów 2017.
- [19] Zamkowska A., *Wsparcie edukacyjne uczniów z upośledzeniem umysłowym w stopniu lekkim w różnych formach kształcenia na pierwszym etapie edukacji*. Wydawnictwo Politechniki Radomskiej, Radom 2009.



NAVA BAR

University of Haifa, Israel

BOSHRA KANJ-SIRHAN

Ministry of Education, Israel

The 'parents' choice': the recent perceptual changes in special education law in israel and its implementation in the field

ABSTRACT: Nava Bar, Boshra Kanj-Sirhan, *The 'parents' choice': the recent perceptual changes in special education law in israel and its implementation in the field*. Interdisciplinary Contexts of Special Pedagogy, no. 26, Poznań 2019. Pp. 143–162. Adam Mickiewicz University Press. ISSN 2300-391X. DOI: <https://doi.org/10.14746/ikps.2019.25.07>

The Israeli educational system is dealing intensively for the last two decades in the assimilation of the inclusion approach of student with special needs (SwSN) in general education. The first part of the article presents the historical development of special education in Israel as a background to the presentation of the new amendment of Special Education Law - Amendment 11 (2018). The current stage of the Eleventh Amendment implementation aims to ensure the inclusion of SwSN in the general education by an allocation of budget for his needs according to a standard assessment of his functioning level, in addition to his disability. The SwSN parents' will decide about their child placement according to the model of "The Parents' Choice", and the student's budget will be transferred to the chosen educational framework according to the "Funding Follows the Child" principle. The second part of the article presents a case study of special education school in Israel for students with intellectual developmental disabilities that gradually assimilate the spirit of the law amendment from both aspects - standard assessment of the students functioning and parental partnership, as part of professional work processes carried out at school in Activities of Daily Living (ADL) field.

KEY WORDS: Special Education, Special Education Law in Israel, Activities of Daily Living (ADL) Assessment, 'Parents' Choice'

Stages in Special Education Development in Israel

The Israeli educational system is dealing intensively for the last two decades in a process of assimilation of the inclusion approach of students with special needs (SwSNs) in one educational system with their peers, members of the same age group, and in developing of a continuum of educational frameworks that will enable an appropriate solution for the needs of the diverse population of SwSNs. From the establishment of the State of Israel (1948) until the 1970s, the perception was that the special education school has clear advantages over the general education framework and provides the best treatment to the SwSN.¹ The guiding concept was of separateness from general education.² The number of special education schools in Israel constantly increased during this period.³

In the 1970s, a “normalization” approach developed and placed at the center the right of the individual in the society, including the individual with special needs, to a normal lifestyle. On the light of this approach, the inclusion movement began to grow in Israel that was based upon the humanistic philosophical approach, which emphasizes that SwSN is equal in his rights to the student who is not disabled. Accordingly, the basic right of SwSN is to learn together with his peers, in one educational system.⁴ The proponents of this approach maintained that the inclusion will help the “regular” students to understand that diversity between people exists in our so-

¹ G. Avissar, Ts. Bab, *Processes and trends in the planning of the studies in Israel for students with disabilities*, Theory and Practice in the Planning of the Studies, 2010, 21.

² M. Marom, K. Bar-Simon Tov, A. Kron, P. Koren, *Inclusion of special needs children in the regular educational system: A review of the literature*, The Center for the Research of Social Policy in Israel Press, Jerusalem 2006.

³ H. Ronen, *Inclusion: Issues and disputes*, [in:] *Inclusiveness: Learners with disabilities in education*, eds S. Reiter, Y. Leyser, G. Avissar, AHVA Publishers, Haifa 2007; B. Nirje, *The basis and logic of the normalization principle*, Australia and New Zealand Journal of Developmental Disabilities, 1985, 11(2).

⁴ G. Avissar, *Inclusion and accessibility: Curriculum planning and implementation for students with disabilities*, Mofet Institute, Tel Aviv 2010; M. Marom et al., *Inclusion of special needs children in the regular educational system*.

ciety, when each one has a basic right for presence, for expression, for acceptance.⁵

The adoption of the inclusion approach by the Israeli educational system has been expressed from the 1990s in the gradual process of creation a continuum of educational frameworks that provided adequate and adjusted solutions for the diversity among SwSN, for their needs and development, their quality of life and the achievement of the goals set for their education to the least possible extent.⁶ The continuum of educational frameworks for SwSNs in Israel ranges from the school of special education, the special class in the general school, and inclusion in the regular class – the more separate the framework, the services are given there to the student are more comprehensive.

The recognition of the rights of SwSN was expressed in the legislation of the Special Education Law in Israel on July 12, 1988.⁷ The spirit and the content of the law protect the rights of the SwSN from age 3 to age 21 who have a variety of needs. The law determined special education as a right.⁸ This entitlement for special education ensured that the SwSNs will enjoy systemic learning-teaching processes alongside a series of treatments and services adjusted to their special needs. Above all, the law determined the preference of the general educational system over the special education system in the placement of SwSN⁹, assuming that the integration, as much as pos-

⁵ Y. Harpaz, *Every Student Is a Student with Special Needs* (Interview with Prof. Shunit Reiter) Hed Hahinuch (Echo of Education), 2013, 87(6), p. 44.

⁶ J.B. Crockett, J.M. Kauffman, *The least restrictive environment*. Lawrence Erlbaum, New Jersey, 1999; P. Howard, *The Least Restrictive Environment: How to tell*, Journal of Law & Education, 2004, 33.

⁷ *The Special Education Law*, 5748, State of Israel, 1988.

⁸ N. Blass, A. Laor, *Special education in Israel and the policy of inclusion*. The Center for the Research of Social Policy in Israel Press, Jerusalem 2002; D. Neon, M. Milshstein, M. Marom, *Integration of children with special needs in the elementary schools: Follow up after the implementation of the 'Book of Inclusion' in the Special Education Law*. The Center for the Research of Disabilities and Employment of Special Populations, Jerusalem 2012.

⁹ M. Marom et al., *Inclusion of special needs children in the regular educational system*.

sible, in general education will prepare him for integration in the society outside of the school. Practically, the students with severe difficulties remained in the special schools¹⁰, the hours allotted for the inclusion of the SwSNs in the regular classes were few and the teachers in the regular classes did not have the knowledge for coping with children with disabilities. The research study of Reiter, Schanin, and Tirosh (1998) indicated that the teachers did not support the inclusion and preferred the opening of special education classes in their schools.¹¹

Following the implementation of the Special Education Law in 1988 and the public discussion, public committees were established for the examination of the Special Education Law implementation. Margalit committee that published its report in 2000¹² determined that there are significant discrimination and inequality in the allocation of budgets, resources and services of special education, especially in the inclusion framework.¹³ While the Special Education Law emphasizes the priority of the placement of SwSNs in the general education¹⁴, with their transition to general education framework their right to receive budgets as they have got in the special education school was canceled, therefore their chances of development, learning and adaptation were compromised.¹⁵ Against the background of these developments, in 2002, Amendment 7 (B) was

¹⁰ Margalit Committee, *Report of the Committee for the Examination of the Realization of the Ability of Students with Learning Disabilities*. Ministry of Education, Culture, and Sport, Department of Special Education, Jerusalem 1997; D. Neon, M. Milshtein, M. Marom, *Integration of children with special needs in the elementary schools*.

¹¹ S. Reiter, M. Schanin, E. Tirosh, *Israeli elementary school students' and teachers' attitudes towards mainstreaming children with disabilities*, *Special Services in the Schools*, 1998, 13(1/2).

¹² Margalit Committee, *Report of the Committee for the Examination of the Implementation of the Special Education Law*, Ministry of Education, Jerusalem 2000.

¹³ Margalit Committee, *Report of the Committee for the Examination of the Implementation of the Special Education Law*, p. 30.

¹⁴ *The Special Education Law*, 1988.

¹⁵ Margalit Committee, *Report of the Committee for the Examination of the Implementation of the Special Education Law*, pp. 47–48.

added to Special Education Law.¹⁶ The main point of this amendment is the arrangement of the inclusion implementation of SwSNs in general education and primarily the anchoring of their rights and the services to be provided to them by law.¹⁷

The Eleventh Amendment of the Special Education Law as a Perceptual Change

In September 2007, against the background of the inclusion implementation and the continued arguments about inequality and lack of effectiveness in the division of the special education budget, the Minister of Education reached the conclusion that the policy of the care of SwSNs had not been discussed in depth and decided to establish a public committee under the leadership of the retired Supreme Court Justice Dalia Dorner, for the examination of the special education system in Israel.¹⁸ The stated purposes of the committee were to examine the Ministry of Education policy regarding the SWSNs care and the manner of the budget allocation for these children. An additional purpose was to determine an action plan and priorities for action in this area.¹⁹ Most arguments put before the committee focused on the inclusion of SwSNs in general education (like in Margalit Committee in 2000²⁰) and in the gap exists between

¹⁶ *The Special Education Law 5762 (Amendment No. 7)*, State of Israel, 2002.

¹⁷ G. Avissar, Ts. Bab, *Processes and trends in the planning of the studies in Israel for students with disabilities*; G. Avissar, A. Moshe, P. Licht, "These are basic democratic values": *The perceptions of policy makers in the Ministry of Education with regard to inclusion*, [in:] *Inclusiveness: From theory to practice*, eds S. Reiter, G. Avissar, AHVA Publishers, Haifa, 2013; D. Neon, M. Milshtein, M. Marom, *Integration of children with special needs in the elementary schools*.

¹⁸ Dorner Committee, *Report of the Public Committee for the Examination of the Special Education System in Israel*, Ministry of Education, Jerusalem 2009, p. 3.

¹⁹ Dorner Committee, *Report of the Public Committee*, p. 35, pp. 57–59.

²⁰ Margalit Committee, *Report of the Committee for the Examination of the Implementation of the Special Education Law*.

the priority determined by the Special Education Law enacted in 2002²¹ for the inclusion of SwSNs in general education, and the low priority and the inappropriate funding given to it by the Ministry of Education.²²

The committee indicated in the final report the lack of adequate budget for the inclusion track and reached the conclusion that the existing method of budgeting does not always enables a suitable response to the needs of the SwSN. Thus, it causes discrimination since two children with a similar functioning level obtain a different scope of services because each one of them learns in a different education framework – inclusion in general education or special education framework.²³ Therefore, the current budgetary method influences the choice of the framework in which the SwSN will study. The committee proposed the **“Funding Follows the Child”** principle²⁴ that is used also in other countries.²⁵ The budget allocation for the SwSN will be determined by an “Eligibility Committee” and will be based on a standard measurement. Consequently, the budget allocation will be differential that rely not only on the student’s disability, but also on a clear criteria based on an assessment of his functioning level. For this purpose, an assessment tool was constructed for the measurement of the SwSN’s observed behaviors in the aspects of behavior and functioning that can be observed during the everyday life²⁶ in the educational institution, without the need to hold diagnostic tests for the student. In addition, the committee recommended setting certain groups that are distinct from one another in the degree to which they need special education resources.

²¹ *The Special Education Law, 2002.*

²² Dorner Committee, *Report of the Public Committee*, pp. 35–37.

²³ Dorner Committee, *Report of the Public Committee*, pp. 37–38, p. 53.

²⁴ Dorner Committee, *Report of the Public Committee*, p. 54, 57.

²⁵ C. Robson, *Students with disabilities, learning difficulties and disadvantages: statistics and indicators*. OECD: Organisation for Economic Cooperation and Development, France 2005, p. 20. ISBN 9264009809.

²⁶ Dorner Committee, *Report of the Public Committee*, p. 58, 73, 76.

Every group will be allotted the special education services adapted according to a “budgetary key” and every SwSN will be ascribed to one of the groups.²⁷

The budget that will be determined for the student will be conveyed to an educational framework, according to “**The Parents’ Choice**” model²⁸, whether it is a separate special education framework or inclusion framework – in general education, so that the student’s eligibility for professional services will be maintained. This model is already activated in some other countries.²⁹ The committee noted that the recognition of the parents’ right to be involved in the process of their child’s education is recognition of their human rights and is perceived today as essential and vital involvement. The parents are those who can represent their child in the most dedicated manner, and this will encourage them to invest efforts in their child’s education and their advancement.³⁰ The committee holds that a change in the legal regime, which at its center are the budgeting method of “Funding Follows the Child”, according to a standard assessment tool and the SwSN placement based on “The Parents’ Choice”, will allow the state to provide the resources necessary in a more tailored and just manner, and will enable every SwSN to move between the existing various educational frameworks according to his needs.³¹ This method is considered as enhancing and encouraging the inclusion assimilation.³²

The recommendations of the Dorner Committee published in 2009 were adopted and anchored in Amendment 11 of the Special

²⁷ Dorner Committee, *Report of the Public Committee*, p. 58, 76.

²⁸ Dorner Committee, *Report of the Public Committee*, p. 53.

²⁹ *Students with Disabilities, Learning Difficulties and Disadvantages Policies: Statistics and Indicators*. OECD: Organization for Economic Cooperation and Development, 2007, p. 30. ISBN 978-92-64-02762-6.

³⁰ Dorner Committee, *Report of the Public Committee*, p. 52.

³¹ Dorner Committee, *Report of the Public Committee*, p. 54, 58.

³² *Students with Disabilities, Learning Difficulties and Disadvantages Policies: Statistics and Indicators*, p. 30.

Education Law that was enacted in 10 July 2018.³³ The Ministry of Education started off the implementation in December 2018 in the Northern District of the State of Israel.

Implementation of the Change Spirit in Special Education School: Case Study

Amendment 11 of the Special Education Law emphasizes the standard assessment of the SwSN functioning as a basis for the determination of his eligibility for special education services. In addition, it emphasizes the parents' choice of their child's placement, a perception that sees the student from a holistic view that places at the center of the educational process not only the student but also his family. The second part of the article will present a process undertaken in an Arab special education school in the northern district of Israel for students with an intellectual developmental disability in low, moderate, and high functioning. The goal of the process is to assimilate gradually the spirit of the law amendment in two mentioned aspects³⁴ – a measurable assessment of the students' functioning and the parents' involvement, as a perception, as a language and as a part of the professional work processes in the school. To achieve the goal, the school implemented a process of measurable assessment of the functioning of twelve students from two adult classes in the school, ages 16–21, in the field of activities of daily living (ADL). The students' parents were involved in the assessment findings, in the process of building an individualized educational plan (IEP) for their children in the ADL field, and in the implementation of the plan during the school year. The ADL was

³³ *The Special Education Law 2734 (Amendment No. 11)*, State of Israel, 2018.

³⁴ Amendment 11 to the Special Education Law (2002; 2018) raises the question of the relevance of the special education school in the new era of the two amendments to the Special Education Law (2002, 2018), which emphasizes the preference of the inclusion in the general education system over separate special education frameworks, as Ronen discussed this before: H. Ronen, *The future of the special school*, Issues in Special Education and Rehabilitation, 2003, 18(1).

chosen as the first field of implementation because of its importance to the development of students with an intellectual developmental disability, for their independence and their preparation for integration into society and the workforce.³⁵

Measurable Assessment of the Students' Functioning in ADL Field (ADL)

The assessment tool chosen for the assessment of the two classes' students in the ADL field is a questionnaire developed in 1992 by the World Federation of Occupational Therapists (WFOT) in collaboration with the World Health Organization (WHO)³⁶ which translated into Hebrew by Sachs, Yaakobi-Vekert and Zussman.³⁷ The questionnaire was adapted to a population of students by Sachs, Schreuer, and Adato-Biram in 2008.³⁸ In the examination of the questionnaire reliability after the changes, high reliability was found for the entire questionnaire ($\alpha = .92$) and for daily instrumental activities ($\alpha = .88$).³⁹ The questionnaire examines the independence degree in the performance of daily living activities (ADL) and includes assessment of the performance level in twelve basic everyday activities - six basic activities of everyday living (BADL): Transitions (to lying, sitting, standing, standing up...), self-care (brush-

³⁵ *The Special Education Law, 1988; 2002; "Assif", a collection kit for the "transition" program for special needs students studying in special education frameworks, ages 16-21, Ministry of Education, Special Education Department, 2012.*

³⁶ Project protocol WHO and WFOT, *Quality assurance project concerning CVA- patients*, Denmark: The Danish Occupational Therapy Association, 1992.

³⁷ D. Sachs, R. Yaakobi-Vekert, N. Zussman, *A survey of treatment frameworks, methods and assessment methods and treatment which are customary in occupational therapy with patients after a stroke*, The Israeli Journal of Occupational Therapy, 1995. H147-H127, 4(4).

³⁸ D. Sachs, N. Schreuer, I. Adato-Biram, *Academic, physical and human support to promote participation of people with disabilities in higher education*. Paper presented at the conference of Council of Occupational Therapists in European Countries (COTEC), Hamburg, Germany (2008, May).

³⁹ D. Sachs, N. Schreuer, I. Adato-Biram, *Academic, physical and human support to promote participation of people with disabilities*.

ing teeth, combing, treating wounds...), dressing, toileting, getting around inside and bathing. In addition, it includes six daily instrumental activities (IADL): preparing meals (coffee, tea, sandwich, preparing a snack...), getting around outside, use of transportation, house maintenance, shopping, and use of public institutions (bank, post office...). The interdisciplinary team of each class⁴⁰ along with the student's parents filled out the questionnaire and indicated the functioning level of every student in each of the twelve activities on a five-point scale: 1 = cannot perform; 2 = needs verbal/physical help or care; 3 = independent using aids or compensation way, 4 = performs independently but slowly; and 5 = performs independently.⁴¹ As the score is higher, the student is more independent in the everyday activities examined.

The School Work Process Following the Measurable Assessment

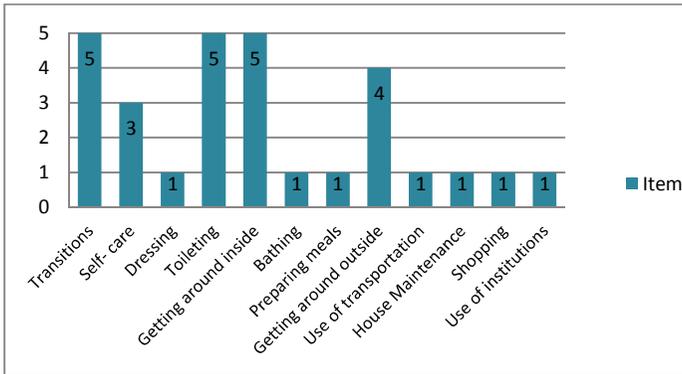
The findings obtained from the measurable assessment of the students' functioning in ADL field were processed on three levels – The level of the single student (see figures 1 and 2), the level of the class (see figures 3, 4, 5, and 6) and the level of both classes that took part in the assessment process (see figure 7). The findings were presented in two stages. In the first stage, they were presented to the interdisciplinary staff of each class that began to build an IEP for each student in the ADL field, and a class plan. In the second stage, the findings and the IEP were presented to every student's parents. The parents meeting focused on the way in which the parents can implement parts of the IEP in the family-home framework after the study hours. At the end of the first half of the year, the parents were

⁴⁰ The interdisciplinary team of the class includes the homeroom teacher, the subject matter teachers, the school counselor, the paramedical therapists of the class, and in some cases the school psychologist.

⁴¹ D. Sachs, R. Yaakobi-Vekert, N. Zussman, *A survey of treatment frameworks, methods and assessment methods*.

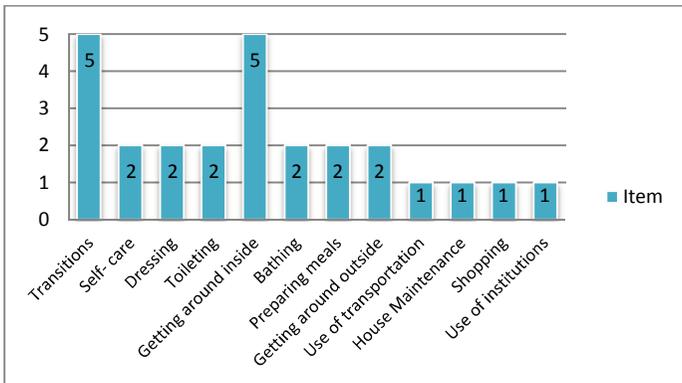
partners in the formative assessment process and presented their point of view on their child’s functioning in the ADL field in the home framework. The findings obtained in the three levels of processing are as follows:

1. Findings on the individual student level



N=1; Range: 1-5

Figure 1. ADL - Assessment of the Individual Student’s functioning - Class 1 (Ages 16-19)

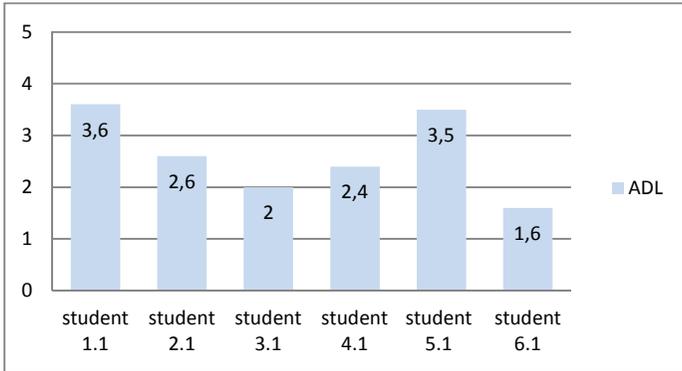


N=1; Range: 1-5

Figure 2. ADL - Assessment of the Individual Student’s functioning - Class 2 (Ages 19-21)

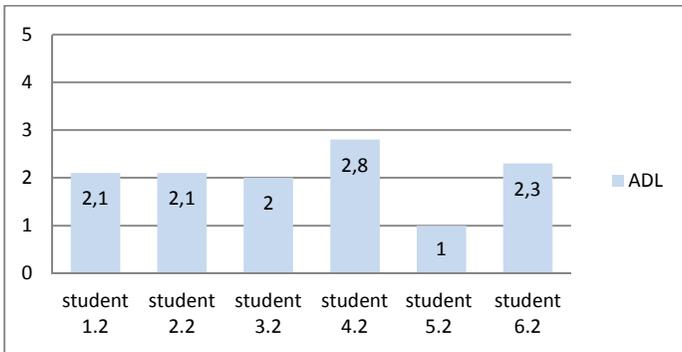
The findings obtained on the individual student level indicate that the different class students function on different levels in the twelve activities of ADL and necessitate the building of a personal work plan tailored to every student in this field.

2. Findings on the class level



N=6; Range: 1-5

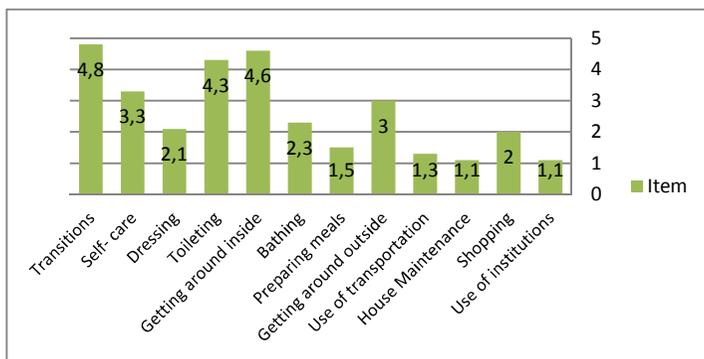
Figure 3. ADL –Assessment Averages of the Students Functioning – Class 1 (Ages 16-19)



N=6; Range: 1-5

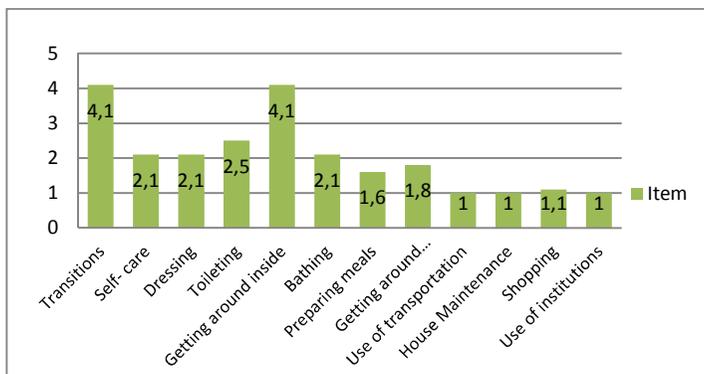
Figure 4. ADL Assessment Averages of the Students Functioning – Class 2 (Ages 19-21)

The findings on the class level obtained from the functioning assessment of all students in every class indicate the diversity that exists between students of each one of the classes in functioning in the ADL field.



N=6; Range: 1-5

Figure 5. Assessment Averages of Class 1 Students (Ages 16-19) Divided into 12 ADL Activities

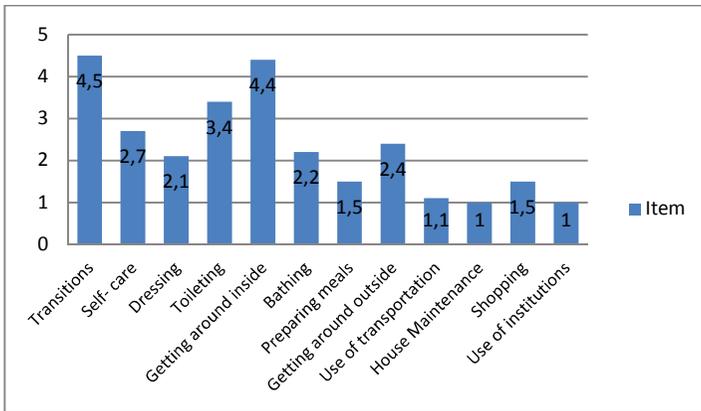


N=6; Range: 1-5

Figure 6. Assessment Averages of Class 2 Students (Ages 19-21) Divided into 12 ADL Activities

The averages of the students functioning of every class in each one of the 12 ADL activities indicate the diversity that exists in the functioning of the class students in various activities. The picture obtained enables the identification of the activities in which the functioning of all the class students is low or high and therefore enables the building of a tailored class work plan.

3. Findings on the level of the adult students' classes of the school



N=12; Range: 1-5

Figure 7. Assessment Averages of the adult students' classes divided into 12 ADL activities

The assessment averages of the adult classes' in each one of the 12 ADL activities indicate the diversity that exists in the students functioning of the two classes in the various activities. The picture obtained enables the identification of the activities in which the functioning of all the adult students is low or high and therefore enables comprehensive overview of the school in the ADL field, writing of a data-based school work plan, setting of objectives for school staff professional development, and the staff instruction in the field of the preparation of students for life.

To learn and draw conclusions from the process performed on the topic of measurable assessment in the field of ADL in the school and the involvement of the parents in the process, three staff meetings were held during the year under the leadership of the school principal. The staff was asked to provide feedback by answering to reflective questions in four categories: (1) *backward-looking* - a question aiming at the previous knowledge before the work with the assessment tool; (2) *inward-looking* - a question aimed at the work process with the assessment tool; (3) *outward-looking* - a question aimed at the work product of the assessment tool; and (4) *forward-looking* - a question aimed at the drawing of conclusions following work with the assessment tool and for future planning. The following paragraph presents an example of a question asked the staff members in each category and an example of an answer given by one of the staff members who took part in the process.

1. *Backward-looking*: How much did you know about the subject before we started? - "I knew the field of assessment in general, we did assessment processes in the school for students, but the assessment was always based on the impression of the student according to which a verbal assessment was written. Regarding the tool - I knew the ADL tool, but this is the first time that we work with it in a computerized, quantitative, and measurable manner. The tool focused our work, and thus the degree of responsibility towards the progress of every student has increased".

2. *Inward-looking*: What did you learn about yourself while working on measurable assessment subject? - "From the work process in the field of assessment through the ADL tool, I reached a number of insights about myself. First, that I have the ability to work in a team, since the tool requires teamwork, and that I have the ability of interpersonal communication with the staff, the parents, and the students. I was afraid of working with a computerized and measurable tool; only during the work, I have learned how to use it and this strengthened my desire to learn new tools and to be open to changes in assessment ways".

3. *Outward-looking*: In what ways did your work meet the standards for this assignment? – “The process that we experienced in the use of measurable assessment tool in the ADL field contributed to the building of a shared professional language that sees the student’s needs and simultaneously the needs of the staff, such as professional development in the field of assessment. The use of the tool emphasized the importance of building an individualized plan based on an assessment that involves the parents and recruited me for a shared mission”.

4. *Forward-looking*: What would you like to invest more time on in school? – “I think that it is important to invest more time in building and operating of assessment tools and formative assessment. The use of the tool and the analysis performed indicated that even if two students reached the same average in their total functioning in ADL, this does not indicative of the same function level since it may be that there are differences between them in the various measured activities. Therefore, it is necessary to invest time to review them in-depth manner so as to build a tailored program. Moreover, effort must be taken to increase parental involvement in the process since it ensures continuity in the work with the student at home on defined and clear activities. The presentation of the findings on graphs enabled visual and focused feedback for the parents and helped them understanding of the student’s needs”.

From the answers of the staff members in the four categories, it is possible to learn about the contribution of the process that was performed. The first contribution is the acquisition of a measurable professional tool for the assessment of the SwSNs functioning in one of the important areas of work with students with an intellectual developmental disability – the ADL. Further contributions are the increased responsibility for the students’ advancement in light of overt measurable data, the promotion of teamwork and a shared language when the needs of the student are at the center, and the identification of the staff needs for professional development. The process contributed to perceive the parents as partners in the work process with the students, for their advancement and development.

The staff's openness to changes and the motivation to acquire additional professional assessment tools (instead of fear of these tools that are ascribed by the teachers to professional diagnostic factors) are apparent.

Summary

The perception that arises from the Eleventh Amendment of the Special Education law which was enacted in Israel in 2018 emphasizes the budgeting of the services the SwSN is eligible to receive according to a standard assessment of his functioning (in addition to the reference to the type of disability) and his “Parents’ Choice” of his placement.⁴² The implementation of this perception was examined in one school of special education as a test case that sharpens the importance of the implementation of educational processes centered on the students’ needs, which are examined professionally and measurably and from a broad view of the various life circles of the SwSN, through the sharing and involvement of his parents in the performed educational processes. It is possible to see this as an extension of the “Parents’ Choice” principle – from the choice of the educational framework to parents’ involvement in processes related to their child.

The use of exists tool for measurable assessment, which is an available and useful for the teachers, enabled immediate and uncomplicated analysis of the findings, and accordingly work on three levels: the level of the individual student, the level of the class, and the level of the school. The work process was characterized by the transition from work based, partly, on intuition and impression to professional data-based work, by the transition to a long-term process approach, and by the transition from a “closed” work inside school to openness characterized by partnership and involvement of the parents. These were expressed in the focus on the individual –

⁴² *The Special Education Law, 2018.*

the building of tailored personal plans in the ADL field and the follow up after the student's progress and the providing a relevant and ongoing answer to his needs. On the class level, the assessment enabled mapping of the classes in the ADL field and the planning of adjusted class programs. In the systemic aspect, the work according to the ADL assessment enabled an overview on the school conduct on the topic of the "preparation for life", focus on the curriculum on this topic, and identification of the needs when allocating resources. In addition, the process focused on the identification of the school staff needs for professional development and appointment of role-holders for leading the ADL field in the school. The tool helped the homeroom teachers direct the parents for the work continuation with their children according to data-based assessment and reinforced the partnership with them and their involvement in the process of their children's progress.

The presented case study is a single case of a special education school. It is necessary to broaden the examination of the implementation of Amendment 11 of the Special Education Law perception in additional special education schools and in additional frameworks – special education classes in general schools and in the inclusion framework, and in additional aspects and areas in the educational field. And most importantly, examine the implementation of Amendment 11 of the Special Education Law from the central aspect of its legislation – the inclusion of SwSNs in general education.

Bibliography

- [1] Avissar G., *Inclusion and accessibility: Curriculum planning and implementation for students with disabilities*, Mofet Institute, Tel Aviv, 2010. [Hebrew]
- [2] Avissar G., Bab Ts., *Processes and trends in the planning of the studies in Israel for students with disabilities*, Theory and Practice in the Planning of the Studies, 2010, 21. [Hebrew]
- [3] Avissar G., Moshe A., Licht P., "These are basic democratic values": The perceptions of policy makers in the Ministry of Education with regard to inclusion, [in:] *Inclusiveness: From theory to practice*, eds S. Reiter, G. Avissar, AHVA Publishers, Haifa, 2013. [Hebrew]

- [4] "Assif", a collection kit for the „transition“ program for special needs students studying in special education frameworks, ages 16–21, Ministry of Education, Special Education Department, 2012. [Hebrew]
- [5] Blass N., Laor A., *Special education in Israel and the policy of inclusion*. The Center for the Research of Social Policy in Israel Press, Jerusalem 2002. [Hebrew]
- [6] Crockett J.B., Kauffman J.M., *The least restrictive environment*. Lawrence Erlbaum, New Jersey 1999.
- [7] Dorner Committee, *Report of the Public Committee for the Examination of the Special Education System in Israel*, Ministry of Education, Jerusalem, 2009. [Hebrew]
- [8] Harpaz Y., *Every Student Is a Student with Special Needs*, Hed Hahinuch, Echo of Education, 2013, 87(6). [Hebrew]
- [9] Howard P., *The Least Restrictive Environment: How to tell*, Journal of Law & Education, 2004, 33.
- [10] Margalit Committee, *Report of the Committee for the Examination of the Realization of the Ability of Students with Learning Disabilities*. Ministry of Education, Culture, and Sport, Department of Special Education, Jerusalem 1997. [Hebrew]
- [11] Margalit Committee, *Report of the Committee for the Examination of the Implementation of the Special Education Law*, Ministry of Education, Jerusalem 2000. [Hebrew]
- [12] Marom M., Bar-Simon Tov K., Kron A., Koren P., *Inclusion of special needs children in the regular educational system: A review of the literature*, The Center for the Research of Social Policy in Israel Press, Jerusalem 2006. [Hebrew]
- [13] Neon D., Milshtein M., Marom M., *Integration of children with special needs in the elementary schools: Follow up after the implementation of the 'Book of Inclusion' in the Special Education Law*. The Center for the Research of Disabilities and Employment of Special Populations, Jerusalem 2012. [Hebrew]
- [14] Nirje B., *The basis and logic of the normalization principle*, Australia and New Zealand Journal of Developmental Disabilities, 1985, 11(2).
- [15] Project protocol WHO and WFOT, *Quality assurance project concerning CVA-patients*, Denmark: The Danish Occupational Therapy Association (1992).
- [16] Reiter S., Schanin M., Tirosh E., *Israeli elementary school students' and teachers' attitudes towards mainstreaming children with disabilities*, Special Services in the Schools, 1998, 13(1/2).
- [17] Robson C., *Students with disabilities, learning difficulties and disadvantages: statistics and indicators*. OECD: Organisation for Economic Cooperation and Development, France 2005, 20. ISBN 9264009809.
- [18] Ronen H., *The future of the special school*, Issues in Special Education and Rehabilitation, 2003, 18(1). [Hebrew]
- [19] Ronen H., *Inclusion: Issues and disputes*, [in:] *Inclusiveness: Learners with disabilities in education*, eds S. Reiter, Y. Leyser, G. Avissar, AHVA Publishers, Haifa, 2007. [Hebrew]

- [20] Sachs D., Schreuer N., Adato-Biram I., *Academic, physical and human support to promote participation of people with disabilities in higher education*, Paper presented at the conference of Council of Occupational Therapists in European Countries (COTEC), Hamburg, Germany, May 2008.
- [21] Sachs D., Yaakobi-Vekert R., Zussman N., *A survey of treatment frameworks, methods and assessment methods and treatment which are customary in occupational therapy with patients after a stroke*, Israeli Journal of Occupational Therapy, 1995, H147-H127, 4(4).
- [22] *The Special Education Law, 5748*, State of Israel, 1988. [Hebrew]
- [23] *The Special Education Law 5762 (Amendment No. 7)*, State of Israel, 2002. [Hebrew]
- [24] *The Special Education Law 2734 (Amendment No. 11)*, State of Israel, 2018. [Hebrew]
- [25] *Students with Disabilities, Learning Difficulties and Disadvantages Policies: Statistics and Indicators* OECD: Organization for Economic Cooperation and Development, 2007, 30. ISBN 978-92-64-02762-6.



Parenting of people with visual disabilities as an interdisciplinary context of contemporary special education

*"(...) Blind girls want to get married,
have their own families and children, similarly to blind men"²*

ABSTRACT: Magdalena Wałachowska, *Parenting of people with visual disabilities as an interdisciplinary context of contemporary special education*. Interdisciplinary Contexts of Special Pedagogy, no. 26, Poznań 2019. Pp. 163–190. Adam Mickiewicz University Press. ISSN 2300-391X. DOI: <https://doi.org/10.14746/ikps.2019.25.08>

The aim of the article is to present the issues of parenting of people with visual disabilities as a factor that dynamizes development, against the background of selected interdisciplinary contexts (psychological, functional, pedagogical). The sphere of personality-emotional development was presented through a psychological context. The functional sphere is represented by the functional context, and the development in the cognitive area has been based on the pedagogical context. The study was summarized indicating areas requiring scientific penetration in the social context of the functioning of the parental practice of the blind and visually impaired. The text was based on the method of descriptive and critical literature analysis.

KEY WORDS: a person with visual disability, parenting, interdisciplinary contexts

¹ PhD in the humanities in the field of education, assistant professor in the Department of Fundamentals of Special Education of the Maria Grzegorzewska University, mwalachowska@aps.edu.pl

² M. Oczkowska, *Sytuacja niewidomej kobiety. A typescript of the paper presented during the Conference of the Polish Association of the Blind*, PZN, Muszyna 1958, pp. 7–8.

Introduction

“They [disabled people, author’s note] have always made friends, loved, started families, gave birth to children, undertaken the effort of raising them and given them their love. Without special permits, instructions or support. Just by simply accepting the joys, concerns and challenges of human existence”.³ Performing a role in the family is one of the central needs⁴, that a person undertakes in the period of middle adulthood, despite numerous dangers arising from contemporary social changes affecting families.⁵ Blind and partially sighted people, having additional obstacles to overcome, also have a strong natural motivation to start their own family. The aim of this choice is to achieve emotional and psychological interdependence, a close intimate relationship by stabilizing sexual life,

³ D. Podgórska-Jachnik, *Problem ojcostwa w kontekście niepełnosprawności z perspektywy naukowej*, [in:] *Ja ojciec*, ed. M. Rydzewski, Wydawnictwo Fundacji „Otwórz Oczy”, Warsaw 2013, p. 4; after: B. Górnicka, *Pomimo niepełnosprawności... – wybrane aspekty rodzicielstwa w różnych fazach funkcjonowania rodziny z problemem niepełnej sprawności dziecka lub rodzica*, [in:] *Rodzicielstwo w różnych fazach rozwoju rodziny*, ed. J. Brągiel, B. Górnicka, Wydawnictwo Uniwersytetu Opolskiego, Opole 2017, p. 73.

⁴ R. Ossowski, *Kształtowanie obrazu własnej sytuacji i siebie u inwalidów wzroku w procesie rehabilitacji*, Wydawnictwo Uczelniane WSP Bydgoszcz, Bydgoszcz 1982, p. 30.

⁵ Changes and threats to the contemporary family include: dominance of the elementary family as a separate economic unit, blurring of relationships and contacts with the extended family; decrease in elderly people’s influence; revolution in male-female relations, mass entry of women into the labour market, devaluation of family life, pessimistic attitude towards the institution of marriage; development of medicine serving, among others, to sanction contraceptives and abortion; disintegration of the traditional family model by the promotion of gender ideology and legalization of homosexual partnerships; changes in sexual ethics; promotion of mass culture popularizing a consumer lifestyle through mass media; progressive process of secularization of society resulting in moral breakdown and increase of aggression, as well as brutalization of life; after: M. Orłowska, B. Sobczyk, *Współczesny obraz rodziny – hit czy kit?*, [in:] *Rodzicielstwo w sytuacji dezorganizacji rodziny i możliwości wspomaganie rodziców*, ed. J. Brągiel, B. Górnicka, Wydawnictwo Uniwersytetu Opolskiego, Opole 2014, pp. 17-26.

raising self-esteem and security (mutual protection), ensuring biological continuity of generations (the birth of offspring), as well as ensuring the transmission of cultural and normative tradition and creating close autonomous community (recreational and social environment).⁶ „Family, as the closest group of people, can significantly influence the rehabilitation process”.⁷ It gives meaning to life. It allows for a proper functioning thanks to maximum and purposeful use of one’s capabilities⁸, resulting in the enhancement of the development of an adult on an individual and social level by permanent acquisition of new experiences and skills.⁹

Parenting as a factor enhancing human development

Parenting means being a parent, father or mother.¹⁰ This word is associated with the verb “give birth”, which means “give origin to something or give birth to offspring”.¹¹ Parenting, due to the durability and type of relationship between adults and a child, can take different forms. Genetic and biological parenthood is its original natural face. The establishment of a close emotional bond between the child and their parents, and gradual raising them to perform

⁶ S. Kotowski, *Przewodnik po problematyce osób niewidomych i słabowidzących*, Foundation of the Polish Blind and Visually Impaired “Trakt”; State Fund for Rehabilitation of Disabled People, Warsaw 2008, p. 164.

⁷ R. Ossowski, *Kształtowanie obrazu własnej sytuacji i siebie u inwalidów wzroku w procesie rehabilitacji*, Wydawnictwo Uczelniane WSP Bydgoszcz, Bydgoszcz 1982, p. 30.

⁸ K. Obuchowski, *Psychologia dążeń ludzkich*, Wydawnictwo Naukowe PWN, Warsaw 1966, p. 232.

⁹ A. Kwak, *Rozwojowy charakter rodzicielstwa – podstawowe zakresy zmian*, [in:] *Rodzicielstwo w różnych fazach rozwoju rodziny*, ed. J. Brągiel, B. Górnicka, Wydawnictwo Uniwersytetu Opolskiego, Opole 2017, pp. 37–39.

¹⁰ *Uniwersalny Słownik Języka Polskiego*, ed. S. Dubisz, vol. 3, Wydawnictwo Naukowe PWN, Warsaw 2003, p. 961.

¹¹ K. Długosz-Kurczatowa, *Wielki Słownik Etymologiczno-Historyczny Języka Polskiego*, Wydawnictwo Naukowe PWN, Warsaw 2008, p. 550.

roles is social parenthood, while taking care of a young person as a result of the ritual is called ceremonial parenthood.¹²

Parenthood involves a number of interactions that contribute to the implementation of parental role. The first dimension of this role is care, serving to meet both basic human needs (shelter, food, cleanliness etc.) and higher ones, which can be described as a feeling of emotional comfort, guaranteeing mutual love and safety. Another task of parental role is control, which means educational commitment consisting in setting boundaries. The last area of parental involvement is ensuring development, and therefore conditions and activities supporting the natural resources (talents and predispositions) of the offspring.¹³

The performance of parental role requires a potential that includes non-material and material means (finances, social resources). Non-material means include primarily a mature personality¹⁴, psychological and social competences, knowledge and motivation to make commitments for the child.

A person with a mature personality, according to Gordon W. Allport, is characterised by three most important characteristics: an extended self-image, an objective attitude towards themselves and a crystallized world view.

¹² D. Jabłoński, D. Ostasz, *Zarys wiedzy o rodzinie, małżeństwie, kohabitacji i konkubinacie. Perspektywa antropologii kulturowej i ogólnej*, Wydawnictwo Adiaphora, Olsztyn 2001, pp. 111–120.

¹³ A. Kwak, *Rodzicielstwo – przejaw społecznej współzależności*, [in:] *Rodzicielstwo między domem, prawem, służbami społecznymi*, ed. A. Kwak, Wydawnictwo Akademii Pedagogiki Specjalnej, Warsaw 2008, pp. 24–25.

¹⁴ Personality, according to L.A. Pervin “is a complex whole of thoughts, emotions and behaviours, giving direction and pattern (coherence) to human life. Similarly to the body, personality consists of both structures and processes, and reflects the activity of both nature (genes) and the environment. The concept of personality also includes the temporal aspect of human functioning, because the personality contains memories of the past, mental representations of the present, as well as ideas and expectations about the future”. Personality is responsible for the coherence of human behaviour, feelings and thoughts; after: L.A. Pervin, *Psychologia osobowości*, Gdańskie Wydawnictwo Psychologiczne, Gdańsk 2002, p. 416.

An extended self-image means limiting selfish attitudes, authentic interest in other people and their good (having friends, children, interest in the problem of the surrounding), internalization of moral patterns and behaviours which comply with them. An objective attitude towards oneself is the ability to take self-criticism, a self-distance, while having a crystallized world view is equivalent to a professed hierarchy of values.¹⁵ Maturity to undertake parental duties is manifested in the ability to establish and maintain intimate relationships and responsibility for another person.¹⁶

Parental competence is different for mother and father. The father's role is to be an authority and a giver of life. This primary function implies the father's authority towards the child, as well as his responsibility for them. The father provides care, gives emotional support and helps the offspring achieve full autonomy and dignity, and thus serves to bring up a person who is free, responsible, self-confident and able to decide about themselves. The father's role is to create an atmosphere of confidence, security and openness to the world. He should set an example for his children.¹⁷ Entering the role of mother begins from the moment of conceiving a child, through the period of pregnancy, childbirth and feeding. Culturally, motherhood is associated with the expression of feelings and the creation of an emotional atmosphere in the family, satisfying various needs, and introducing offspring into the wider circle of family community and tradition. Customarily, the mother's role is to organise and run a household, to provide care and upbringing, to give inspiration for family life and to act as a social and sexual partner for her husband. Motherhood of modern times is the need to simul-

¹⁵ G.W. Allport, *Personalisty: a psychological interpretation*, H. Holt, New York 1937, pp. 217-223.

¹⁶ E. Gurba, *Wczesna dorosłość*, [in:] *Psychologia rozwoju człowieka. Charakterystyka okresów życia człowieka*, ed. B. Harwas-Napierała, J. Trempała, Wydawnictwo Naukowe PWN, Warsaw 2008, p. 219.

¹⁷ R. Fernández, *Rola ojca*, „*Communio. Międzynarodowy Przegląd Teologiczny*” 1999, no. 2, p. 111, 115, 121-122.

taneously perform parental, marital and professional roles with conflicting priorities.¹⁸

Acquiring and possessing knowledge, as a non-material factor supporting the fulfilment of parental roles, is a sign of active parenthood. Thanks to the knowledge, the parent recognizes developmental norms, needs, as well as properly develops relationships with the child. Knowledge helps in making right decisions at various stages of parenting. Acquiring knowledge is preceded by an internal motivation to take up parental tasks, which is caused by the characteristics of the mental development of a person in early adulthood¹⁹, personal needs and cultural pressure associated with the need to have own reproductive family

Parenting is a process in the life of an adult that enhances their individual development. According to Maria Tyszkowa, "Family, and respective fulfilment of social family roles and participation in a specific system of relationships and personal interactions, implying a specific activity of the individual, becomes a source of experience. This experience, after being developed in the mental apparatus of the individual, is incorporated into the psychological subsystem, initiating its transformation and gradually leading to developmental changes in the entire mental system of the individual".²⁰ There-

¹⁸ A. Kwak, *Rodzicielstwo – przejaw społecznej współzależności*, [in:] *Rodzicielstwo między domem, prawem, służbami społecznymi*, ed. A. Kwak, Wydawnictwo Akademii Pedagogiki Specjalnej, Warsaw 2008, p. 23; M. Matuszewska, *Funkcjonowanie w rolach rodzicielskich jako źródło rozwoju młodych dorosłych*, [in:] *Rodzina a rozwój człowieka dorosłego*, ed. B. Harwas-Napierała, Wydawnictwo Naukowe Uniwersytetu im. Adama Mickiewicza, Poznań 2003, p. 34.

¹⁹ Adulthood is a phase of human life that follows rapid developmental changes of a biological and social nature. It is characterised by the ability to procreate and responsibly undertake new social roles related to starting own family, giving birth to children and raising them, conducting professional activity and autonomous management of own life. The period of early adulthood is between 23–35 years of age; after: E. Gurba, *Wczesna dorosłość*, [in:] *Psychologia rozwoju człowieka. Charakterystyka okresów życia człowieka*, ed. B. Harwas-Napierała, J. Trempała, Wydawnictwo Naukowe PWN, Warsaw 2008, p. 203.

²⁰ M. Tyszkowa, *Jednostka a rodzina: interakcje, stosunki, rozwój*, [in:] *Psychologia rozwoju człowieka. Zagadnienia ogólne*, eds. M. Przetacznik-Gierowska, M. Tyszkowa, Wydawnictwo Naukowe PWN, Warsaw 2009, p. 136.

fore, family is not only the smallest social group in the sociological perspective and the educational care environment for the child, guaranteeing their development through interaction²¹, but it constitutes the “developmental context (...) of an adolescent and adult²². Development occurs through experience and positive multi-directional relationships of the person with the environment. Unfavourable, pathological family experiences can, by analogy, disturb the psychological and social development of the person. At the same time, developmental changes taking place in family members and their activity affect changes in the functioning of the family as a whole, transforming interpersonal relationships and the operation of the entire system.²³

Fulfilling parental role is an entry into the development process. The fundamental task of this process is to make a lasting contribution to social life and leave a heritage in the form of offspring. Parenting gives this opportunity by favouring the achievement of marital satisfaction, becoming one of the conditions for a peaceful ageing process²⁴ and allowing for permanent learning.²⁵ An adult, thanks

²¹ According to U. Bronfenbrenner “Primary developmental context is a context in which a child can observe and adopt patterns, increasingly complex activities in cooperation or under the direct guidance of people who have knowledge and skills not yet mastered by a child and with whom the child has a positive emotional relationships”; after: U. Bronfenbrenner, *The ecology of human development: Experiments by nature and design*, Harvard University Press, Cambridge 1979, p. 845.

²² M. Tyszkowa, *Jednostka a rodzina: interakcje, stosunki, rozwój*, [in:] *Psychologia rozwoju człowieka. Zagadnienia ogólne*, eds. M. Przetacznik-Gierowska, M. Tyszkowa, Wydawnictwo Naukowe PWN, Warsaw 2009, p. 126.

²³ M. Tyszkowa, *Jednostka a rodzina: interakcje, stosunki, rozwój*, [in:] *Psychologia rozwoju człowieka. Zagadnienia ogólne*, eds. M. Przetacznik-Gierowska, M. Tyszkowa, Wydawnictwo Naukowe PWN, Warsaw 2009, pp. 136–139; B. Harwas-Napierała, *Zmiany w funkcjonowaniu rodziny i ich konsekwencje dla rozwoju rodziców*, [in:] *Rodzina a rozwój człowieka dorosłego*, ed. B. Harwas-Napierała, Wydawnictwo Naukowe Uniwersytetu im. Adama Mickiewicza, Poznań 2003, p. 11.

²⁴ Engagement in parenthood is a solution to the developmental crisis of adulthood, which, as one of many, is described by Erik H. Erikson (1968) in his generativity theory. According to E.H. Erikson (1968), parenting is the most important activity of adulthood, which determines human creativity in other areas of life; after:

to fulfilling parental tasks, is constantly expanding their experience, knowledge and skills, which allows them to more fully use their own biological and psychosocial potential.²⁶ Engaged parenthood results in changes especially in the functional (new duties and skills), personality and emotional (new quality in interpersonal relationships) and cognitive (new knowledge) areas.²⁷

Do people with disabilities have a chance to develop through parenting? The desire to have own family and to be a parent is a common desire that is equivalent to various anxieties. One of them includes social barriers in the form of prejudices.²⁸ The right to achieve one's happiness through an intimate relationship with another person in Polish society is associated with the stereotypical

B. Harwas-Napierała, *Zmiany w funkcjonowaniu rodziny i ich konsekwencje dla rozwoju rodziców*, [in:] *Rodzina a rozwój człowieka dorosłego*, ed. B. Harwas-Napierała, Wydawnictwo Naukowe Uniwersytetu im. Adama Mickiewicza, Poznań 2003, p. 20.

²⁵ Fulfilling developmental tasks in human life is inseparably associated with learning. This relationship was described by Robert J. Havighurst (1981), claiming that psychological development is accomplished by changing the activity in which a human is involved in specific developmental periods; after: L. Bakiera, *Zaangażowane rodzicielstwo a autokreacyjny aspekt rozwoju dorosłych*, Wydawnictwo Difin S.A., Warsaw 2013, p. 106.

²⁶ The concept of psychotransgressionism described by Józef Koziński (1987) defines a human as a person undertaking transgressive activities, or intentional acts of causative activity. Parenting is one of such acts that proceeds "towards oneself", "towards people", "towards symbols" and "towards things"; after: L. Bakiera, *Zaangażowane rodzicielstwo a autokreacyjny aspekt rozwoju dorosłych*, Wydawnictwo Difin S.A., Warsaw 2013, p. 115.

²⁷ M. Matuszewska, *Petnienie społecznych ról rodzinnych przez młodych dorosłych i ich rozwój indywidualny*, [in:] *Rodzina a rozwój jednostki*, ed. M. Tyszkowa, Central Program for Basic Research CPBP, Poznań 1990, p. 87; M. Matuszewska, *Funkcjonowanie w rolach rodzicielskich jako źródło rozwoju młodych dorosłych*, [in:] *Rodzina a rozwój człowieka dorosłego*, ed. B. Harwas-Napierała, Wydawnictwo Naukowe Uniwersytetu im. Adama Mickiewicza, Poznań 2003, p. 31; L. Bakiera, *Petnienie ról rodzicielskich a rozwój dorosłych w wieku średnim*, „Psychologia Rozwojowa” 2004, vol. 9, no. 2, p. 40, 45.

²⁸ D. Kornas-Biela, *Postawy społeczne wobec małżeństwa i macierzyństwa kobiet z niepełnosprawnością*, [in:] *Kobiecość a niepełnosprawność*, ed. W. Janocha i K. Zielińska-Król, Wydawnictwo KUL, Lublin 2015, p. 19.

image of youth, attractiveness and physical fitness. The general image of people with disabilities does not fit this stereotype, in which, in public discourse, the right to transfer life is suspended.²⁹

Psychological context of parenting of people with visual impairment

The condition of visual perception, the co-occurrence of chronic multiple diseases, as well as the time of acquisition of disability have an impact on the mental functioning of a born blind, and partially sighted person and a person who became blind later, as well as the planned and fulfilled parental roles.³⁰ Being a parent requires internal self-creation. It becomes an impulse to overcome the mental barrier created as a result of disability.

Blind people, because of the total loss of a possibility to receive visual sensation, experience limitations in the area of cognitive, orientation and spatial, and performance (everyday activities) capabilities. The indicated difficulties can only be overcome in part with a huge effort involved. Personality and everyday functioning of a blind person depend on the model of upbringing in a family of origin, their own activity, as well as their attitude towards the environment and its attitudes towards a disabled person. Household members who are Indifferent, have a negative attitude or are over-protective bring up a person unable to take on basic activities enabling independent life. Lack of own activeness will inhibit the development of cognitive and practical activities. Conscious isolation from the environment or its negative attitudes will result in a lack of social skills and resignation from undertaking tasks. Unfavourable experience accumulated in the course of individual life will deter-

²⁹ S. Waszczak, *Stosunek społeczeństwa do osób niepełnosprawnych*, „Problemy Polityki Społecznej” 2000, no. 2, p. 96.

³⁰ A. Bojarska, *Uwarunkowania macierzyństwa kobiet niewidomych i słabowidzących*, [in:] *Kobiecość a niepełnosprawność*, ed. W. Janocha, K. Zielińska-Król, Wydawnictwo KUL, Lublin 2015, p. 68.

mine the shape of adult life of a blind person and effectiveness in fulfilling parental roles.³¹

Partially sighted people, with limited vision, function better than blind people. At the same time, possessed perceptual resources can paradoxically be a burden when performing daily activities, because the state of visual functioning of partially sighted people is variable, which ultimately puts this group in an ambiguous situation. This is because they are not blind or fully sighted people, therefore they are less likely to accept their disability. Partially sighted people constantly confront their functional skills with the capabilities of the sighted, assessing them as limited and preventing the fulfilment of dreams and life plans. The social environment perceives this group as less competent at undertaking significant tasks, which results in the formation of an introvert attitude, lower self-esteem, as well as a tendency to isolate and resign from important life goals.³²

Blind people, as a result of partial or complete loss of vision during the course of their life, experience permanent stress that hinders adaptation activities and the ability to cope with specific situations. Severe visual disability destroys the already formed personality (a sense of physical difference, destruction of the system of knowledge about oneself and relationships with the environment) and creates the need for psychological adaptation to a new situation. A blind person experiences disturbances in terms of exploration of reality, spatial orientation, loses a sense of security and many practical skills mastered during previous life. Limitation of activity

³¹ T. Majewski, *Psychologia niewidomych i niedowidzących*, Państwowe Wydawnictwo Naukowe, Warsaw 1983, pp. 70–147; S. Kotowski, *Przewodnik po problematyce osób niewidomych i słabowidzących*, Foundation of the Polish Blind and Visually Impaired “Trakt”; State Fund for Rehabilitation of Disabled People, Warsaw 2008, pp. 35–49.

³² T. Majewski, *Psychologia niewidomych i niedowidzących*, Państwowe Wydawnictwo Naukowe, Warsaw 1983, p. 174; S. Kotowski, *Przewodnik po problematyce osób niewidomych i słabowidzących*, Foundation of the Polish Blind and Visually Impaired “Trakt”; State Fund for Rehabilitation of Disabled People, Warsaw 2008, pp. 35–39.

causes apathy, helplessness and confusion. A blind man loses his position as a leader who conquers and modifies reality. A woman feels less attractive and competent in the potential role of partner and parent. If she is a wife and mother, she has to overcome the difficulties associated with running a household, caring for children and maintaining social status. A blind person is forced to temporarily resign or completely change the performed tasks (change or resignation from work). The previous contacts with the extra-familial environment are weakened, and access to various forms of cultural, educational and relaxation activities can be hindered, which has an adverse effect on the mental functioning of the person.³³

Table 1. Characteristics of the mental functioning of people with visual impairment

People born blind	Partially sighted people	People who became blind in later period
Limited cognitive ability	limited visual capability	permanent stress hindering adaptation
Limited orientation and spatial ability	Limited executive possibilities (life activities)	loss of male position / devaluation of female role
Limited executive possibilities (life activities)	confrontation of own visual capabilities with those of the sighted	new difficulties and limitations in everyday life / loss of practical skills
Motivation to undertake activities and integrate with the environment required	introverted attitude and lower self-esteem	self-esteem crisis and loss of sense of security
Training in cognitive and practical skills required	tendency to isolation from the environment	personality disintegration / apathy and feeling of being lost

Source: own work.

The psychological situation of parents who were born blind, are partially blind and lost their sight in a later period depends not only on the health condition, but also on the partnership configuration in

³³ T. Majewski, *Psychologia niewidomych i niedowidzących*, Państwowe Wydawnictwo Naukowe, Warsaw 1983, pp. 175–189.

the relationship, which can take the following forms: both partners with visual impairment, a blind or partially sighted partner or a partner who lost their sight in a later period. Single parenthood (usually motherhood) of people with visual impairment is not uncommon. Most often relationships are formed by blind men with sighted women. Pairs of two blind people are also full of harmony. Blind women starting families with sighted men are most rare.³⁴ In all of the mentioned cases, the condition of visual functioning and the level of general rehabilitation affect the way of fulfilling parental roles.

Table 2. Partnership configurations in relationships of people with visual impairment

Partnership configurations	Positive characteristics	Negative characteristics
Sighted woman / man with visual impairment	<ul style="list-style-type: none"> • professional and financial independence of the man • harmony of life despite difficulties / connection and understanding 	<ul style="list-style-type: none"> • conflict and misunderstanding of the man by the family of the woman • making first intimate contacts is difficult
Both partners with visual impairment	<ul style="list-style-type: none"> • honesty / mutual understanding of needs and difficulties / partnership • good preparation for life is necessary • activity / financial independence 	<ul style="list-style-type: none"> • lack of mutual efficient help • childcare is difficult • contact with the environment is difficult
Sighted man / woman with visual impairment	<ul style="list-style-type: none"> • characteristics of women: physical attractiveness, independence in life, integration with the environment 	<ul style="list-style-type: none"> • the necessity to meet various household responsibilities / resourcefulness in life, spatial orientation, efficient movement
Life alone	<ul style="list-style-type: none"> • desire for a close lasting relationship • desire to start a family 	<ul style="list-style-type: none"> • lower physical attractiveness / worse professional perspective, anxiety, loneliness

Source: own work.

³⁴ J. Kawka, *Warunki wychowawcze dzieci w rodzinach inwalidów wzroku*, Wydawnictwo UMCS, Lublin 1996, pp. 26-27; A. Duracz-Walczakowa, *Wybrane problemy życia rodzinnego niewidomych*, „Studia Socjologiczne” 1966, no. 1, p. 213.

Desirable characteristics of a woman as a partner and mother are: attractiveness, independence, resourcefulness, diligence, self-esteem and no additional disability. A man with visual impairment who wants to start a family should be professionally and financially resourceful, able to move independently around the world, socially integrated and positively assessing himself.

Functional context of parenting of people with visual impairment

Parents with visual impairment also experience developmental dynamics in the sphere of activity (new responsibilities and skills). Achieving success, however, requires overcoming existing functional obstacles. Difficulties of blind people's spouses in taking care of their offspring and running a household are greater than in marriages where one person is blind or partially sighted, or both have visual impairment, but to varying degrees.

Regardless of the encountered difficulties, according to the results of J. Kawka's study, "Families of people with visual impairment correctly fulfilled the tasks arising from the basic functions," and "The educational conditions of children in these families, (...), did not differ significantly from the accepted social standards".³⁵

The basic care-providing and upbringing tasks include the ability to organise the care of children of different ages at home and to cooperate with preschool, school, non-school educational and upbringing institutions as well as healthcare facilities.

³⁵ J. Kawka, *Warunki wychowawcze dzieci w rodzinach inwalidów wzroku*, Wydawnictwo UMCS, Lublin 1996, p. 165; J. Kawka (1996) conducted comparative studies in a group of 60 families of people with visual impairment and 60 families of able-bodied people analysing the socialization values of the following basic functions: material and economic, protective and securing, emotional and expressive, recreational and social, as well as cultural ones, which had an impact on shaping the educational conditions of children in the families of people with visual impairment.

Table 3. Developmental dynamism and functional barriers of parenthood of people with visual impairment

Development spheres	Developmental dynamism stages	Person with visual impairment
Functional sphere	undertaking new forms of activity as part of family roles / low level of organization	<ul style="list-style-type: none"> • need for functional adaptations in all spheres of life
Personality And adaptation sphere	ANTICIPATION (thinking about parenthood) / mental growing to be a parent	<ul style="list-style-type: none"> • anxiety / difficult duties / inheritance of disability • risk of deterioration of health • criticism of the environment
	HONEYMOON (shortly after childbirth) / learning the role of a parent / building connections with the child	<ul style="list-style-type: none"> • new life goals / higher self-esteem • building relationships with the child / alternative ways • functional difficulties associated with childcare
	PLATEAU (childhood, adolescence) / constant adaptation of attitudes, knowledge, experience	<ul style="list-style-type: none"> • functional adjustment of everyday activities • control of school progress is difficult • need to build good / difficult relationships with the environment • sometimes living in adverse material conditions
	RELEASE / end of active parent role	<ul style="list-style-type: none"> • loneliness
Cognitive sphere	acquiring new knowledge / creative thinking / willingness to change	<ul style="list-style-type: none"> • difficult / lack of education and professional information services for parents

Source: own work; Parenting phases are presented on the basis of the Group for the Advancement of Psychiatry (GAP), after: M. Matuszewska, *Funkcjonowanie w rolach rodzicielskich jako źródło rozwoju młodych dorosłych*, [in:] *Rodzina a rozwój człowieka dorosłego*, ed. B. Harwas-Napierała, Wydawnictwo Naukowe Uniwersytetu im. Adama Mickiewicza, Poznań 2003, p. 31.

The challenge of infancy includes care of a small child, ensuring their safety and harmonious development. Parents with visual impairment acquire first nursing skills, benefiting from the assistance

of friendly sighted people (immediate family, friends with children) or the advice of qualified medical staff in hospital and outpatient settings right after the birth of the child.

„My family, a friend who had a few months older child and a midwife from the clinic who came for a home visit helped me a lot”.³⁶

The organization of parental duties at home requires preparation of a place to sleep, play and nursing activities. The latter cause some difficulties, especially for inexperienced parents, and they include: feeding, changing clothes of the baby, changing a diaper, bathing, cutting nails, checking the quality of the child's skin, and in case of illness: measuring temperature, cleaning the nose or dosing medicines. The main channel of contact with the child, in the case of blind parents, is touch (carrying in hands, embracing, caressing, hugging), sound stimulation (voice of parents) and hearing enabling the control of child's behaviour. Preparation of a place for nursing requires functional solutions. Parents with visual impairment will perform all necessary activities if the necessary objects are within the reach of their hands, left in good order, and if they have the opportunity to learn about their proper and safe performance. A wide range of items for nursing available on the market allows for the choice of those that will help in relatively efficient and safe performance of nursing tasks.

„It is important for us to have those activities shown or very precisely described by someone. It should also be remembered that we must learn a good organisation in the place where these activities are performed, the child must lie safely (...).”³⁷

³⁶ Author of the statement Dominika Buchalska; after: E. Fraszka, E. Oleksiak, *Być mamą, być Tatą. Poradnik dla niewidomych rodziców*, Polish Association of the Blind, Warsaw 2017, p. 19.

³⁷ Author of the statement Dominika Buchalska; after: E. Fraszka, E. Oleksiak, *Być mamą, być Tatą. Poradnik dla niewidomych rodziców*, Polish Association of the Blind, Warsaw 2017, pp. 21–22.

The period of early childhood and the time of beginning of school duties are turning points that impose on parents and children new challenges that go beyond the scope of care and nursing duties. The child demands emotional contact through mutual communication and play.

They acquire new intellectual and motor skills. The living environment expands beyond the boundaries of the immediate environment. Progressive development, high mobility of the child, ability to move efficiently combined with curiosity about the world and unawareness of parental restrictions pose an organizational, as well as orientation and cognitive challenge for parents.

The immediate surroundings must be safe.

„(...) The most important thing is to create a safe environment. It is necessary to secure electrical sockets, hide (...) cables, (...) hide sharp tools (knives, scissors). (...) Do not leave cups with hot drinks (...) near the child. (...) If the environment is secured, then the child (...) can move freely around the house (...). It is necessary to teach children safe behaviours (...).³⁸

Common walks require the use of solutions that allow for locating the child and controlling them during the play. A lot of help is provided by safely organized recreation areas and the help of sighted friends who observe the activity of the child. Support of sighted people can also be useful in situations where the preferred activity exceeds the capabilities and skills of parents. This happens when the time comes to learn how to ride a bike, roller skate, ride a scooter or train swimming. Properly selected equipment along with the necessary security and the help of a volunteer or professional instructor supports disabled parents.

„Walking with the first child was a difficult challenge. (...) Leading reins proved to be a very good solution (...). When the child was a bit older and ran

³⁸ Author of the statement Dominika Buchalska; after: E. Fraszka, E. Oleksiak, *Być mamą, być Tatą. Poradnik dla niewidomych rodziców*, Polish Association of the Blind, Warsaw 2017, pp. 43–44.

around the playground alone, the bell tied to the clothes worked very well (...). When the child was older (...) they were coming if they needed help".³⁹

Starting preschool and school education requires more frequent contact with the staff of these institutions and parents of other students. Difficulties in this integration deprive parents with disabilities of information about the school situation of their own child. Therefore, a friendly understanding of the teaching environment for the restrictions of disabled parents and assistance in the area of integration and adaptation are necessary. The period of education entails a number of functional dilemmas. The first is to prepare the student's workshop and check the state of preparation for school activities. Children of disabled parents learn responsibility and discipline in this respect.

"(...) School age is the time when we teach a child responsibility for their behaviour, so also packing a backpack and preparing for classes must be gradually passed into the hands of the child".⁴⁰

Performing artistic work and learning colours together, reading picture books, writing exercises and supporting the child during homework are not easy tasks.

Full control of the quality, correctness and completeness of the performed work by a blind parent is impossible. In this regard, cooperation with the teacher and the help of the sighted person at the initial stage of child's education are necessary. Performing artistic work at home will become easier thanks to the preparation of simple aids introducing the names of colours and ready-made templates to help draw shapes. The works may also be of a spatial nature requiring cutting, wrapping, sticking or gluing ready elements.

³⁹ Author of the statement Dominika Buchalska; after: E. Fraszka, E. Oleksiak, *Być mamą, być Tatą. Poradnik dla niewidomych rodziców*, Polish Association of the Blind, Warsaw 2017, p. 42.

⁴⁰ Author of the statement Dominika Buchalska; after: E. Fraszka, E. Oleksiak, *Być mamą, być Tatą. Poradnik dla niewidomych rodziców*, Polish Association of the Blind, Warsaw 2017, p. 39.

Art education is conducted during preschool and school classes. If the family there are siblings, children learn many skills from each other. Reading picture books together requires the addition of a black print text with a Braille version (print on a transparent tape stuck to the pages of the book). Parents are also supported by sound books, audiobooks and the help of sighted people. Initial learning of letters, numbers, writing, reading and counting can be supported by the use of spatial models (letters and numbers, magnets), educational games available for the blind (“Ludo”, “Nine men’s morris”), books for graphomotor exercises. The correctness of the text read by the child is controlled by providing the alphabet book with a Braille text.

„We decided that our child would not attend kindergarten, so we tried to teach them as much as possible”.⁴¹

The development of social contacts is an essential element of proper socialization. The children of parents with visual impairment, entering the world of peer contacts, must face the need to explain the consequences of their parents’ disability. They are also forced to individually understand and accept these consequences. Some parents, feeling too little trust from their surroundings, try to constantly prove that they are competent guardians. The quality of social perception of the functioning of a special family will be a condition for the adaptation of this family in the environment.

“(…) Some [parents, author’s note], living under great social pressure, believe that they should feel three times more responsible for the child than sighted parents, because they belong to a high risk group (...)”.⁴²

⁴¹ Author of the statement Anna Ponichtyra; after: E. Fraszka, E. Oleksiak, *Być mamą, być Tatą. Poradnik dla niewidomych rodziców*, Polish Association of the Blind, Warsaw 2017, p. 51.

⁴² Author of the statement Monika Marczuk-Engelsma; after: E. Fraszka, E. Oleksiak, *Być mamą, być Tatą. Poradnik dla niewidomych rodziców*, Polish Association of the Blind, Warsaw 2017, p. 59.

Child care of parents with visual impairment is slightly different from care and upbringing activities undertaken by sighted people. The main difference consists in the functional adaptation of everyday activities and the need to use, in some situations, the assistance of sighted people. Raising a child in the situation of the mentioned disability is an undoubted developmental impulse for parents, because "(...) *Along with (...) the acquisition of new skills by a child, parents also learn new things*".⁴³

Educational context of parenting of people with visual impairment

Performing parental tasks in a mature way requires skills in self-esteem of own mental and moral attitudes, their improvement and gradual acquisition of practical knowledge, skills and experience. People can and should prepare for the role of a parent in a planned way.

Parents and the environment of a family of origin should be the first teachers of femininity and masculinity. The second place of education and upbringing is the school and a substantively prepared teacher who is able to tactfully talk to young people about their needs, doubts and hopes. Since 2009, the subject "Preparation for family life" has been introduced in the framework of school curricula".⁴⁴ According to the data of the Educational Research Insti-

⁴³ Author of the statement Dominika Buchalska; after: E. Fraszka, E. Oleksiak, *Być mamą, być Tatą. Poradnik dla niewidomych rodziców*, Polish Association of the Blind, Warsaw 2017, p. 34.

⁴⁴ Based on the: Regulation of the Minister of National Education of 12 August 1999 on the method of school teaching and the scope of content regarding knowledge on the sexual life of an individual, principles of conscious and responsible parenthood, the value of the family, life in the prenatal phase, as well as on methods and measures of conscious procreation contained in the general education program (Journal of Laws 1999, No. 67, item 756) and the Regulation of the Minister of National Education of 28 March 2017 on the outline timetables in public schools (Journal of Laws 2017, item 703) the subject "Preparation for family life" (as op-

tute, 87% of lower secondary high school students and 48% of upper secondary school students participated in these activities. According to the respondents, the significant drop in attendance between both types of schools was caused by the inadequate location of "Preparation for family life" in the teaching schedule. Other reasons for this lack of interest are: an uninteresting program and a teacher who runs the classes in the incorrect way. Students attending "Preparation for family life" rated it very positively (62% of lower secondary school students; 71% of upper secondary students), indicating the presence of useful content consistent with the professed system of values. However, the existing formula for the optionality of these lessons was confirmed, by the fact that students who did not attend classes had slightly better results in the test checking basic knowledge of human sexuality.⁴⁵

Blind and partially sighted youth is often educated in boarding school and education centres, so the obligation to solve problems in

posed to the "Sex education" classes) was introduced, covering knowledge about the sexual life of an individual, principles of conscious and responsible parenthood, the value of the family, life in the prenatal phase, as well as on methods and measures of conscious procreation. In public schools, in the school curriculum, "Preparation for family life" classes comprise, in each school year, 14 hours for students of individual grades, including 5 hours with the division into groups of girls and boys. Classes are organized within grades or inter-grade groups of no more than 28 students. The subject is conducted in grades IV–VIII of primary school and in secondary schools including: vocational school of the first grade, grades I–III of general secondary school and grades I–III of technical secondary school. A minor student is not obliged to take part in the classes if their parents (legal guardians) notify the headmaster in writing of their resignation from the participation in the classes. An adult student does not take part in the classes if they notify the headmaster in writing of their resignation. "Preparation for family life" lessons are not subject to assessment and do not affect the promotion of the student to a higher form or the graduation of the student.

⁴⁵ K. Bulkowski, M. Federowicz, W. Grajkowski, R. Kaczan, K. Maliszewska, D. Marszał, M. Męziński, U. Poziomek, P. Rycielski, D. Walczak, A. Wichrowski, *Opinie i oczekiwania młodych dorosłych (osiemnastolatków) oraz rodziców dzieci w wieku szkolnym wobec edukacji dotyczącej rozwoju psychoseksualnego i seksualności. Raport z badania*, Educational Research Institute, Warsaw 2015, p. 39–45.

the field of “sex education” falls on educators, teachers and school psychologists who often do not have proper content-related and methodological preparation, and do not have teaching materials and visual means adapted to the needs of people with visual impairment adjusted to their different perceptual needs.⁴⁶ If the daily life environment is a family home because a teenager attends school near their place of residence, conversations about adolescence-related topics are still not easy for many parents.⁴⁷ In some families, a blind or partially sighted teenager will not get the right support, and parents do not set a good example. People with visual impairment are quite often treated as asexual, permanently immature, provided with excessive care, having no intimate life needs. Knowledge gathered incidentally from uncertain sources places a person with visual impairment in a situation of permanent and infantile misinformation, which condemns them to fleeting relationships that may end with premature sexual initiation and unplanned parenthood.⁴⁸

The curriculum of preparation for family life should be adapted to the needs of people with visual impairment not only in view of the content correlated with the age of listeners, but also related to the effects of disability, which affects the emerging difficulties in creating intimate partnerships of adolescents with visual impairment. These difficulties concern: barriers to establishing contacts with peers (no opportunity to enter into a relationship, time spent

⁴⁶ M. Zaorska drew attention to the important ethical dimension of the behaviour, attitudes and activities of specialists working in the field of sex education of people with disabilities: M. Zaorska, *Etyka a problematyka seksualności osób z poważnymi, głębokimi niepełnosprawnościami*, „Niepełnosprawność i Rehabilitacja” 2018, no. 1, pp. 46–52.

⁴⁷ K. Czerwińska, I. Kucharczyk, *Tyflopsychologia*, Wydawnictwo Naukowe PWN S.A., Warsaw 2019, p. 127.

⁴⁸ I. Fornalik, *Edukacja seksualna osób niepełnosprawnych. Notatki na marginesach ministerialnych rozporządzeń*, „Kwartalnik Pedagogiczny” 2010, no. 2, p. 106; G. Kapperman, T. Brown-Ogilvie, J. Yesaitis, A. Peskin, *Prevention of sexual assault against children who are visually impaired*, “Division on Visual Impairments Quarterly” 2014, no. 59(2), p. 33.

mainly alone or with family, close relationship with parents), negative reactions of the environment (a disabled person is perceived as less attractive as a potential partner) and emotional problems of people with visual impairment (loneliness, depression).⁴⁹

Therefore, the primary needs associated with the curriculum of preparation for family life, should include personal and social functional aspects. The first of them comprises skills in the area of performing everyday activities, the purpose of which is to ensure personal independence. The main scope of everyday activities includes: self-care skills (preparing meals, cleaning, washing, ironing), professional activities (vocational skills, professional work), specific activities (nursing infants and young children, care-providing and upbringing activities in the case of older children).

The second important group are social skills, which include: effective spatial orientation and independent movement, skills in social interaction and non-verbal communication to facilitate functioning in social situations, ability to spend free time favouring the establishment of advantageous social relationships. The third scope is the development of individual mental skills serving for: building self-esteem, developing leadership competences (self-confidence) correlated with predispositions to take up employment, and developing the ability to create one's own image (improving physical attractiveness by choosing the right clothing, hairstyle, make-up, knowledge of individual values and defects in the physical appearance). The fourth attribute of full preparation for life in the family and society is knowledge and access to the latest technical solutions that facilitate functioning.⁵⁰

Another pillar of the curriculum of preparation for family life is knowledge about the physical aspects of human sexuality. A person with visual impairment, should obtain information about the ana-

⁴⁹ K. Czerwińska, I. Kucharczyk, *Tyflopsychologia*, Wydawnictwo Naukowe PWN S.A., Warsaw 2019, p. 124.

⁵⁰ G. Kapperman, K. Page, S. Kelly, *Finding the One: Human mate selection applied to persons who are visually impaired*, "Division on Visual Impairments Quarterly" 2014, no. 59(2), pp. 38–44.

tomical and physiological attributes characteristic for a woman and a man, the characteristics of the intimate life of mature people, conscious fatherhood and motherhood (natural methods of regulating fertility, advantages and side effects of contraception) in a manner adapted to their individual perceptive abilities. The subject of sexual intercourse and procreation should refer to the aspects of the consequences of inheritance of some visual disorders⁵¹, the impact of multiple disability on the health of future parents and planned offspring, as well as indicate preventive solutions for the incidence of sexually transmitted diseases.⁵² Blind and partially sighted people

⁵¹ Genetically determined visual system diseases constitute a significant group of diseases. For this reason, a separate sub-speciality, ophthalmic genetics, has been created within clinical genetics. The occurring genetic disorders of the eye include: tapetoretinal degeneration (retinitis pigmentosa), age-related macular degeneration, glaucoma, cataract in the course of myotonic dystrophy, aniridia (congenital absence of the iris), skin and ocular albinism, colour blindness, juvenile retinal detachment, corneal dystrophies, cone-rod dystrophies, retinoblastoma, numerous metabolic diseases, Axenfeld syndrome, Marfan syndrome, Stickler syndrome, Kjer's optic atrophy, Stargardt disease (juvenile macular degeneration), Usher syndrome (dystrophia retinae dysacusis syndrome), Leber congenital amaurosis, Louis-Bar syndrome, Kearns-Sayre syndrome. Every person (family) with suspected or diagnosed genetic eye disease should have a possibility to obtain genetic advice about medical and genetic aspects of the disease. Advice may be provided by clinical genetics specialists and ophthalmologists; after: A. Wawrocka, M. Krawczyński, *Genetyka w okulistyce*, [in:] *Okulistyka*, ed. A. Grzybowski, Edra Urban & Partner, Wrocław 2018, pp. 305–314.

⁵² S.M. Kelly, G. Kapperman, *Sexual activity of young adults who are visually impaired and the need for effective sex education*, AFB "Journal of Visual Impairment & Blindness" 2012, no. 106, pp. 519–526; S.M. Kelly, G. Kapperman (2012), researchers from Illinois State University and Northern Illinois University (USA) conducted a comparative study between a group of 9,850 people with visual impairment (33% of blind people; 67% of partially sighted people) and a group of 10,904 able-bodied people aged 19–23. The aim of the study was to measure and compare sexual behaviour within both study groups. The conclusions of the conducted analysis were as follows: 1) Sexual activity of people with visual impairment was similar to the activity of able-bodied respondents (the sample of respondents with visual impairment was slightly older than the sample of able-bodied people); 2) Blind and partially sighted people started active sex life from two to three years later than healthy

should also be aware that as disabled people they are more often exposed to acts of sexual aggression (paedophilia, sexual harassment). Education in the field of preparation for family life also serves to raise awareness, vigilance and safety of people with disabilities in the face of these threats.⁵³

The basis for establishing and maintaining a lasting close intimate relationship, in which one of the partner's characteristic is visual impairment, is undoubtedly the preparation for family life. In the case of people with profound visual impairment, the sex education program is not enough, because knowledge about the characteristics of intimate human life should be correlated with mental, social and functional preparation for undertaking tasks of the period of adulthood.

people; 3) Later interest in sexual activity may have been a result of less social activity; 4) Answers given to the questions of the survey questionnaire raised doubts as to whether people with a disability had sufficiently reliable knowledge about the methods of conscious parenthood planning; 5) Youth with visual impairment should be provided with age-appropriate sex education containing relevant methods and materials adapted to their perceptive abilities; 6) Subsequent research should provide information on the design of effective sex education curricula and appropriate tools and techniques for those activities that will bring benefit to young people with visual impairment (C. Krupa and S. Esmail, 2010), warning against undertaking premature and risky sexual behaviours.

⁵³ W.S. Pava, *Visually impaired persons' vulnerability to sexual and physical assault*, AFB "Journal of Visual Impairment & Blindness" 1994, no. 88, pp. 103–112; W.S. Pava (1994), a clinical psychologist from the Department of Veterans Affairs (Tacoma, USA), found in the conducted studies that factors such as impaired mobility (hindered fight or flight attempt), inability to identify attackers, less access to safety measures, use of less common means of transport (a taxi) or the occasional need of help from sighted people during independent travel can cause a person with a visual impairment (female or male) to become the target of sexual or physical assault. M. Oczkowska (1958), in one of the first Polish studies concerning plans for family life and its reality based on the stories of blind women, described cases of abuse in the form of: offensive insults or dirty jokes, proposals with sexual overtones, assaults under the guise of help, sexual abuse resulting in an unplanned pregnancy. All those acts were committed by able-bodied men towards women with visual impairment.

Conclusion

The limited framework of this study did not allow for raising a number of issues from the area of further interdisciplinary perspective, which are a condition for the personal and parental success of people with visual impairment. The first of them is the insufficient availability of rehabilitation training and the latest rehabilitation technologies, which serve to equalise life chances. The level of vocational skills and the opportunity to find one's place on the labour market also seem to be a separate issue. This is because financial and housing independence are the basis for starting an independent life. The second area of difficulties is the social sphere, which includes: social attitudes reluctant to family life and parenthood of people with disabilities, still existing barriers in access to public space or insufficient involvement of the non-government organizations sector in diagnosing the needs of special families, creating support groups and lobbying for their benefit.⁵⁴

The last issue comprises the deficiencies in building a reliable image of parenting of people with disabilities in the media. These above-mentioned issues will be the subject of analysis in subsequent studies.

Bibliography

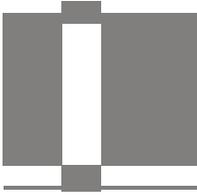
- [1] Allport G.W., *Personalisty: a psychological interpretation*, H. Holt, New York 1937.
- [2] Bakiera L., *Pełnienie ról rodzicielskich a rozwój dorosłych w wieku średnim*, „Psychologia Rozwojowa” 2004, vol. 9 no. 2, pp. 37–46.
- [3] Bakiera L., *Zaangażowane rodzicielstwo a autokreacyjny aspekt rozwoju dorosłych*, Wydawnictwo Difin S.A., Warsaw 2013.
- [4] Bojarska A., *Uwarunkowania macierzyństwa kobiet niewidomych i słabowidzących*, [in:] „Kobiecość a niepełnosprawność”, ed. W. Janocha, K. Zielińska-Król, Wydawnictwo KUL, Lublin 2015, pp. 67–83.

⁵⁴ M. Wałachowska, *Edukacja i rehabilitacja osób niewidomych i słabowidzących w działalności organizacji pozarządowych i wybranych instytucji rządowych III RP*, Faculty of Educational Sciences, Maria Grzegorzewska University, Warsaw 2010, pp. 149–228, unpublished doctoral dissertation.

- [5] Bronfenbrenner U., *The ecology of human development: Experiments by nature and design*, Harvard University Press, Cambridge 1979.
- [6] Bulkowski K., Federowicz M., Grajkowski W., Kaczan R., Maliszewska K., Marszał D., Męziński M., Poziomek U., Rycielski P., Walczak D., Wichrowski A., *Opinie i oczekiwania młodych dorosłych (osiemnastoletków) oraz rodziców dzieci w wieku szkolnym wobec edukacji dotyczącej rozwoju psychoseksualnego i seksualności. Raport z badania*, Educational Research Institute, Warsaw 2015.
- [7] Czerwińska K., Kucharczyk I., *Tyflopsychologia*, Wydawnictwo Naukowe PWN, Warsaw 2019.
- [8] Długosz-Kurczabowa K. (ed.), *Wielki Słownik Etymologiczno-Historyczny Języka Polskiego*, Wydawnictwo Naukowe PWN, Warsaw 2008.
- [9] Dubisz S. (ed.), *Uniwersalny Słownik Języka Polskiego*, vol. 3, Wydawnictwo Naukowe PWN, Warsaw 2003.
- [10] Duracz-Walczakowa A., *Wybrane problemy życia rodzinnego niewidomych*, "Studia Socjologiczne" 1966, no. 1, pp. 213–238.
- [11] Erikson E.H., *Identity: Youth and crisis*, W.W. Norton & Company, Inc., New York – London 1968.
- [12] Fernández R., *Rola ojca*, "Communio. Międzynarodowy Przegląd Teologiczny" 1999, no. 2, pp. 99–124.
- [13] Fornalik I., *Edukacja seksualna osób niepełnosprawnych. Notatki na marginesach ministerialnych rozporządzeń*, „Kwartalnik Pedagogiczny” 2010, no. 2, pp. 103–119.
- [14] Fraszka E., Oleksiak E., *Być mamą, być Tatą. Poradnik dla niewidomych rodziców*, Polish Association of the Blind, Warsaw 2017.
- [15] Górnicka B., *Pomimo niepełnosprawności... – wybrane aspekty rodzicielstwa w różnych fazach funkcjonowania rodziny z problemem niepełnej sprawności dziecka lub rodzica*, [in:] *Rodzicielstwo w różnych fazach rozwoju rodziny*, ed. J. Brągiel, B. Górnicka, Wydawnictwo Uniwersytetu Opolskiego, Opole 2017, pp. 73–88.
- [16] Gurba E., *Wczesna dorosłość*, [in:] „Psychologia rozwoju człowieka. Charakterystyka okresów życia człowieka”, ed. B. Harwas-Napierała, J. Trempała, Wydawnictwo Naukowe PWN, Warsaw 2008, pp. 202–233.
- [17] Harwas-Napierała B., *Zmiany w funkcjonowaniu rodziny i ich konsekwencje dla rozwoju rodziców*, [in:] „Rodzina a rozwój człowieka dorosłego”, ed. B. Harwas-Napierała, Wydawnictwo Naukowe Uniwersytetu im. Adama Mickiewicza, Poznań 2003, pp. 11–23.
- [18] Havighurst R.J., *Developmental tasks and education*, Longman, New York – London 1981.
- [19] Jabłoński D., Ostasz D., *Zarys wiedzy o rodzinie, małżeństwie, kohabitacji i konkubinacie. Perspektywa antropologii kulturowej i ogólnej*, Wydawnictwo Adiphora, Olsztyn 2001.
- [20] Kapperman G., Brown-Ogilvie T., Yesaitis J., Peskin A., *Prevention of sexual assault against children who are visually impaired*, "Division on Visual Impairments Quarterly" 2014, no. 59(2), pp. 33–38.

- [21] Kapperman G., Page K., Kelly S., *Finding the One: Human mate selection applied to persons who are visually impaired*, "Division on Visual Impairments Quarterly" 2014, no. 59(2), pp. 38–45.
- [22] Kawka J., *Warunki wychowawcze dzieci w rodzinach inwalidów wzroku*, Wydawnictwo UMCS, Lublin 1996.
- [23] Kelly S.M., Kapperman G., *Sexual activity of young adults who are visually impaired and the need for effective sex education*, AFB "Journal of Visual Impairment & Blindness" 2012, no. 106, pp. 519–526.
- [24] Kornas-Biela D., *Postawy społeczne wobec małżeństwa i macierzyństwa kobiet z niepełnosprawnością*, [in:] „Kobiecość a niepełnosprawność”, ed. W. Janocha, K. Zielińska-Król, Wydawnictwo KUL, Lublin 2015, pp. 18–48.
- [25] Kotowski S., *Przewodnik po problematyce osób niewidomych i słabowidzących*, Foundation of the Polish Blind and Visually Impaired "Trakt", State Fund for Rehabilitation of Disabled People, Warsaw 2008.
- [26] Kozielecki J., *Koncepcja transgresyjna człowieka*, PWN, Warsaw 1987.
- [27] Krupa C., Esmail S., *Sexual health education for children with visual impairments: Talking about sex is not enough*, AFB "Journal of Visual Impairment & Blindness" 2010, no. 104, pp. 327–337.
- [28] Kwak A., *Rodzicielstwo – przejaw społecznej współzależności*, [in:] „Rodzicielstwo między domem, prawem, służbami społecznymi”, ed. A. Kwak, Wydawnictwo Akademii Pedagogiki Specjalnej, Warsaw 2008, pp. 7–39.
- [29] Kwak A., *Rozwojowy charakter rodzicielstwa – podstawowe zakresy zmian*, [in:] „Rodzicielstwo w różnych fazach rozwoju rodziny”, ed. J. Brągiel, B. Górnicka, Wydawnictwo Uniwersytetu Opolskiego, Opole 2017, pp. 37–49.
- [30] M. Orłowska, B. Sobczyk, *Współczesny obraz rodziny – hit czy kit?*, [in:] „Rodzicielstwo w sytuacji dezorganizacji rodziny i możliwości wspomagania rodziców”, ed. J. Brągiel, B. Górnicka, Wydawnictwo Uniwersytetu Opolskiego, Opole 2014, pp. 17–26.
- [31] Majewski T., *Psychologia niewidomych i niedowidzących*, Państwowe Wydawnictwo Naukowe, Warsaw 1983.
- [32] Matuszewska M., *Funkcjonowanie w rolach rodzicielskich jako źródło rozwoju młodych dorosłych*, [in:] „Rodzina a rozwój człowieka dorosłego”, ed. B. Harwas-Napierała, Wydawnictwo Naukowe Uniwersytetu im. Adama Mickiewicza, Poznań 2003, pp. 25–46.
- [33] Matuszewska M., *Pełnienie społecznych ról rodzinnych przez młodych dorosłych i ich rozwój indywidualny*, [in:] „Rodzina a rozwój jednostki”, ed. M. Tyszkowa, Centralny Program Badań Podstawowych CPBP, Poznań 1990, pp. 75–87.
- [34] Obuchowski K., *Psychologia dążeń ludzkich*, PWN, Warsaw 1966.
- [35] Oczkowska M., *Sytuacja niewidomej kobiety. A typescript of the paper presented during the Conference of the Polish Association of the Blind*, PZN, Muszyna 1958.
- [36] Ossowski R., *Kształtowanie obrazu własnej sytuacji i siebie u inwalidów wzroku w procesie rehabilitacji*, Wydawnictwo Uczelniane WSP Bydgoszcz, Bydgoszcz 1982.

- [37] Pava W.S., *Visually impaired persons' vulnerability to sexual and physical assault*, AFB "Journal of Visual Impairment & Blindness" 1994, no. 88, pp. 103-112.
- [38] Pervin L.A., *Psychologia osobowości*, Gdańskie Wydawnictwo Psychologiczne, Gdańsk 2002.
- [39] Regulation of the Minister of National Education of 12 August 1999 on the method of school teaching and the scope of content regarding knowledge on the sexual life of an individual, principles of conscious and responsible parenthood, the value of the family, life in the prenatal phase, as well as on methods and measures of conscious procreation contained in the general education program (Journal of Laws 1999, no. 67, item 756).
- [40] Regulation of the Minister of National Education of 28 March 2017 on the outline timetables in public schools, in particular (Journal of Laws 2017, item 703).
- [41] Tyszkowa M., *Jednostka a rodzina: interakcje, stosunki, rozwój*, [in:] „Psychologia rozwoju człowieka. Zagadnienia ogólne”, eds. M. Przetacznik-Gierowska, M. Tyszkowa, Wydawnictwo Naukowe PWN, Warsaw 2009, pp. 124-150.
- [42] Wałachowska M., *Edukacja i rehabilitacja osób niewidomych i słabowidzących w działalności organizacji pozarządowych i wybranych instytucji rządowych III RP*, Faculty of Educational Sciences, Maria Grzegorzewska University, Warsaw 2010, unpublished doctoral dissertation.
- [43] Waszczak S., *Stosunek społeczeństwa do osób niepełnosprawnych*, „Problemy Polityki Społecznej” 2000, no. 2, pp. 89-99.
- [44] Wawrocka A., Krawczyński M., *Genetyka w okulistyce*, [in:] „Okulistyka”, eds. A. Grzybowski, Edra Urban & Partner, Wrocław 2018, pp. 305-314.
- [45] Zaorska M., *Etyka a problematyka seksualności osób z poważnymi, głębokimi niepełnosprawnościami*, „Niepełnosprawność i Rehabilitacja” 2018, no. 1, pp. 42-53.



Satisfaction with the support received by parents of children with disabilities and the diversity of parental behaviour towards the child

ABSTRACT: Kamil Kuracki, *Satisfaction with the support received by parents of children with disabilities and the diversity of parental behaviour towards the child*. Interdisciplinary Contexts of Special Pedagogy, no. 26, Poznań 2019. Pp. 191-215. Adam Mickiewicz University Press. ISSN 2300-391X. DOI: <https://doi.org/10.14746/ikps.2019.25.09>

Raising, caring and rehabilitation of children with disabilities and developmental disorders is a serious challenge for their parents, because everyday situations associated with fulfilling parental duties generate a lot of various stress factors. Hence, receiving various kinds of social support seems to be an important factor affecting the well-being of parents. Thanks to this form of aid, it is possible to deal with a difficult situation and to reduce the disorder in family life. Moreover, the received support can significantly affect the parent-child relationship. This is particularly important in the context of reducing unfavourable behaviour and to intensify constructive parenting behaviour.

The main aim of the study was to recognise the type of aid provided to parents of disabled children and to determine the relationship between the support received by parents and the development of the parent-child relationship. The research group consisted of 66 parents of preschool children with disabilities and 40 parents of children without disabilities. The tools used in the research were: the Parent Behavior Inventory by M.C. Lovejoy, R. Weis, E. O'Hare & E.C. Rubin, the Parent Cognition Scale by J.D. Snarr, A.M.S. Slep & V.P. Grande and the Parents' Questionnaire by Agnieszka Dłużniewska. The study was conducted according to the correlation model.

KEY WORDS: Support for parents, parent-child relationship, children with disabilities

Introduction

Parents raising children with disabilities frequently experience many difficulties related to various aspects of life. This fact is confirmed by numerous scientific studies conducted in Poland and abroad, proving that families of children with developmental difficulties are threatened by decidedly many more stress factors as compared to families of children developing correctly¹. These factors, frequently not without influence on developing parental behaviour with respect to the child, may be related to a lack of efficient aid by medical and rehabilitation facilities, lack of social support from the closest family, neighbours and acquaintances, as well as unsatisfactory operation of the state's social policy or the stereotypical social attitudes towards their children observed on a daily basis. It is clear that it is difficult for parents not to see signs of emotional attachment by the child, in particular in the form of spontaneous expression of feelings towards parents or caretakers, and uncertainty as to the future of the child, the organisation of family life, the financial situation of the family and the possibility of achievement of own life goals and professional development that emerge in many situations. In many cases, a child's disability constitutes a factor that significantly destabilises the family life and necessitates the reorganisation of duties of the individual family members with respect to their previous order.² The emerging feeling of

¹ N.O. Davis, A.S. Carter, *Parenting stress in mothers and fathers of toddlers with autism spectrum disorders: Associations with child characteristic*, "Journal of Autism and Developmental Disorders" 2008, no. 38(7), p. 1278-1291; A. Estes, J. Munson, G. Dawson, E. Koehler, X.H. Zhou, R. Abbot, *Parenting stress and psychological functioning among mothers of preschool children with autism and developmental delay*, "Autism" 2009, no. 13(4), pp. 375-387; E. Pisula, D. Noińska, *Stres rodzicielski i percepcja doświadczeń związanych z opieką nad dzieckiem u rodziców dzieci z autyzmem uczestniczących w różnych formach terapii*, "Psychologia rozwojowa" 2011, no. 3, pp. 75-88; L.M. Silva, M. Schalock, *Autism parenting stress index: Initial psychometric evidence*, "Journal of Autism and Developmental Disorders" 2012, no. 42(4), pp. 566-574.

² Ł. Koperski, *Rodzina dziecka z niepełnosprawnością a wsparcie społeczne*, [in:] *Zasoby rodziny. Wychowanie, Poradnictwo, Praca socjalna*, ed. by E. Czerka-Fortuna,

the lack of specialist knowledge and skills in the area of support for the disabled child as well as the parents' conviction about the minor chances for effectiveness of rehabilitation may also turn out to be a significant burden for the parents.

Theoretical basis for the research

Situations emotionally burdening the parents of children with development disorders may stem from the limited possibility of contact with the child caused by flaws in communication, and also due to the child presenting a lot of behaviour that escapes adaptation, in light of which parents might feel lost, powerless and helpless. This is proven, among others, by research by Monique Seymour, Catherine E. Wood, Rebecca Giallo et al.³, conducted on a group of mothers of children with ASD, which showed significant relations between problematic behaviour patterns of children and the stress experienced by mothers. The study showed that difficult behaviour patterns of a child translate to increases in mother fatigue, and, as a consequence, to them implementing inefficient strategies of coping with stress – frequently focused on emotions, and not on the problem at hand. Such a style of coping, in light of the results of many empirical analyses, may directly translate to the generation of diverse behaviour patterns against own children that prevent adaptation⁴, in literature placed along the continuum be-

K. Kmita-Zaniewska, A. Zbierchowska, Wydawnictwo Naukowe Katedra, Gdańsk 2016, pp. 156–177.

³ M. Seymour, C.E. Wood, R. Giallo, R. Jellett, *Fatigue, Stress and Coping in Mothers of Children with an Autism Spectrum Disorder*, "Journal of Autism & Developmental Disorders" 2013, no. 43, pp. 1547–1554.

⁴ L.E. Smith, M.M. Seltzer, H. Tager-Flusberg, J.S. Greenberg, A.S. Carter, *A Comparative Analysis of Well-Being and Coping among Mothers of Toddlers and Mothers of Adolescents with ASD*, "Journal of Autism and Developmental Disorders" 2008, no. 38(5), pp. 876–889; A. Ghasempour, E. Akbari, M. Taghipour, Z. Azimi, E. Refaghat, *Comparison of psychological well-being and coping styles in mothers of deaf and normally-hearing children*, "Audiology" 2012, no. 21(4), pp. 51–59.

tween enmity and compulsion.⁵ Moreover, it must be underscored that stress frequently accompanying families raising children with disabilities is long-term and cumulative in nature.

The influence of internalising and externalising behaviour of ill children and children with development disabilities on the increase of experienced parental stress is also shown by studies by Marieke Verkleij, Erik J. van de Griendt, Vivian Colland et al.⁶ conducted on a group of parents of children with asthma, and also work by Wei Wei Lai, Tze Jui Goh, Tian Po Oei et al.⁷, who showed that parents raising children with ASD declare significantly many more symptoms of experienced stress, such as: a lower level of satisfaction with parent-child relations, negative self-presentation of parents, intense negative emotions emerging in relation to the presence of difficult behaviour of the child, and more symptoms of depression than parents of correctly developing children. Similar conclusions are provided by research of Agnieszka Dłużniewska and Kamil Kuracki⁸, who showed that parents of disabled children experience decidedly many more feelings such as disquiet, stress, loneliness and exhaustion, emerging in relation to disconcerting behaviour of their own child, as compared to parents of children developing correctly. It must be stated, however, that parents do not always see the difficult behaviour patterns of their children exclusively in the category of symptoms accompanying their disability or development dysfunc-

⁵ M.Ch. Lovejoy, R. Weis, E. O'Hare, E.C. Rubin, *Development and Initial Validation of the Parent Behavior Inventory*, "Psychological Assessment" 1999, no. 11(4), pp. 534-545.

⁶ M. Verkleij, E.J. van de Griendt, V. Colland, N. van Loey, A. Beelen, R. Geenen, *Parenting Stress Related to Behavioral Problems and Disease Severity in Children with Problematic Severe Asthma*, "Journal of Clinical Psychology in Medical Settings" 2015, no. 22, pp. 179-193.

⁷ W.W. Lai, T.J. Goh, T.P. Oei, M. Sung, *Coping and Well-Being in Parents of Children with Autism Spectrum Disorders (ASD)*, "Journal of Autism & Developmental Disorders" 2015, no. 45, pp. 2582-2593.

⁸ A. Dłużniewska, K. Kuracki, *Parents' well-being and coping with problematic behavior of their child with disability*, "10th International Conference on Education and New Learning Technologies. Conference Proceedings" 2018, no. 1, pp. 5039-5046.

tions. As proven for instance by the qualitative research by Myrthe Jacobs, Lisa M. Woolfson and Simon C. Hunter⁹, conducted within a group of parents raising children with intellectual disabilities, parents relatively frequently perceive non-adaptive behaviour of their child as a result of their own unsuitable methods of upbringing as well as the influence of the environment. Hence, frequently, they notice long-term effects of shortcomings of their own work with the child, e.g. in terms of being consequent, patient, calm, self-certain; this includes spontaneous reactions to unwanted behaviour of the child and excess demands of them.

Despite the fact that the mode of perception of the child's disability and the entire life situation of the entire family system by the parents seems to be varied and dependent on many factors such as: the moment when the development difficulties are recognised; the type of disability of the child or the family financial situation¹⁰, etc., experiencing stress factors related to the prevailing life situation, with a lack of relevant resistance resources constituting protective factors may quite probably result with social isolation, loneliness or even fatigue syndromes emerging in the parents. Such consequences may in turn significantly translate to the quality of the relations between parents and their disabled children. They can in particular result in limited engagement of the parents in the establishment of proper relations with the child, as well as the emergence of parental behaviour that does not provide support.¹¹ Stress related to a child with a disability or development dysfunctions coming to the family

⁹ M. Jacobs, L.M. Woolfson, S.C. Hunter, *Attributions of Stability, Control and Responsibility: How Parents of Children with Intellectual Disabilities View their Child's Problematic Behaviour and Its Causes*, "Journal of Applied Research in Intellectual Disabilities" 2016, no. 29, pp. 58-70.

¹⁰ A. Twardowski, *Sytuacja rodzin dzieci niepełnosprawnych*, [in:] *Dziecko niepełnosprawne w rodzinie*, ed. by I. Obuchowska, Wydawnictwa Szkolne i Pedagogiczne, Warszawa 2008, pp. 18-54.

¹¹ K. Kuracki, A. Dłużniewska, *Support for parents of children with disabilities and development of parent-child relationships*, "10th International Conference on Education and New Learning Technologies. Conference Proceedings", no. 1, pp. 5032-5038.

may also be related to the selection of a particular style of upbringing.¹² For this reason, empirical studies usually indicate psychological constructs that may constitute for parents of disabled children potential factors of psychological resistance and factors predicting well-being. These include, among others, self-efficiency¹³, a positive attitude¹⁴, acceptance¹⁵, awareness.¹⁶ As Hanna Kubiak pointed out¹⁷, a significant role of moderator in the course of coping processes with difficult situations in parents with cerebral palsy is also optimism, encouraging parents to select creative coping strategies. A factor protecting parents of children with disabilities is also hope that, according to assumptions of positive psychology, can be analysed as behaviour aimed at a specific goal.¹⁸

¹² A. Twardowski, *Wczesne wspomaganie rozwoju dzieci z niepełnosprawnościami w środowisku rodzinnym*, Wydawnictwo UAM, Poznań 2012; S.A. Esdaile, K.M. Greenwood, *A comparison of mothers' and fathers' experience of parenting stress and attributions for parent-child interaction outcomes*, "Occupational Therapy International" 2003, no. 10(2), pp. 115-126; L.M. Woolfson, R.J. Taylor, L. Mooney, *Parental attributions of controllability as a moderator of the relationship between developmental disability and behaviour problems*, "Child: care, health and development" 2010, no. 37(2), pp. 184-194.

¹³ R.P. Hastings, T. Brown, *Coping strategies and the impact of challenging behaviors on special educators' burnout*, "Mental Retardation" 2002, no. 40, pp. 148-56; J.C. Kuhn, A.S. Carter, *Maternal self-efficacy and associated parenting cognitions among mothers of children with autism*, "American Journal of Orthopsychiatry" 2006, no. 76, pp. 564-75.

¹⁴ B.L. Baker, J. Blacher, M.B. Olsson, *Preschool children with and without developmental delay: behaviour problems, parents' optimism and well-being*, "Journal of Intellectual Disability Research" 2005, no. 49, pp. 575-590.

¹⁵ T.J. Lloyd, R.P. Hastings, *Psychological variables as correlates of adjustment in mothers of children with intellectual disabilities: cross-sectional and longitudinal relationships*, "Journal of Intellectual Disability Research" 2008, no. 52, pp. 37-48.

¹⁶ N.N. Singh, G.E. Lancioni, A.S.W. Winton, B.C. Fisher, R.G. Wahler, K. McAlevy, *Mindful parenting decreases aggression, noncompliance, and self-injury in children with autism*, "Journal of Emotional and Behavioral Disorders" 2006, no. 14, pp. 169-77.

¹⁷ H. Kubiak, *Optymizm jako czynnik wspomagający radzenie sobie ze stresem przez matki dzieci z mózgowym porażeniem*, Wydawnictwo Naukowe UAM, Poznań 2012.

¹⁸ T.J. Lloyd, R.P. Hastings, *Hope as a psychological resilience factor in mothers and fathers of children with intellectual disabilities*, "Journal of Intellectual Disability Research" 2009, no. 53(12), pp. 957-968.

An external resources that is important for the resistance and psychological flexibility of parents of children with disabilities and development dysfunctions is also broadly understood social support¹⁹, defined, among others, as "a particular type of aid provided to individuals and groups mainly to mobilise their power, potential and resources that they have retained in order for them to be able to handle their problems"²⁰, a type of social interaction undertaken by participants in difficult situations, as a result of which information, material goods or instruments of action are exchanged²¹, or as aid behaviour or aid available to an individual in difficult situations.²²

¹⁹ Issues concerning social aid for families of people with disabilities were described in Polish literature more broadly e.g. in: J. Kirenko, *Wsparcie społeczne rodzin z dzieckiem niepełnosprawnym i jego uwarunkowania*, [in:] *Rodzina: źródło życia i szkoła miłości*, ed. by D. Kornas-Biela, Towarzystwo Naukowe KUL, Lublin 2000, pp. 385–393; A. Krause, *Ryzyko osłabienia wsparcia społecznego jako podstawowy dylemat współczesnej rehabilitacji* [in:] *Wsparcie społeczne w rehabilitacji i resocjalizacji*, ed. by Z. Palak, Z. Bartkiewicz, Wydawnictwo Uniwersytetu Marii Curie-Skłodowskiej, Lublin 2004, pp. 47–54; A. Maciarz, *Znaczenie więzi i społecznego wsparcia w wypelnianiu rodzicielsstwa wobec niepełnosprawnego dziecka*, [in:] *Wątki zaniedbane, zamiechane, nieobecne w procesie edukacji i wsparcia społecznego osób niepełnosprawnych*, ed. by Z. Gajdzica, A. Klinik, Wydawnictwo UŚ, Katowice 2004, pp. 91–94; M. Parchomiuk, *Sieć wsparcia społecznego rodzin z dzieckiem niepełnosprawnym*, „Zeszyty Naukowe. Wyższa Szkoła Społeczno-Przyrodnicza im. Wincentego Pola w Lublinie” 2015, vol. 2, pp. 115–131; M. Sekułowicz, *Problematyka funkcjonowania rodzin dzieci niepełnosprawnych*, „Teraźniejszość-Człowiek-Edukacja” 1998, no. 1, pp. 61–8; B. Szluz, *Wsparcie społeczne rodziny osoby niepełnosprawnej*, „Roczniki Teologiczne” 2015, vol. LIV, issue 10, pp. 201–214; J. Wyczesany, *Rodzaje wsparcia udzielanego rodzicom przez terapeutów w świetle ich wypowiedzi*, [in:] *Wspomaganie rozwoju dzieci z genetycznie uwarunkowanymi zespołami zaburzeń*, ed. by J. Wyczesany, Stowarzyszenie na Rzecz Dzieci z Zaburzeniami Genetycznymi GEN, Poznań 2010, pp. 133–140; A. Żyta, K. Ćwirynkało, *Wspieranie rodzin dzieci z niepełnosprawnością – perspektywa zmiany*, „Wychowanie w rodzinie” 2015, vol. XI, no. 1, pp. 377–396.

²⁰ Z. Kawczyńska-Butrym, *Niepełnosprawność – specyfika pomocy społecznej*, Wydawnictwo Naukowe Śląsk, Katowice 1998, p. 87.

²¹ H. Sęk, *Wsparcie społeczne – co zrobić aby stało się pojęciem naukowym*, „Przegląd Psychologiczny”, 1986, no. 3, pp. 791–800. In the current research project, social aid is understood primarily as social interactions in line with the presented psychological concept.

²² T. Rostkowska, *Matężństwo, rodzina i praca a jakość życia*, Oficyna Wydawnicza „Impuls”, Kraków 2008, p. 53.

Social sciences stress that this stems from the attitude of others towards that person and that it provides them, beside a good mood and the conviction that they can count on others, also with a feeling of security and belonging to a certain community.²³ Social aid that is informative, instrumental, emotional or material or spiritual,²⁴ stemming from various sources, may contribute not only to the parents' adaptation to the child's disability²⁵, but also to the reduction of stress accompanying the education of a disabled child.²⁶ As shown by studies of Brian A. Boyd²⁷ conducted on a group of mothers of children with autism, a low level of satisfaction with the received social aid turned out to be a significant predictive factor both of depressive behaviour as well as of fear. Significant importance of social aid as well as of the feeling of coherence and internal control for the development of the ability of constructive coping with stress by parents of children with development dysfunctions was stressed among others in the work of Ayelet Siman-Tov and Shlomo Kaniel²⁸ as well as Pilar Pozo and Encarnacion Sarriá.²⁹ Moreover, according to the results of research by Mauricio Feldman, Linda McDonald, Lisa Serbin et al.,³⁰ the experience by parents of children with au-

²³ G. Filipiak, *Funkcja wsparcia społecznego w rodzinie*, „Roczniki Socjologii Rodziny” 1991, no. XI, pp. 131–144.

²⁴ H. Sęk, R. Cieślak, *Wsparcie społeczne, stres i zdrowie*, Polskie Wydawnictwo Naukowe, Warszawa 2005.

²⁵ M. Kościelska, *Trudne macierzyństwo*, Wydawnictwa Szkolne i Pedagogiczne, Warszawa, 1998.

²⁶ H.D. Luther, L.D. Canham, Y.V. Cureton, *Coping and social support for parents of children with autism*, “Journal of School Nursing” 2005, no. 21, pp. 40–47.

²⁷ B.A. Boyd, *Examining the relationship between stress and lack of social support in mothers of children with autism*, “Focus on autism and other developmental disabilities” 2002, no. 17(4), pp. 208–215.

²⁸ A. Siman-Tov, S. Kaniel (2011), *Stress and personal resource as predictors of the adjustment of parents to autistic children: A multivariate model*, “Journal of Autism and Developmental Disorders”, no. 41(7), pp. 879–890.

²⁹ P. Pozo, E. Sarriá, *Still stressed but feeling better: Well-being in autism spectrum disorder families as children become adults*, “Autism” 2015, no. 19(7), pp. 805–813.

³⁰ M. Feldman, L. McDonald, L. Serbin, *Predictors of depressive symptoms in primary caregivers of young children with or at risk for developmental delay*, “Journal of Intellectual Disability Research” 2007, no. 51, pp. 606–619.

tism of high levels of social aid can reduce negative effects that stress has on the behaviour of the mother during interaction with the child. At the same time, according to the assumptions of the transactional model, it may be assumed that satisfaction with the received social aid will most probably contribute to the reduction of rather unconstructive behaviour presented by parents of disabled children and to the intensification of supporting behaviour towards the child.³¹

Considering the significance of social aid for the well-being of parents raising children with special needs, one must stress the significant role of the parents making up formal and informal support networks and groups. Despite the fact that studies exist indicating limited significance of strong network bonds for the well-being of parents of children with development disabilities³², a significant part of them indicate high efficiency of aid in groups of parents of disabled children, who want to share their experiences with other parents in similar situations.³³ The openness of parents to receive aid and the quality of the aid received may also significantly influence the engagement of parents in revalidation. As one may see in the analyses conducted by Agnieszka Sakowicz-Boboryko³⁴, the

³¹ B.L. Baker, L.L. McIntyre, J. Blacher, K. Crnic, C. Edelbrock, C. Low, *Pre-school children with and without developmental delay: behaviour problems and parenting stress over time*, "Journal of Intellectual Disability Research" 2003, no. 47(4-5), pp. 217-230.

³² J. Khun, K. Ford, L.S. Dawalt, *Brief report: Mapping system of support and psychological well-being of mother of adolescents with autism spectrum disorders*, "Journal of Autism and Developmental Disorders" 2018, no. 48(3), pp. 940-946.

³³ S.M. Kerr, J.B. McIntosh, *Coping when a child has a disability: exploring the impact of parent-to-parent support*, "Child: Care, Health and Development" 2000, no. 26(4), p. 309-322; M. Phillips, *Support groups for parents of chronically ill children*, "Pediatric Nursing" 1990, no. 16, pp. 404-406; E.T. Matloff, S.J. Zimmerman, *Framework for a proactive parents support group: the Syracuse cystic fibrosis model*, "Journal of Pediatric Health Care" 1996, no. 10, pp. 264-271; B. Santelli, A. Turnbull, C. Higgins, *Parent to parent support and health care*, "Pediatric Nursing" 1997, no. 23, p. 303-306.

³⁴ A. Sakowicz-Boboryko, *Wsparcie rodziców w rehabilitacji dzieci z niepełnosprawnością słuchową. W kręgu odpowiedzialności*, Wydawnictwo Akademickie Żak, Warszawa 2016.

received social aid fulfils a significant function of support for rehabilitation activity of parents of children with development dysfunctions. Still, irrespective of the rouse of the social aid received, it is significant for parents of children with disabilities and development dysfunctions to experience social aid in line with their needs and expectations, as inadequate aid related e.g. to overprotectiveness in the support of others – reduces the adaptation capacities of the family. It may thus become a further burden³⁵, disturbing the homeostasis of the family system.

Methodological assumptions of own research

The objective of the conducted research was an exploration of the issue of satisfaction with social aid experienced by parents raising children with various kinds of disabilities, the exploration and comparison of the levels of supporting/ engaged and hostile/ compulsive parental behaviour and the levels of self-assessment of parental behaviour and the parental assessment of undesirable child behaviour in parents raising children with disabilities and parents of children without disabilities, as well as the determination of relations between the support experienced by parents raising children with disabilities and parental behaviour in the parent-child relation.³⁶ The objective described in this way was aided by the following research questions:

1. What is the level of satisfaction with the social aid by medical facilities, therapists and family experienced by parents of children with disabilities?

³⁵ A. Banasiak, *Wsparcie społeczne a poziom doświadczanego stresu rodzicielskiego u ojców dzieci z zaburzeniami rozwoju*, „Pedagogika rodziny. Family Pedagogy” 2014, no. 4, pp. 177-188.

³⁶ The study was a pilot one and was conducted as part of the broader research project numbered BSTP 14/17-I entitled *Behavioural problems of children with disabilities and the qualitative and quantitative dimension of aid received by parents*, headed by Dr Agnieszka Dłużniewska and financed by The Maria Grzegorzewska University in Warsaw.

2. What is the level of supportive/ engaged and hostile/ compulsive parental behaviour in parents of children with disabilities and of children without disabilities?
3. Do differences exist between the level of supportive/ engaged and hostile/ compulsive parental behaviour in parents raising children with disabilities and parents raising children without disabilities, and what are they?
4. Do differences exist between the level of self-assessment of parental behaviour and parental assessment of undesirable child behaviour in parents raising children with disabilities and parents of children without disabilities, and what are they?
5. Does there exist a relation between the experienced social aid on the one hand and the supportive/ engaged and hostile/ compulsive parental behaviour and the level of self-assessment of parental behaviour and the parental assessment of undesirable child behaviour on the other hand in parents raising children with disabilities, and what is it?
6. Does there exist a relation between supportive/ engaged and hostile/ compulsive parental behaviour and the level of self-assessment of the behaviour of parents and the parental assessment of undesirable behaviour of the child in parents raising children without disabilities, and what is it?

Due to the exploratory nature of the research, hypotheses were omitted from the project. The study uses the diagnostic survey method. The following questionnaires were used as research tools: the Parent Behavior Inventory by M. Christina Lovejoy, Robert Weis, Elizabeth O'Hare and Elizabeth C. Rubin³⁷; the Parent Cognition Scale by Jeffery D. Snarr, Amy M. Smith Slep and Vincent P. Grande³⁸ and the questionnaire for parents as developed by Ag-

³⁷ M.Ch. Lovejoy, R. Weis, E. O'Hare, E.C. Rubin, *Development and Initial Validation of the Parent Behavior Inventory*, "Psychological Assessment" 1999, no. 11(4), pp. 534-545.

³⁸ J.D. Snarr, A.M. Slep, and V.P. Grande, *Validation of a New Self-Report Measure of Parental Attributions*, "Psychological Assessment" 2009, no. 21(3), pp. 390-401.

nieszka Dłużniewska.³⁹ The Parent Behavior Inventory (PBI) is composed of 20 items and is used to assess parental behaviour in contact with the child, across two dimensions: hostile/ compulsive behaviour, understood as such that expresses a negative or indifferent attitude towards the child, and may encompass among others threats, physical punishment and forceful reactions to the child's needs, and supportive/ engaged behaviour, meaning, such that indicates acceptance of the child, expressed in, among others, undertaking common activities, expressing warm feelings towards them and assurance of emotional support. Each statement uses a six-degree Likert scale. Due to the translation of the tool into Polish, within the project, the executed study was analysed for test reliability, with high levels of Cronbach's Alpha found for both studied groups, both for the hostility/ compulsion scale ($\alpha=0.85-0.86$) as well as for the support/ engagement scale ($\alpha=0.69-0.82$).

The Parent Cognition Scale (PCS) is composed of 30 items and is used to assess two factors: undesirable child behaviour (from the parent's point of view), such as: stubbornness, de, demanding, failure to submit to parental pleas, excess resistance, etc., and the self-assessment of parental behaviour in contact with the child, taking into account the level of perception by the parent of their own negative behaviour, e.g. lack of consequence in action, failure to give the child sufficient attention, difficulty setting boundaries for the child, lack of patience and self-certainty in contact with the child. The conducted reliability analysis showed high levels of Cronbach's Alpha for both groups: factor I ($\alpha=0.61-0.91$), factor II ($\alpha=0.89-0.91$).

The questionnaire for parents in turn is made up of 97 statements, and is foreseen for analysing satisfaction with the received feeling of aid (both from medical facilities, therapists and the family) that the parents have received from the moment of diagnosing of their child's disability, as well as parental expectations concerning the forms of support that they feel they should get. The tool shows

³⁹ K. Kuracki, A. Dłużniewska, op. cit.

high levels of reliability ($\alpha=0.96$ for the entire scale, $\alpha=0.94$ for the subscale of support by medical facilities, $\alpha=0.95$ for the subscale of support by therapists, $\alpha=0.87$ for the subscale of family support and $\alpha=0.94$ for the subscale of expected support).

The conducted research assumed a purposeful-random sample selection. The research group was composed of 66 parents (49 women, 17 men) raising little children three to six years of age with various disabilities such as ASD, sight disability, Down syndrome, malformative syndrome and compound disability, and the control group consisted of 40 parents (28 women and 12 men) of children three to six years of age, developing correctly. The age of the analysed parents fit in between 25 to over 45 years. The study was conducted at preschools and early development support facilities in the Polish Masovian, Warmian-Masurian, Lower Silesian and Pomeranian voivodeships.

Achieved results

According to results presented in table 1, in the subjective assessment of parents of children with disabilities, the decisively most satisfying source of support turns out to be the family ($M=9.91$, $SD=1.13$), which is indicated much more frequently than support received from therapists. Decidedly least satisfying is in turn support by medical facilities ($M=2.30$, $SD=1.35$). Considering the six-grade Likert scale assumed in the questionnaire (with one being „strongly disagree” and six being „strongly agree”) one can assume that parental satisfaction with various sources of formal and informal aid received ranges low to average.

As shown in table 2, the mean level of hostile-compulsive behaviour represented by parents of children with disabilities ($M=2.21$) does not differ significantly from the mean level of behaviour represented by parents of children without disabilities ($M=3.38$) ($t_{(103,52)}=-1.89$, $p>0.05$). Similarly, the mean level of supportive-engaged behaviour represented by parents of children with disabili-

ties ($M=4.30$) also does not differ significantly from the mean level of behaviour represented by parents of children without disabilities ($M=4.46$) ($t_{(104)}=-1.08$, $p>0.05$).

Table 1. Assessment of satisfaction of parents of children with disabilities with the aid received ($N=66$)

Variable	M	SD
Aid by medical facilities	2.3040	1.35127
Aid by therapists	2.7763	1.15736
Aid by the family	3.9072	1.12521

Legend: M-arithmetic mean, SD-standard deviation

Source: Own research, work based upon SPSS 25.0.

Table 2. Differences in hostile/ compulsive and supportive/ engaged behaviour presented by parents of children with disabilities ($N=66$) and of children without disabilities ($N=40$)

Variable	Parents of children with disabilities		Parents of children without disabilities		t	Df	p
	M	SD	M	SD			
Hostile/ compulsive behaviour	2.21	0.788	2.38	0.816	-1.885	103.518	0.062
Supportive/ engaged behaviour	4.30	0.521	4.46	0.336	-1.083	104	0.281

Legend: M-arithmetic mean, SD-standard deviation, t-Student's t-test value, Df-degrees of freedom, p-significance.

Source: Own research, work based upon SPSS 25.0.

The obtained results suggest the conclusion that parents of children with special needs, similarly to parents of children with no discerned developmental deviations, present behaviour supporting the child as well as such that indicates parental attitudes providing little support. It seems thus that a child's disability does not constitute a factor differentiating parental behaviour in contact with the child.

Statistical analysis using Student's t-test for dependent samples (Table 3) indicates that the assessment of undesirable behaviour of children by parents of children with disabilities ($M=34.71$) does not differ significantly from the assessment made by parents of children without disabilities ($M=36.30$) ($t_{(104)}=-1.04$, $p>0.05$). Moreover, the study did not show statistically significant differences between both parent groups in terms of the self-assessment of own behaviour.

Table 3. Differences in the mean scores of parents of children with disabilities ($N=66$) and of children without disabilities ($N=40$) with respect to the assessment of children's behaviour and the self-assessment of own behaviour

Variable	Parents of children with disabilities		Parents of children without disabilities		t	Df	p
	M	SD	M	SD			
Child Responsible (child behaviour assessment)	34.71	7.198	36.30	8.290	1.039	104	0.301
Parent Causal (parent behaviour self-assessment)	30.681	4.843	31.575	5.368	0.883	104	0.379

Legend: M - arithmetic mean, SD - standard deviation, t - Student's t-test value, Df - degrees of freedom, p - significance

Source: Own research, work based upon SPSS 25.0.

Attempting to determine the relations between the aid received by parents raising children with disabilities and the supportive/engaged, hostile/ compulsive behaviour patterns presented by them in contact with the child, and the self-assessment of parental behaviour along with the parental assessment of undesirable child behaviour, the study tested Pearson's r. According to data contained in table 4, the analyses showed significant moderate correlations between the self-assessment of parental behaviour and the assessment of child behaviour ($r=0.53$, $p<0.01$), indicating that as parents' satisfaction with their own behaviour towards the child

improves, the positive assessment of the behaviour of the child themselves improves along. Low assessment of own parental behaviour is in turn related to parents perceiving decidedly more symptoms of improper behaviour in their children.

Table 4. Pearson's *r*. of the tested variables: Social aid received by parents – by medical facilities, therapists, the family, supportive-engaged behaviour, hostile-compulsive behaviour, and the assessment of the behaviour of the child and self-assessment of parental behaviour in the group of parents of children with disabilities (N=66)

Variables	1	2	3	4	5	6
1. Parent causal (parent behaviour self-assessment)						
2. Child responsible (child behaviour assessment)	0.531**					
3. Supportive-engaged behaviour	0.229	0.011				
4. Hostile-compulsive behaviour	-0.591**	-0.336**	0.054			
5. Aid by medical facilities	-0.080	0.013	-0.174	0.126		
6. Aid by therapists	-0.100	-0.074	-0.161	0.080	0.748**	
7. Aid by the family	-0.114	-0.141	0.065	0.185	0.459**	0.276*

Legend: ** correlation significance at $p < 0.01$ * correlation significance at $p < 0.05$

Source: Own research, work based upon SPSS 25.0.

The analyses also showed negative moderate correlations between parent compulsive/ hostile behaviour and the self-assessment of their behaviour towards the children ($r = -0.59$, $p < 0.01$). The more unfavourable behaviour instances towards own children expressed by parents, the worse do they evaluate their own behaviour. Statistically significant weak negative correlations were also found between hostile/ compulsive parental behaviour and the parental assessment of child behaviour ($r = 0.34$, $p < 0.01$). Hence, the more

unfavourable behaviour towards the child expressed by parents, meaning, the more frequently they do not show sufficient attention, they lose control when in contact with the child or they tell them things that could hurt them, the worse to they assess their behaviour.

The obtained scores could indicate self-reflection by parents and their awareness of the consequences of their own actions with respect to the shaping of attitudes and behaviour of the child and the establishment of proper relations with them. The conducted analyses did not show the presence of a significant relationship between the assessment of aid received by parents and their expressed behaviour in terms of support/ engagement and hostility/ compulsion towards the child. No significant relations were also found between parental assessment of the received aid and self-assessment of parental behaviour and the parental assessment of child behaviour.

Significant moderate and strong positive correlations are in turn found between the subjective perception by parents of aid by medical facilities and the experience of aid by therapists ($r=0.75$, $p<0.01$) and by the family ($r=0.46$, $p<0.01$). Weak moderate positive correlations were finally found between support by the family and support by therapists ($r=0.28$, $p<0.05$). The obtained results could hint that the better the assessment by parents of children with disabilities of their experience of various forms of aid by medical facilities, the better they assess the quality of aid provided by specialists working with the child and the higher level of satisfaction they experience from support provided by their closest ones. Moreover, satisfaction with aid provided by the family also improves in parents of children with special needs, along with positive experiences in terms of aid received from therapists.

Similarly to parents raising children with disabilities, the group of parents of children without disabilities also expressed strong positive correlations between the self-assessment of parental behaviour and the assessment of the child's behaviour ($r=0.78$, $p<0.01$) (Table 5).

Table 5. Correlations (Pearson's r .) of tested variables: parent behaviour self-assessment, child behaviour assessment, supportive-engaged behaviour and hostile-compulsive behaviour in the group of parents of children without disabilities ($N=40$)

Variables	1	2	3
1. Parent causal (parent behaviour self-assessment)			
2. Child responsible (child behaviour assessment)	0,778**		
3. Supportive-engaged behaviour	0.189	-0.017	
4. Hostile-compulsive behaviour	-0.456**	-0.51**	-0.012

Legend: ** correlation significance at $p < 0,01$ * correlation significance at $p < 0,05$
Source: Own research, work based upon SPSS 25.0.

On the basis of the conducted analysis, one could conclude on finding in this group of respondents significant relations between hostile/ compulsive behaviour and self-assessment of parental behaviour ($r = -0.456$, $p < 0.01$) and the parental assessment of the child's behaviour ($r = -0.51$, $p < 0.01$).

Discussion of results and conclusions

The conducted research project saw an attempt at assessing the satisfaction of parents raising children with disabilities with the aid they receive and the relation between the aid received on the one hand and the diversity of parental behaviour patterns towards the child. The achieved results allow the observation that parents raising children with disabilities and development dysfunctions experience aid from various sources, the most important of which seems to be the family, with the least satisfying one being medical facilities. Similar data is provided, e.g., by studies of Janusz Kirenko⁴⁰, which stress that the best source of aid for families raising children with disabilities are persons of significance, meaning, the closest

⁴⁰ J. Kirenko, op. cit.

family, the spouse, friends. The acquired aid, as assessed by parents, is, however, insufficient, as proven, among others, by quite low parental satisfaction scores with the aid received. These results correspond with other studies, e.g. by Agnieszka Żyta and Katarzyna Ćwirynka⁴¹, who showed in the conducted qualitative analyses of interviews with parents of children with intellectual disabilities many discernible shortcomings, in terms of support offered to them and stemming from various sources. It thus seems that despite the fact that parents raising disabled children are frequently able to precisely describe their needs in terms of the resources that they would like to receive both from their closest environment, medical, educational and therapeutic facilities, or even the state's social policy, there exists great disparity between the needs of the family and their satisfaction. Studies also suggest one more conclusion: As parental satisfaction grows with aid received from one source, the satisfaction also improves with aid received from other sources. This state of affairs may constitute the impetus for considerations on the need to develop a comprehensive aid system for families raising children with disabilities and development dysfunctions, allowing e.g. the parents to acquire exhaustive information on the child's health, the functional diagnosis and institutional forms of aid, the discussion of diverse pathways of the further education of the child, the determination, together with specialists, of the plan of medical treatment, revalidation, rehabilitation, discussion of any sort of extended diagnosis of prognosis, participation in instruction and psychoeducation seminars organised for parents concerning, for instance, the recommended methods and forms of work with the child and countering their difficult behaviour.

It is very probable that the lack of parental experience of satisfactory social aid may substantiate results suggesting the lack of relationship between the assessment of aid and the parental behaviour expressed in contact with the child and the self-assessment of parental behaviour as well as the parental assessment of unwanted behaviour of the child. On the basis of the conducted analysis of

⁴¹ A. Żyta, K. Ćwirynka, *op. cit.*

studies⁴² one could thus conclude that satisfaction with the received aid will be a significant predictor for constructive coping by parents with difficult situations, and a factor reinforcing parental well-being. One could thus expect for satisfaction from the received aid to be directly translated to the reduction of parental behaviour along the scale of hostility/ compulsion and intensification of supportive/ engaged behaviour.

The studies did not show significant differences between parents raising disabled children and parents of children without disabilities, in terms of the levels of presented supportive/ engaged, supportive/ hostile behaviour, as well as in terms of the assessment of child behaviour and self-assessment of own behaviour in the relation with the child. It may be that it is not the child's disability but other psychological or environmental factors determine specific actions of the parents towards their children. The lack of relations between the subjective assessment of the experienced aid and parental behaviour towards children may also be the result of the study group for the conducted pilot project being too limited. Perhaps this is also the reason why the study did not find significant differences between the behaviour of parents of disabled children and parents of children without disabilities, which is surprising due to the results of research discussed earlier on the psychological strength of parents of children with disabilities.

According to the achieved results, both the group of parents of children with disabilities as well as of children developing correctly, see, along with an improvement of the assessment of their own behaviour towards the child, improvements in child behaviour assessment as perceived by the parent. The more constructive behaviour towards the child expressed by parents, meaning, the more frequently do they express warm feelings towards the child, spend free time together, listen to it, praise it, provide it with attention, etc., the more frequently do they notice positive changes in the

⁴² B.L. Baker, L.L. McIntyre, J. Blacher, K. Crnic, C. Edelbrock, C. Low, op. cit.; B.A. Boyd, op. cit.; H.D. Luther, L.D. Canham, Y.V. Cureton, op. cit.; P. Pozo, E. Sarriá, op. cit.; A. Siman-Tov, S. Kaniel, op. cit.

child's behaviour. The inefficiency of unconstructive parental behaviour is also confirmed by the significant negative moderate correlations between hostile-compulsive behaviour by parents and the parental assessment of the child's behaviour as found by the study, indicating that the more hostile-compulsive behaviour towards the child expressed by parents, the worse do they assess the child's behaviour. The optimistic conclusion from the conducted project is the fact that the analysed parents seem to offer quite a high level of self-reflection. The study has found significant negative moderate correlations between compulsive/ hostile behaviour of parents and the self-assessment of their behaviour towards the child, indicating that the more unconstructive behaviour towards the child is expressed by parents, the worse their assessment of their own behaviour, with the parents frequently noticing lack of consequence, patience, engagement in their work with the child – with all of these failing to provide advantageous education results. These results correspond with results achieved in the studies of Myrthe Jacobs, Lisa M. Woolfson and Simon C. Hunter.⁴³

The conducted research show the need of suitable preparation of personnel of medical facilities as well as therapists spanning the provision of emotional, information and instrumental aid to parents of children with special needs. The developed activities should take into account both systemic family resources as well as internal psychological resources of parents. It also seems logical to undertake further, deeper studies that could amend the missing area of nescience, e.g. in terms of predictors of parental behaviour that determine the parent-child relation.

Bibliography

- [1] Baker B.L., McIntyre L.L., Blacher J., Crnic K., Edelbrock C., Low C. *Pre-school children with and without developmental delay: behavior problems and parenting stress over time*, "Journal of Intellectual Disability Research" 2003, no. 47(4-5), pp. 217-230.

⁴³ M. Jacobs, L.M. Woolfson, S.C. Hunter, op. cit.

- [2] Baker B.L., Blacher J., Olsson M.B., *Preschool children with and without developmental delay: behavior problems, parents' optimism and well-being*, "Journal of Intellectual Disability Research" 2005, no. 49, pp. 575–590.
- [3] Banasiak A., *Wsparcie społeczne a poziom doświadczanego stresu rodzicielskiego u ojców dzieci z zaburzeniami rozwoju*, „Pedagogika rodziny. Family Pedagogy” 2014, no. 4, pp. 177–188.
- [4] Boyd B.A., *Examining the relationship between stress and lack of social support in mothers of children with autism*, "Focus on autism and other developmental disabilities" 2002, no. 17(4), pp. 208–215.
- [5] Davis N.O., Carter A.S., *Parenting stress in mothers and fathers of toddlers with autism spectrum disorders: Associations with child characteristic*, "Journal of Autism and Developmental Disorders" 2008, no. 38(7), pp. 1278–1291.
- [6] Dłużniewska A., Kuracki K., *Parents' well-being and coping with problematic behavior of their child with disability*, "10th International Conference on Education and New Learning Technologies. Conference Proceedings" 2018, no. 1, pp. 5039–5046.
- [7] Eisenhower A., Baker B., Blacher J., *Preschool children with intellectual disability: syndrome specificity, behaviour problems, and maternal well-being*, „Journal of Intellectual Disability Research" 2005, no. 49(9), pp. 657–671.
- [8] Esdaile A.S., Greenwood K.M., *A comparison of mothers' and fathers' experience of parenting stress and attributions for parent-child interaction outcomes*, "Occupational Therapy International" 2003, no. 10 (2), p. 115–126
- [9] Estes A., Munson J., Dawson G., Koehler E., Zhou X.H., Abbot R., *Parenting stress and psychological functioning among mothers of preschool children with autism and developmental delay*, "Autism" 2009, no. 13(4), pp. 375–387.
- [10] Feldman M., McDonald L., Serbin L., *Predictors of depressive symptoms in primary caregivers of young children with or at risk for developmental delay*, "Journal of Intellectual Disability Research" 2007, no. 51, pp. 606–619.
- [11] Filipiak G., *Funkcja wsparcia społecznego w rodzinie*, „Roczniki Socjologii Rodziny" 1991, no. XI, pp. 131–144.
- [12] Ghasempour A., Akbari E., Taghipour M., Azimi Z., Refaghat E., *Comparison of psychological well-being and coping styles in mothers of deaf and normally-hearing children*, "Audiology" 2012, no. 21(4), pp. 51–59.
- [13] Hastings R.P., Brown T., *Coping strategies and the impact of challenging behaviors on special educators' burnout*, "Mental Retardation" 2002, no. 40, p. 148–56.
- [14] Jacobs M., Woolfson L.M., Hunter S.C., *Attributions of Stability, Control and Responsibility: How Parents of Children with Intellectual Disabilities View their Child's Problematic Behaviour and Its Causes*, "Journal of Applied Research in Intellectual Disabilities" 2016, no. 29, pp. 58–70.
- [15] Kawczyńska-Butrym Z., *Niepełnosprawność – specyfika pomocy społecznej*, Wydawnictwo Naukowe Śląsk, Katowice 1998.

- [16] Kuhn J.C., Carter A.S., *Maternal self-efficacy and associated parenting cognitions among mothers of children with autism*, "American Journal of Orthopsychiatry" 2006, no. 76, pp. 564–575.
- [17] Kuhn J., Ford K., Dawalt L.S., *Brief report: Mapping system of support and psychological well-being of mother of adolescents with autism spectrum disorders*, "Journal of Autism and Developmental Disorders" 2018, no. 48(3), pp. 940–946.
- [18] Kerr S.M., McIntosh J.B., *Coping when a child has a disability: exploring the impact of parent-to-parent support*, "Child: Care, Health and Development" 2000, no. 26(4), pp. 309–322.
- [19] Kirenko J., *Wsparcie społeczne rodzin z dzieckiem niepełnosprawnym i jego uwarunkowania*, [in:] *Rodzina: źródło życia i szkoła miłości*, ed. by D. Kornas-Biela, Towarzystwo Naukowe KUL, Lublin 2000, pp. 385–393.
- [20] Koperski Ł., *Rodzina dziecka z niepełnosprawnością a wsparcie społeczne*, [in:] *Zasoby rodziny. Wychowanie, Poradnictwo, Praca socjalna*, ed. by E. Czerka-Fortuna, K. Kmita-Zaniewska, A. Zbierzchowska, Wydawnictwo Naukowe Katedra, Gdańsk 2016, pp. 156–177.
- [21] Kościelska M., *Trudne macierzyństwo*, Wydawnictwa Szkolne i Pedagogiczne, Warszawa, 1998.
- [22] Krause A., *Ryzyko osłabienia wsparcia społecznego jako podstawowy dylemat współczesnej rehabilitacji*. [in:] *Wsparcie społeczne w rehabilitacji i resocjalizacji*, ed. by Z. Palak, Z. Bartkiewicz, Wydawnictwo Uniwersytetu Marii Curie-Skłodowskiej, Lublin 2004, pp. 47–54.
- [23] Kubiak H., *Optymizm jako czynnik wspomagający radzenie sobie ze stresem przez matki dzieci z mózgowym porażeniem*, Wydawnictwo Naukowe UAM, Poznań 2012.
- [24] Kuracki K., Dłużniewska A., *Support for parents of children with disabilities and development of parent-child relationships*, "10th International Conference on Education and New Learning Technologies. Conference Proceedings", no. 1, pp. 5032–5038.
- [25] Lai W.W., Goh T.J., Oei T.P., Sung M., *Coping and Well-Being in Parents of Children with Autism Spectrum Disorders (ASD)*, "Journal of Autism & Developmental Disorders" 2015, no. 45, pp. 2582–2593.
- [26] Lloyd T.J., Hastings R.P., *Psychological variables as correlates of adjustment in mothers of children with intellectual disabilities: cross-sectional and longitudinal relationships*, "Journal of Intellectual Disability Research" 2008, no. 52, p. 37–48.
- [27] Lloyd T.J., Hastings R.P., *Hope as a psychological resilience factor in mothers and fathers of children with intellectual disabilities*, "Journal of Intellectual Disability Research" 2009, no. 53(12), pp. 957–968.
- [28] Lovejoy M.Ch, Weis R., O'Hare E., Rubin E.C., *Development and Initial Validation of the Parent Behavior Inventory*, "Psychological Assessment" 1999, no. 11(4), pp. 534–545.

- [29] Luther H.D., Canham L.D., Cureton V.Y., *Coping and social support for parents of children with autism*, „Journal of School Nursing” 2005, no. 21, pp. 40–47.
- [30] Maciarz A., *Znaczenie więzi i społecznego wsparcia w wypełnianiu rodzicielstwa wobec niepełnosprawnego dziecka*, [in:] *Wątki zaniedbane, zaniechane, nieobecne w procesie edukacji i wsparcia społecznego osób niepełnosprawnych*, ed. by Z. Gajdzica, A. Klinik, Wydawnictwo UŚ, Katowice 2004, pp. 91–94.
- [31] Matloff E.T., Zimmerman S.J., *Framework for a proactive parents support group: the Syracuse cystic fibrosis model*, „Journal of Pediatric Health Care” 1996, no. 10, pp. 264–271.
- [32] Parchomiuk M., *Sieć wsparcia społecznego rodzin z dzieckiem niepełnosprawnym*, „Zeszyty Naukowe. Wyższa Szkoła Społeczno-Przyrodnicza im. Wincentego Pola w Lublinie” 2015, vol. 2, pp. 115–131.
- [33] Phillips M., *Support groups for parents of chronically ill children*, „Pediatric Nursing” 1990, no. 16, pp. 404–406.
- [34] Pisula E., Noińska D., *Stres rodzicielski i percepcja doświadczeń związanych z opieką nad dzieckiem u rodziców dzieci z autyzmem uczestniczących w różnych formach terapii*, „Psychologia rozwojowa” 2011, no. 3, pp. 75–88.
- [35] Pozo P, Sarriá E., *Still stressed but feeling better: Well-being in autism spectrum disorder families as children become adults*, „Autism” 2015, no. 19(7), pp. 805–813.
- [36] Rostkowska T., *Matężństwo, rodzina i praca a jakość życia*, Oficyna Wydawnicza „Impuls”, Kraków 2008.
- [37] Santelli B., Turnbull A., Higgins C., *Parent to parent support and health care*, “Pediatric Nursing” 1997, no. 23, p. 303–306.
- [38] Sakowicz-Boboryko A., *Wsparcie rodziców w rehabilitacji dzieci z niepełnosprawnością słuchową. W kręgu odpowiedzialności*, Wydawnictwo Akademickie Żak, Warszawa 2016.
- [39] Sekulowicz M., *Problematyka funkcjonowania rodzin dzieci niepełnosprawnych*, „Terazniejszość-Człowiek-Edukacja” 1998, no. 1, pp. 61–78.
- [40] Seymour M., Wood C.E., Giallo R., Jellet R., *Fatigue, Stress and Coping in Mothers of Children with an Autism Spectrum Disorder*, “Journal of Autism & Developmental Disorders” 2013, no. 43, pp. 1547–1554.
- [41] Sęk H., *Wsparcie społeczne – co zrobić aby stało się pojęciem naukowym*, „Przegląd Psychologiczny”, 1986, no. 3, pp. 791–800.
- [42] Sęk H., Cieślak R., *Wsparcie społeczne, stres i zdrowie*, Polskie Wydawnictwo Naukowe, Warszawa 2005.
- [43] Silva L.M., Schalock M., *Autism parenting stress index: Initial psychometric evidence*, “Journal of Autism and Developmental Disorders” 2012, no. 42(4), pp. 566–574
- [44] Siman-Tov A., Kaniel, S. (2011), *Stress and personal resource as predictors of the adjustment of parents to autistic children: A multivariate model*, “Journal of Autism and developmental Disorders”, no. 41(7), pp. 879–890.

- [45] Singh N.N., Lancioni G.E., Winton A. S., Fisher B.C., Wahler R.G., McAleavey K., *Mindful parenting decreases aggression, noncompliance, and self-injury in children with autism*, "Journal of Emotional and Behavioral Disorders" 2006, no. 14, pp. 169-77.
- [46] Snarr J.D., Slep A.M., and Grande V.P., *Validation of a New Self-Report Measure of Parental Attributions*, "Psychological Assessment" 2009, no. 21(3), pp. 390-401.
- [47] Smith L.E., Seltzer M.M., Tager-Flusberg H., Greenberg J.S., Carter A.S., *A Comparative Analysis of Well-Being and Coping among Mothers of Toddlers and Mothers of Adolescents with ASD*, "Journal of Autism and Developmental Disorders" 2008, no. 38(5), pp. 876-889.
- [48] Szluz B., *Wsparcie społeczne rodziny osoby niepełnosprawnej*, „Roczniki Teologiczne” 2015, vol. LIV, issue. 10, pp. 201-214.
- [49] Twardowski A., *Sytuacja rodzin dzieci niepełnosprawnych*, [in:] *Dziecko niepełnosprawne w rodzinie*, ed. by I. Obuchowska, Wydawnictwa Szkolne i Pedagogiczne, Warszawa 2008, pp. 18-54.
- [50] Twardowski A., *Wczesne wspomaganie rozwoju dzieci z niepełnosprawnościami w środowisku rodzinnym*, Wydawnictwo UAM, Poznań 2012
- [51] Verkleij M., van de Griendt E. J., Colland V., van Loey N., Beelen A., Geenen R., *Parenting Stress Related to Behavioral Problems and Disease Severity in Children with Problematic Severe Asthma*, "Journal of Clinical Psychology in Medical Settings" 2015, no. 22, pp. 179-193.
- [52] Woolfson L.M., Taylor R.J., Mooney L., *Parental attributions of controllability as a moderator of the relationship between developmental disability and behaviour problems*, "Child: care, health and development" 2010, no. 37(2), pp. 184-194.
- [53] Wyczesany J., *Rodzaje wsparcia udzielanego rodzicom przez terapeutów w świetle ich wypowiedzi*, [in:] *Wspomaganie rozwoju dzieci z genetycznie uwarunkowanymi zespołami zaburzeń*, ed. by J. Wyczesany, Stowarzyszenie na Rzecz Dzieci z Zaburzeniami Genetycznymi GEN, Poznań 2010, pp. 133-140.
- [54] Żyta A., Ćwirynkało K., *Wspieranie rodzin dzieci z niepełnosprawnościami – perspektywa zmiany*, „Wychowanie w rodzinie” 2015, vol. XI, no. 1, pp. 377-396.



Lifestyles of Intellectually Disabled Adults

ABSTRACT: Jarosław Bąbka, *Lifestyles of Intellectually Disabled Adults*. Interdisciplinary Contexts of Special Pedagogy, no. 26, Poznań 2019. Pp. 217–235. Adam Mickiewicz University Press. ISSN 2300-391X. DOI: <https://doi.org/10.14746/ikps.2019.25.10>

The purpose of the paper is to show lifestyles of intellectually handicapped adults in the context of the Andrzej Siciński concept. The paper presents the results of research carried out following the interpretive trend, in the hermeneutic-phenomenological perspective, using the dialogue method. The study shows that the disabled manifest habits indicating a blocked, withdrawal as well as a here-and-now-oriented style. The analysed persons exhibited a searching style only in a small extent. There were no statements indicating a change-oriented style. The respondents adapted passively to the conditions of their lives, they were reluctant to speak about the future and about the need to change something in their own lives. The analysis and interpretation of the research results revealed three incompatible areas: (1) culture patterns (the way of thinking, norms of functioning in a particular community), (2) resources of their environment, and (3) resources of an individual, which explains why the lifestyles of intellectually handicapped people analysed in the study were oriented towards passive adaptation rather than to development and changes.

KEY WORDS: adulthood, intellectual disability, lifestyles

Introduction

Attempts are being made to describe the psycho-social functioning of adults with intellectual disabilities through the use of the

lifestyle concept.¹ Such an approach finds its substantiation in contemporary special education paradigms, which describe the direction of changes in thinking about intellectually-disabled persons, their lives and their place in the world.² The normalisation paradigm substantiates activities aimed at countering the social exclusion of persons with disabilities by establishing pro-inclusive conditions of life in terms of education, free time, professional employment, independent living as part of protected or supported residence systems. The emancipation paradigm is related to attempts at liberating people with intellectual disabilities from the limitations that society as ascribed them with for decades, considering them deviants, „eternal children”, persons returning to children’s age or moving to old age, persons with delayed adulthood.³ Economic as well as socio-cultural transformations do not omit intellectually-disabled persons. A sign of contemporary times is the confusion of people stemming from the relativism of values, consumerism, the uncertainty of tomorrow, difficulty in finding employment, all of which shines through in their way of life. In the opinion of Amadeus Krause, „Disability does not immunise against these changes, but it delays their internalisation”.⁴ The objective of the study is to show the lifestyles of intellectually-disabled adults within the context of the possibility of them to make choices among the offers available within socio-cultural space.

¹ B. Borowska-Beszta, *Etnografia stylu życia kultury dorosłych torunian z zaburzeniami rozwoju*, Wydawnictwo Naukowe UMK, Toruń 2013; I. Ramik-Mażewska, *Style życia kobiet z niepełnosprawnością intelektualną. Studium socjopedagogiczne*, Wydawnictwo Naukowe FREL, Warszawa 2018; H. Żuraw, *Udział osób niepełnosprawnych w życiu społecznym*, Wydawnictwo Akademickie „Żak”, Warszawa 2008.

² I. Chrzanowska, *Pedagogika specjalna, Od tradycji do współczesności*, Oficyna Wydawnicza „Impuls”, Kraków 2015, s. 410–417; A. Krause, *Współczesne paradygmaty pedagogiki specjalnej*, Oficyna Wydawnicza „Impuls”, Kraków 2007, pp. 197–208.

³ J. Modrzewski, *Socjalizacja i uczestnictwo społeczne – studium socjopedagogiczne*, Wydawnictwo Naukowe UAM, Poznań 2007, p. 163.

⁴ A. Krause, *Człowiek niepełnosprawny wobec przeobrażeń społecznych*, Oficyna Wydawnicza „Impuls”, Kraków 2004, p. 162.

Lifestyle as a descriptive category of the psychosocial functioning of intellectually-disabled persons

Among the forerunners of the lifestyle concept must be named authors such as Alfred Adler (1998), Georg Simmel (1900) or Thorstein Veblen (1981).⁵ Depending on the psychological, sociological or philosophical orientation, the focus was on slightly different aspects of this issue. A. Adler analysed the process an individual uses to choose their lifestyle in the context of psychosocial factors, meaning – experiences internalised earlier, including those related to the feeling of being worse, as well as conscious motives and objectives for the future.⁶ G. Simmel studied relations between money and freedom as well as between personal values and lifestyle.⁷ T. Veblen studied the functioning of people in an industrialised society, who have ever more resources facilitating the shaping of their own lifestyles. Of significant importance for an individual are prestige, consumer goods, consumerism as a way of life.⁸ Over the years, lifestyles were defined and operationalised in various ways depending on the scientific discipline and the objective of studies. Polish scientific literature intensely stresses the sociological path. Barbara Fatyga describes lifestyle as the “culturally-conditioned mode of implementation of needs, habits and norms”.⁹ According to Aldona Jałowicka, lifestyle is expressed in three spheres of reality: (1) the world view (values, objectives, aspirations), available only indirectly to the observer, (2) observable behaviour and activities as well as

⁵ A. Adler, *Sens życia*, transl. by M. Kreczowska, PWN, Warszawa 1986; T. Veblen, *Teoria klasy próżniaczej*, transl. by Ferntzel-Zagórska, Wydawnictwo Muza, Warszawa 1998; G. Simmel, *Filozofia pieniądza*, transl. by A. Przyłębski, Wydawnictwo Aletheia, Warszawa 2012.

⁶ A. Adler, *Sens życia*, op. cit., pp. 30 and 60.

⁷ G. Simmel, *Filozofia pieniądza*, op. cit., pp. 485–500.

⁸ T. Veblen, *Teoria klasy*, op. cit., p. 47 and others.

⁹ B. Fatyga, *Szkic o konsumpcyjnym stylu życia i rzeczach jako dobrach kultury*, [in:] *Socjologia i Siciński*, ed. by P. Gliński, A. Kościański, IFiS PAN, Warszawa 2009, p. 150.

(3) the sphere of items that one chooses or makes.¹⁰ Andrzej Siciński defines lifestyle as a „system of daily behaviour patterns (the mode of „action”, „life activity”), which is specific for a given community or individual¹¹. People behave in a manner that allows one to get to know them, define them, determine the choice of patterns of behaviour from among a repertoire of those available in a specific culture, all constituting a specific „life strategy”. One cannot speak of lifestyle when the behaviour is forced. Within musings on lifestyle, stressed is the need of existence of even minor capacity of rational choice of specific behavior.¹² It follows from sociological perspectives that one cannot understand the lifestyles of individuals or social groups without reference to the cultural context and social requirements. Culture is the grammar of lifestyle components, as well as its ideology.¹³

The significance of lifestyle for the biography of an individual is accented in psychological approaches. A healthy lifestyle is one that provides one the strength and power to cope with troubles, difficulties, and facilitates taking on challenges. In the view of Anna I. Brzezińska, lifestyle is the system of reference for the organisation of experiences gained by an individual in adulthood. Meaning, during adulthood, an individual’s lifestyle manifests itself in a particular manner. Lifestyle is composed of: the pace of activity, the work-life balance, the solidification of one’s circle of friends and the choice of life activities, according to the accepted values.¹⁴

¹⁰ A. Jałowiecka, *Styl życia a wartości*, [in:] *Styl życia. Koncepcje i propozycje*, ed. by A. Siciński, Państwowe Wydawnictwo Naukowe, Warszawa 1976, p. 207.

¹¹ A. Siciński, *Styl życia – problemy pojęciowe i teoretyczne*, [in:] *Styl życia. Koncepcje i propozycje*, Państwowe Wydawnictwo Naukowe, Warszawa 1976, p. 15.

¹² A. Siciński, *Styl życia. Kultura. Wybór. Szkice*, Wydawnictwo Instytutu Filozofii i Socjologii PAN, Warszawa 2002, p. 23; P. Taubert, *Lebensstile und Mediennutzung. Theoretische Grundlagen und empirische Umsetzung*, Martin Meidenbauer Verlagsbuchhandlung, München 2006, p. 152.

¹³ M. Czerwiński, *Pojęcie stylu życia i jego implikacje*, [in:] *Styl życia. Koncepcje i propozycje*, ed. by A. Siciński, Państwowe Wydawnictwo Naukowe, Warszawa 1976, p. 60.

¹⁴ A. Brzezińska, *Dorosłość – szanse i zagrożenia dla rozwoju*, [in:] *Szanse i zagrożenia rozwoju w okresie dorosłości*, ed. by A. Brzezińska, K. Appelt, J. Wojciechowska, Wydawnictwo Fundacji Humaniora, Poznań 2002, pp. 17–21.

For the study, the concept of lifestyle according to Andrzej Siciński was assumed. Determining factors of lifestyle are: (1) human behaviour diversified in terms of scope and form, hence, activities and actions, (2) motivations of behaviour that allows the achievement of objectives, as well as the values related to it, as well as (3) the functions of things – the items that one chooses or creates. The author ties lifestyle with culture. One could say that if culture encompasses the entirety of behaviour patterns, then lifestyle is a sign of choices made from among this selection by an individual.¹⁵ A. Siciński presented his typology that corresponds to the following lifestyles¹⁶:

- Blocked/ limited style – applies to situations of limited capacities to make choices.
- Withdrawal style – entails the avoidance of making choices.
- Searching style – related to making use of the possibility to make choices, motivated mainly by searching for values and the meaning of life.
- The „here and now“-oriented style – describes making choices aimed primarily at achieving a good mood and treating the execution of a task as an objective in itself.
- Conservative style – related to making choices aimed at maintaining the status quo, the domination of conservative behaviour that maintains the current situation as it is. The style has two varieties: a conformist and a ritualistic variety.
- Action-oriented lifestyle that can be described as a mature lifestyle. The style has two varieties: the revolutionary variety (changes through rebellion) and the innovative variety (evolutionary changes).

Studies by various authors show that intellectually-disabled adults, despite the changes found in their living environments, experience difficult situations related to the execution of development tasks concerning the satisfaction of the need of love, sexual drive, independent living, social participation, professional employment.

¹⁵ A. Siciński, *Styl życia – problemy pojęciowe*, op. cit., pp. 23–24.

¹⁶ A. Siciński, *Styl życia. Kultura. Wybór. Szkice*, op. cit., pp. 77–86.

The problem is excess dependence on parents, social helplessness, marginalisation, social exclusion, lack of suitable support in the environment.¹⁷ I. Ramik-Mażewska characterised the lifestyle of people with intellectual disabilities as home-centric, ritualised by daily activities, entailing passively living their lives, focused on the here and now, and to a lesser extent as oriented on action and change.¹⁸ This indicates that lifestyle is a part of human identity and that it can be a determining factor concerning their development vs stagnation, adaptation vs disadaptation.

Research methodology

Issues of lifestyles of adults with intellectual disabilities are difficult to scientifically explore. More limited cognitive abilities of intellectually-disabled individuals, including limited communication capacities, caused that the dialogue method was chosen to collect empirical material. It is similar to a narrative interview, but additionally entails a free discussion, an attempt at dialogue and negotiations towards a common position, which is substantiated in terms of the studied group. Discussions using the free interview mode revolved around topics related to development tasks corresponding to adulthood, e.g. professional employment, one's economic situation, the family and residential situation, spending free time, social contacts in the local community.¹⁹ The study saw the

¹⁷ B. Cytowska, *Trudne drogi adaptacji. Wątki emancypacyjne w analizie sytuacji dorosłych osób z niepełnosprawnością intelektualną we współczesnym społeczeństwie polskim*, Oficyna Wydawnicza „Impuls” Kraków 2012; Z. Gajdzica, *Edukacyjne konteksty bezradności społecznej osób z lekkim upośledzeniem umysłowym*, Oficyna Wydawnicza „Impuls”, Kraków 2007; R. Kijak, *Seksualność człowieka z niepełnosprawnością intelektualną a rodzina*, Wydawnictwo Lekarskie PZWL, Warszawa 2014; A. Krause, A. Żyta, S. Nosarzewska, *Normalizacja środowiska społecznego osób z niepełnosprawnością intelektualną*, Wydawnictwo Edukacyjne Akapit, Toruń 2010.

¹⁸ I. Ramik-Mażewska, *Style życia kobiet*, op. cit., pp. 305–314.

¹⁹ P. Łukasiewicz, *Dialog jako metoda*, „Teksty” 1979, no. 5(47), pp. 105–121; K. Konecki, *Studia z metodologii badań jakościowych. Teoria ugruntowana*, Wydawnictwo Naukowe PWN, Warszawa 2000, pp. 169–188.

Table 1. Characteristics of the studied persons

First name and age	Profession	Family situation	Professional situation	Place of residence
Estera (52 years)	knitter	married, no children	unemployed	town up to 10,000 inhabitants
Marzena (34 years)	knitter	single, no children	unemployed	town up to 10,000 inhabitants
Bartosz (29 years)	cook in small gastronomy	single, no children	unemployed	town up to 50,000 inhabitants
Marek (40 years)	bookbinder	single, no children	worker	town up to 10,000 inhabitants
Marta (31 years)	cook in small gastronomy	single, no children	unemployed	town up to 50,000 inhabitants
Janek (38 years)	bookbinder	single, no children	unemployed	town up to 10,000 inhabitants
Małgorzata (24 years)	cook in small gastronomy	single, no children	unemployed	town up to 50,000 inhabitants
Sandra (40 years)	bookbinder	married, no children	unemployed	town up to 50,000 inhabitants
Adrian (35 years)	bookbinder	single, no children	unemployed	town up to 50,000 inhabitants
Janina (40 years)	bookbinder	single, no children	unemployed	town up to 10,000 inhabitants

Source: own work.

participation of ten people aged between 25 and 52, with certified minor intellectual disabilities, which have completed special vocational schools. Five people had the profession of bookbinders, three were cooks in small gastronomy and two gained education as knitters. All the people stemmed from the county of Nowa Sól in the Lubusz voivodeship of Poland. Intellectually-disabled adults and their caretakers consented to participation in the study and were informed about the objective of the study. The empirical material was collected during individual discussions with adults with intel-

lectual disability certificates by Monika Pomorska.²⁰ The acquired empirical material was interpreted using the assumptions of the hermeneutic-phenomenological perspective, which allows the representation of the world experienced by the persons studied, to understand the meaning and significance that they ascribe to life situations in terms of lifestyles of intellectually-disabled adults.²¹ The analysis and interpretations of research results had the objective of getting to know and describing the lifestyles of adults with minor intellectual disabilities, thanks to which answers were provided to the following issues: (1) what are the lifestyles of the studied adults with minor intellectual disabilities?, (2) what factors condition the lifestyle choice of the analysed persons?

Analysis and interpretation of empirical material

A thorough analysis and interpretation of the collected empirical material exceeds the volume capacity of the present article. The lifestyles discerned by A. Siciński are mixed together in the statements of the studied persons. This means that it is difficult to assign one particular lifestyle to them. This part of the study presents selected statements²² indicating that activities of intellectually-disabled adults in terms of their professional work and financial situation, family and residential situation, the mode of spending free time, social contacts, are related to various life styles.

The analysis of statements suggests that the blocked (limited) style in the analysed persons mainly applies to professional work

²⁰ M. Pomorska, *Funkcjonowanie dorosłych osób z niepełnosprawnością intelektualną w stopniu lekkim rolach społecznych*, master's thesis written under the guidance of Dr hab. J. Bąbka, Zielona Góra 2016.

²¹ K. Ablewicz, *Hermeneutyczno-fenomenologiczna perspektywa badań w pedagogice*, Wydawnictwo Uniwersytetu Jagiellońskiego, Kraków 1994, pp. 59–60 and others.

²² The text includes the verbatim mode of expression of the persons studied [the translations make every effort to faithfully convey these styles – translator's note].

and vocational education. The studied persons are similar in the sense that they did not choose their professions independently at school. The path of further vocational education was determined by the school teachers: *One could choose to be a cook, carpenter and book-binder. My head teacher chose my profession, because I didn't want to. The lady from the lower secondary school chose my profession, she guided me (Marta). Well, this is what the school chose for me, decided that it will be so, in vocational school already (Adrian).* These statements might indicate that the studied persons were not ready to make independent choices, which could influence their later life styles. In addition, the studied persons exhibited dislike for further education that would have increased the probability of finding a job, and would constitute a factor encouraging an active life style. This is confirmed by selected statements: *I rather did not go to any courses, I don't remember anything like that (Marzena); When I finished school, I did not learn any more, I did not attend any courses. I did not want to go to any school any more (Marek); I would not want to learn any more, what we were taught, one had to learn, three years of vocational school, three years of lower secondary school and two years of primary school (Adrian).* Limited possibilities of learning stemming from intellectual disability explain the dislike for further education. Disability itself is also a factor influencing the lifestyle related to one's professional activity: *I never worked in my profession. I was rather unable to do other jobs too, yes, it's difficult to get a job. Not only is it difficult to get a job, there's my eyesight (that troubles me - J.B.) (Marzena).* Negative experiences collected by the studied persons in terms of work are an example of a factor limiting motivation to undertake professional activity: *I kind of like the profession. I am not working anywhere now, I get two benefits: family and social. In the future I would like to work in gastronomy, but the people would have to be nice. I had a bad boss, who shouted, was rude, and at that other place it was nice, but too many interns (Marta); It was impossible to work in my profession. I didn't work at all. I have a disability benefit. I never helped anyone for money (Sandra).* The statements of the studied persons show that the local community lacks offers of jobs that would be suitable for their psychological and physical capacities.

The withdrawing lifestyle was related to the avoidance of the need to make choices by some of the analysed persons, to forgoing social contacts, professional employment, intimate relations and parenthood. One of the studied persons, Estera, had forgone social contacts with acquaintances and neighbours due to the negative experiences she had with visitors: *I am home, I just don't want acquaintances to come.* The limited attractiveness of the disabled for fully-able people makes it difficult for them to make social relations in their environment: *I was just trying to make an acquaintance, but he ditched me and all. I know when he comes, but no, I already let go of it* (Marta). The awareness of limitations stemming from disability is a cause for resignation of the studied persons from professional employment and parenthood. The following statements prove this: *I didn't work anywhere. I had an offer from Zielona Góra, work for me, but I said that I couldn't, because I just couldn't handle it (...)* (Małgorzata). *I am not planning on marriage, I would rather not want to have kids, well, one needs to have suitable conditions, don't they? A room with a kitchen and bathroom is not enough* (Małgorzata). *I am not searching for anyone. I would finally like to get a boyfriend. Maybe in the future I would want to live with him. I'd rather not want to have children, because I just could not handle any child. I cannot cope, and much less with a child* (Marta). The lack of preparation of intellectually-disabled people for independent life is the cause of their withdrawal from roles related to keeping a household, e.g. cooking, cleaning, shopping: *It's mum who cooks. When I come back from the workshop, it's mum who rather does it faster* (Sandra). *I rather cannot help at home, my surrogate family doesn't really let me (...)* (Marta). An example of the inability to cope is the transfer of management of finances to others: *My therapist makes the monthly payments, I trust my therapist and she makes the payments. I get my benefit to my account, but she's the one who takes care of things. I know I can afford everything. I used to not be able to, because my cousin would take my money* (Marta).

On the basis of an analysis of these statements one can conclude that just one person exhibited behaviour that would indicate a searching life style, which found its expression in various areas of activity. Bartosz was one of the few who stated that he chose his pro-

fession himself: *I chose my profession myself, there were only three to choose from: cook, carpenter and bookbinder. I am happy with my profession, I learned a little here at school about pork chops and mince-meat chops (...). If I prepared myself, I definitely could teach someone something. Some courses, one could try that, no?* The searching attitude is expressed by his professional activity, interests, as well as the modes of spending free time: *No, I do not work in my profession, but if I have something at home, then I do it, I cook. I have my benefit. If I wanted to, I could work, but I do some work under the radar here and there, as a help (...). I work on the side at times, sometimes, well, recently I helped some acquaintances at a construction site, because somebody is building a house, you know, dig something, anything (...), one does what one does. I search for such work by myself, if I see some flyers or something, I ask (...)* (Bartosz). Of his own accord, Bartosz became a member of a basketball team and finds his fulfilment in sport: *I looked at the website, they needed people, there was an ad that they are recruiting, and I signed up, they said, okay, we'll take you, and so I play. I am also interested in speedway. I go with friends, we have a group, we go my car to races of Falubaz. We have season tickets for the Euroleague and the Polish league. My acquaintances from basketball also go to speedway races sometimes, but they are not really great fans* (Bartosz). The style of searching in terms of interests and the mode of spending free time is proven by statements of two further people: *Me, I go to trips, oh, with this one Danusia, she arranges trips to the mountains, I was in the mountains, in Zakopane, then at Babimost I was for a week, I visited Gdańsk, I travel if I can or if I have some money to spare, I want to go, so I go, and I save up and then go* (Estera). *Last year we were supposed to take a trip to Hungary. We were to go, but there was no money. We collect money for trips during workshops. We are trying to encourage the vicar to arrange some financing from the curia so that we could take a holiday somewhere* (Janek). The here-and-now style is exemplified by statements of the analysed persons concerning the acceptance of their mode of living, enjoying daily rituals and participating in consumption. An example of a person accepting their life situation is Estera: *I just do things, who wants socks, who wants sweaters, if they want it sewn on a machine, I do it. I have a social benefit and I make ends meet with what I sell. I am now 42 years old, where could I go. The money is*

right, it has to be right, I need to have enough to pay my gas bill (Estera). I don't have a thousand from my work, I get up to a thousand. I am satisfied. Once I had almost two thousand (...). We have enough money, we have to. I am happy with my work and my earnings. I also get a social benefit (Marek). The analysed persons did not talk about their passions and interests. They frequently spend their free time at the computer, using the Internet: *On the computer, there's the Internet, games, for instance, I don't know, I play cards, on the computer, and I try (...). I check if the computer is better at cards than me (...)* (Janek). Beside that, the studied persons keenly watch television, go on walks, ride bicycles, work in the garden, do embroidery, crochet, go to stores: *I sometimes watch something, an interesting film. The computer, games and the Internet. I sometimes take trips with the association. When I come back from workshops, I eat and start on my embroidery straight away, and I sell it to a friend, she hangs it in her room* (Sandra); *I watch series, I ride my bicycle. I watch for instance Maria Wesółowska [a court show – translator's note], Detectives, Na Wspólnej [a Polish soap opera – translator's note], Trudne sprawy [Tough affairs, a scripted reality show – translator's note], what else (...)* (Małgorzata). Janek participates in church life in his locality. He is an altar server and actively participates in almost any mass and church event: *What can one do? I go to church. As altar server – acquaintances encouraged me once, once, come, what will you be doing sitting at home (...)* (Janek). Participation in occupational therapy workshops brings a lot into their lives: *I am a member of the association from the very beginning, when it was formed. Now it is not always work any more. Here we learn songs, we had Christmas Eve recently, we sang in the market square, and now we were with the Great Orchestra of Christmas Charity. When there is something going on, I take pictures* (Marek); *Now Mondays we Nordic walking and sing at the association, we have rehearsals. And now shows for the blind, we will be singing* (Sandra). The studied persons have low aspirations concerning their further lives. They live with what the day brings them. They find joy in purchasing clothes, bicycles, a computer: *I just bought a new computer, perhaps I will have a better bicycle one day. Everything will go its own way and that is that..., to see something, all it takes is to get on my bike and go see it. The nearest future: Well, that's going to be tough, I've been thinking a lot, I am thinking*

a lot, but I don't know what will become of it (Marek); I wouldn't want to have a pet, a new computer perhaps. I will save up from my benefit, I will save up and get a new computer (Janina); I spend my money on food, on clothes (Marta); To have my own room (...) That's most important... (Małgorzata).

The conservative (maintaining) style shines through in statements concerning fear of change in the lifestyle, e.g. moving away from home, clear declarations concerning the will to continue living with parents: *We live here in the settlement, we have two bedrooms. I am not planning on moving away for the moment (Marek).* In the discussions, one could see that the studied persons renounced their emotional and sexual needs, concluding that this sphere of life is not as important for them. The studied were aware that they are disabled and that, for this reason, they cannot develop fully: *I am single. I don't have a girlfriend. I don't have any plans yet. I haven't thought about it, I don't know if I would like to start a family yet. I once thought about it, but I rather do not want to move out. I have two brothers, I live with my brothers and parents (Adrian); I don't have a wife. I have a mother, I live with my mother and siblings. I am single. I don't have a girlfriend. I don't have any plans yet (Marek).* Family life provides the studied persons with a feeling of safety, but it limits their autonomy, the ability to set challenges, to change their lifestyles. Only two of the studied women established families. The remaining ones were unmarried and had no children. The analysed persons exhibited no statements proving a mature life style focused on planning, action and change.

Discussion of the study results

The interpretation of the statements shows that the studied persons exhibit behaviour indicative of the blocked, withdrawing and here-and-now-oriented styles. There are hence indications that suggesting thinking of the lifestyles of intellectually-disabled people as home-centric, ritualised through daily activities, entailing passively living lives, focusing on the here and now, and to a lesser extent

oriented towards action and change. The studied persons adapted to the conditions of their existence, but this was passive adaptation that sees the person being subordinate to their environment, adapt to the living conditions.²³ The studied intellectually-disabled persons were not keen to speak about the future and the possibility of changes in their lives, e.g. further education through participation in courses, in employment, moving out of their parents' home. The plans focused on having e.g. their own room, purchasing a computer, a bicycle, going on a trip, etc. No statements were found indicating perspective plans, innovative activities aimed at changes, hence, creative adaptation and a mature life style. The life situation of the studied persons is similar to the existence of intellectually-disabled adults described by Western authors in terms of social inclusion and quality of life. Differences entail social awareness to the benefit of Western countries, in terms of social participation of intellectually-disabled persons, as well as initiatives facilitating their preparation to be independent and autonomous in adulthood, the promotion of supported housing or making changes in the local environment, so as to increase activity and counteract ritualism and the passivity of this social group.²⁴ The graduated concept of lifestyles shows that intellectually-disabled persons can be supported, to the extent of

²³ K. Obuchowski, *Adaptacja twórcza*, Książka i Wiedza, Warszawa 1985, pp. 208–220.

²⁴ I. Ramik-Mażewska, *Style życia kobiet*, op. cit., pp. 305–314; S. Abbot, R. Mcconkey, *The barriers to social inclusion as perceived by people with intellectual disability*, "Journal of Intellectual Disability Research" 2006, 10, pp. 275–287; P. Bramston, H. Chipuer, G. Pretty, *Conceptual principles of quality of life: an empirical exploration*, "Journal of Intellectual Disability Research" 2005, 49, pp. 728–733; I. Hall, A. Strydom, M. Richards, R. Hardy, J. Bernal, M. Wadsworth, *Social outcomes in adulthood of children with intellectual impairment: evidence from a birth cohort*, "Journal of Intellectual Disability Research" 2005, 49, pp. 171–182; M.L. Wehmeyer M.L., N.W. Garner, *The impact personal characteristics of people with intellectual and developmental disability on self-determination and autonomous functioning*, "Journal of Applied Research in Intellectual Disabilities" 2003, 16, pp. 255–265; N.J. Wilson, H. Jaques, A. Johnson, M.L. Brotherton, *From social exclusion to supported inclusion: adults with intellectual disability discuss their lived experiences of a structured social group*, "Journal of Applied Research in Intellectual Disabilities" 2017, 30, pp. 874–858.

their capacities, in transitioning to further lifestyle categories. This remains in line with the assumptions of the emancipation paradigm and the concept of empowerment, meaning, preparation of a disabled individual to take control of their life, and support them in making decisions/²⁵ Every person, regardless of whether they are fully able or disabled, requires such a life style that would enable them to take on challenges stemming from development tasks and facilitates creative adaptation to changing conditions of existence. Life goals provide life with meaning and force the individual to constantly develop.²⁶ Within this context, it is worth searching for factors conditioning the lifestyle choices of the studied persons. The analysis and interpretation of the study results allowed the disclosure of three areas that did not fit in with each other: (1) cultural patterns (mode of thinking, norms of functioning in a community), (2) resources of one's environment, and (3) resources of the individual; these explain, why the lifestyles of intellectually-disabled persons were oriented towards solidifying the present state of affairs, and not towards development. Contemporary paradigms of special education indicate emerging changes in the mode of thinking about intellectually-disabled persons and their place in the world. However, changes in cultural patterns do not translate to relevant resources of the environment, which would take into account e.g. better availability of professional activity centres, protected housing or therapeutic support for disabled persons and their families. The analysed persons did not have suitable internal resources that would facilitate development-oriented lifestyles instead of stagnation. It was noted earlier that during early adulthood, the lifestyle of an individual begins to shine through. An analysis of empirical material permitted the understanding of just how strongly lifestyle is conditioned by the human body, including limitations stemming from intellectual disability, the life experiences collected earlier on

²⁵ A. Krause, *Paradygmaty pedagogiki*, op. cit. pp. 189–202; G. Theunissen, W. Plaute, *Handbuch Empowerment und Heilpädagogik*, Lambertus Verlag, Freiburg 2002, pp. 150–153.

²⁶ K. Obuchowski, *Galaktyka potrzeb. Psychologia dążeń ludzkich*, Zysk i S-ka Wydawnictwo, Poznań 2000, pp. 316–320.

and the resources of the social environment. One cannot escape the attitude towards oneself, the world and others that was shaped in childhood; these have a significant impact on the choice of a specific lifestyle, as is stressed in psychological concepts. The choice of lifestyle is related to processes of establishment of an individual's identity, as well as learning.²⁷ In the period of establishment of identity, an individual must have the possibility to experiment, try out various roles, take on obligations. Disabled persons have limited experiences in this regard, a fact that limits their identity development. The same applies to processes of learning various social behaviour patterns or roles. One can change their behaviour if the array of their activities is not sufficient in light of new requirements. In such a situation, their experiences must be adapted, or transformed²⁸. Thanks to this, an individual's mode of functioning is retuned. Intellectually-disabled persons experience limitations related to learning, which hinders and at times prevents creative adaptation²⁹. Lifestyle should not be tied only to one's adulthood, when it actually manifests itself. One's lifestyle is a consequence of what happens with intellectually-disabled persons during early stages of development. It is important to develop personal resources in intellectually-disabled persons from the yearly years so as to enable them to make choices, set tasks, all of which facilitates a development-oriented lifestyle.

Conclusion

The normalisation and emancipation paradigm allows one to paint alternative visions of life for intellectually-disabled persons,

²⁷ A. Brzezińska, *Współzależność kontekstu rozwoju stylu życia i struktury Ja*, [in:] *Nauka. Humanistyka. Człowiek. Prace dedykowane Profesor Krystynie Zamiarze w czterdziestolecie pracy naukowej*, Wydawnictwo Naukowe UAM, Poznań 2005, pp. 57–74.

²⁸ J. Piaget, *Równoważenie struktur poznawczych*, transl. by Z. Zakrzewska, Państwowe Wydawnictwo Naukowe, Warszawa 1981, p. 16.

²⁹ K. Obuchowski, *Adaptacja twórcza*, op. cit., pp. 208–220.

which will not be available to many of them. Excess demands placed on intellectually disabled persons with respect to a mature lifestyle related to innovation, motivation to change and make choices may contribute to their lack of adaptation and give rise to defence reactions. Helplessness, passivity, focus on the here and how that shone through in the lifestyles of the analysed persons cannot be treated as something bad. There is a need of discourse that accepts the social approval for intellectually-disabled persons being different³⁰, as well as such an approach that would allow them not to choose lifestyles in the way fully able persons do it. The support of such people on their way to an adult, active and happy life remains an open issue.

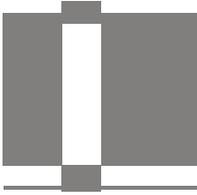
Bibliography

- [1] Ablewicz K., *Hermeneutyczno-fenomenologiczna perspektywa badań w pedagogice*, Wydawnictwo Uniwersytetu Jagiellońskiego, Kraków 1994.
- [2] Abbot S., Mcconkey R., *The barriers to social inclusion as perceived by people with intellectual disability*, "Journal of Intellectual Disability Research" 2006, 10, pp. 275–287.
- [3] Adler A., *Sens życia*, transl. by M. Kreczowska, Państwowe Wydawnictwo Naukowe, Warszawa 1986.
- [4] Borowska-Beszta B., *Etnografia stylu życia kultury dorosłych torunian z zaburzeniami rozwoju*, Wydawnictwo Naukowe UMK, Toruń 2013.
- [5] Bramston P., Chipuer H., Pretty G., *Conceptual principles of quality of life: an empirical exploration*, "Journal of Intellectual Disability Research" 2005, 49, pp. 728–733.
- [6] Brzezińska A., *Dorosłość – szanse i zagrożenia dla rozwoju*, [in:] *Szanse i zagrożenia rozwoju w okresie dorosłości*, ed. by A. Brzezińska, K. Appelt, J. Wojciechowska, Wydawnictwo Fundacji Humaniora, Poznań 2002, pp. 11–22.
- [7] Brzezińska A., *Współzależność kontekstu rozwoju stylu życia i struktury Ja*, [in:] *Nauka. Humanistyka. Człowiek. Prace dedykowane Profesor Krystynie Zamiarze w czterdziestolecie pracy naukowej*, Wydawnictwo Naukowe UAM, Poznań 2005, pp. 57–74.

³⁰ E. Zakrzewska-Manterys, *Upośledzeni umysłowo. Poza granicami człowieczeństwa*, Instytut Stosowanych Nauk Społecznych Uniwersytet Warszawski, Warszawa 2010, p. 108.

- [8] Chrzanowska I., *Pedagogika specjalna. Od tradycji do współczesności*, Oficyna Wydawnicza „Impuls”, Kraków 2015.
- [9] Cytowska B., *Trudne drogi adaptacji. Wątki emancypacyjne w analizie sytuacji dorosłych osób z niepełnosprawnością intelektualną we współczesnym społeczeństwie polskim*, Oficyna Wydawnicza „Impuls”, Kraków 2012.
- [10] Czerwiński, *Pojęcie stylu życia i jego implikacje*, [in:] *Styl życia. Koncepcje i propozycje*, ed. by A. Siciński, Państwowe Wydawnictwo Naukowe, Warszawa 1976, pp. 33–70.
- [11] Fatyga B., *Szkic o konsumpcyjnym stylu życia i rzeczach jako dobrach kultury*, [in:] *Socjologia i Siciński. Style życia – Społeczeństwo obywatelskie – Studia nas przyszłością*, ed. by P. Gliński, A. Kościański, Instytut Filozofii i Socjologii Polskiej Akademii Nauk, Warszawa 2009, pp. 148–159.
- [12] Gajdzica Z., *Edukacyjne konteksty bezradności społecznej osób z lekkim upośledzeniem umysłowym*, Oficyna Wydawnicza „Impuls”, Kraków 2008.
- [13] Hall I., Strydom A., Richards M., Hardy R., Bernal J., Wadsworth M., *Social outcomes in adult hood of children with intellectual impairment: evidence from a birth cohort*, “Journal of Intellectual Disability Research” 2005, 49, pp. 171–182.
- [14] Jałowiecka A., *Styl życia a wartości* [in:] *Styl życia. Koncepcje i propozycje*, ed. by A. Siciński, Państwowe Wydawnictwo Naukowe, Warszawa 1976, pp. 205–240.
- [15] Kijak R., *Seksualność człowieka z niepełnosprawnością intelektualną a rodzina*, Wydawnictwo Lekarskie PZWL, Warszawa 2014.
- [16] Konecki K., *Studia z metodologii badań jakościowych. Teoria ugruntowana*, Państwowe Wydawnictwo Naukowe, Warszawa 2000.
- [17] Krause A., *Człowiek niepełnosprawny wobec przeobrażeń społecznych*, Oficyna Wydawnicza „Impuls”, Kraków 2004.
- [18] Krause A., *Współczesne paradygmaty pedagogiki specjalne*, Oficyna Wydawnicza „Impuls”, Kraków 2004.
- [19] Krause A., Żyta A., Nosarzewska S., *Normalizacja środowiska społecznego osób z niepełnosprawnością intelektualną*, Wydawnictwo Edukacyjne Akapit, Toruń 2010.
- [20] Łukasiewicz P., *Dialog jako metoda*, „Teksty” 1979, 5, pp. 105–121.
- [21] Modrzewski J., *Socjalizacja uczestnictwo społeczne – stadium socjopedagogiczne*, Wydawnictwo Naukowe UAM, Poznań 2007.
- [22] Obuchowski K., *Adaptacja twórcza*, Książka i Wiedza, Warszawa 1985.
- [23] Obuchowski K., *Galaktyka potrzeb. Psychologia dążeń ludzkich*, Zysk i S-ka Wydawnictwo, Poznań 2000.
- [24] Piaget J., *Równoważenie struktur poznawczych*, transl. by Z. Zakrzewska, Państwowe Wydawnictwo Naukowe, Warszawa 1981.
- [25] Pomorska M., *Funkcjonowanie dorosłych osób z niepełnosprawnością intelektualną w stopniu lekkim w rolach społecznych*, master’s thesis written under the guidance of dr hab. J. Bąbka, Zielona Góra 2016.

- [26] Ramik-Mażewska I., *Styl życia kobiet z niepełnosprawnością intelektualną. Studium socjopedagogiczne*, Wydawnictwo Naukowe FREL, Warszawa 2018.
- [27] Siciński A., *Styl życia – problemy pojęciowe i teoretyczne*, [in:] *Styl życia, Koncepcje i propozycje*, Państwowe Wydawnictwo Naukowe, Warszawa 1976, pp. 15–32.
- [28] Siciński A., *Styl życia. Kultura, Wybór. Szkice*, Instytut Filozofii i Socjologii Polskiej Akademii Nauk, Warszawa 2002.
- [29] Simmel G., *Filozofia pieniądza*, transl. by A. Przyłębski, Wydawnictwo Aletheia, Warszawa 2012.
- [30] Taubert P., *Lebensstile und Mediennutzung. Theoretische Grundlagen und empirische Umsetzung*, Martin Meidenbauer Verlagsbuchhandlung, München 2006.
- [31] Theunissen G., Plaute W., *Handbuch Empowerment und Heilpädagogik*, Lambertus Verlag, Freiburg 2002.
- [32] Wilson N.J., Jaques H., Johnson A., Brotherton M.L., *Social inclusion. From social exclusion to supported inclusion: adults with intellectual disability discuss their lived Experiences of a structured social group*, "Journal of Applied Research in Intellectual Disabilities" 2017, 30, pp. 874–858.
- [33] Veblen T., *Teoria klasy próżniaczej*, transl. by Ferntzel-Zagórska, Wydawnictwo Muza, Warszawa 1998.
- [34] Wehmeyer M.L., Garner N.W., *The impact personal characteristics of people with intellectual and developmental disability on self-determination and autonomous functioning*, "Journal of Applied Research in Intellectual Disabilities" 2003, 16, pp. 255–265.
- [35] Zakrzewska-Manterys E., *Upośledzeni umysłowo. Poza granicami człowieczeństwa*, Instytut Stosowanych Nauk Społecznych Uniwersytet Warszawski, 2010.
- [36] Żuraw H., *Udział osób niepełnosprawnych w życiu społecznym*, Wydawnictwo Akademickie „Żak”, Warszawa 2008.



The objectification of adulthood of persons with deeper and deep intellectual disability

ABSTRACT: Dorota Prysak, *The objectification of adulthood of persons with deeper and deep intellectual disability*. Interdisciplinary Contexts of Special Pedagogy, no. 26, Poznań 2019. Pp. 237–254. Adam Mickiewicz University Press. ISSN 2300-391X. DOI: <https://doi.org/10.14746/ikps.2019.25.11>

The adulthood of persons with deeper and deep disability continues to be a challenge not only for specialists and parents or caretakers of the indicated group of persons, but also for us as a society. The objective of the article is the presentation of effects of activities experienced by adults with deeper and deep intellectual disability while inhabitants of a social nursing home. One of the main effects of the mentioned activity is objectification. In the discussed case, the objectification is the effect of lack of trust or limited trust in their potential, which can become a factor of manipulation.

The research material used in the present study constitutes personal experiences gained while working with persons with deeper and deep intellectual disability, their caretakers, parents and other specialists working with them, acquired through participation in diverse activities/ projects aimed at them. Free, narrative discussions as well as focused discussions were conducted with representatives of the indicated groups (save for persons with deep, and in certain cases, significant intellectual disability). The analysis of the research material was conducted according to the action research methodology.¹

¹ I assume that „Action research is that type of cognition that causes searching for new information related to the experienced problem. It occurs already at the stage of the problem situation causing one to search for solutions across many available sources. This encourages the organisation of people around commonly identified problems (mostly local ones, experienced here and now), and cooperation in

KEY WORDS: adulthood, person with deeper and deep intellectual disability, objectification, action research

Action research

The vantage point for the study is the trivial thesis, even though it still must be stated clearly: That persons with intellectual disability continue to be discriminated in Poland. In many areas of daily lives, they do not have the same conditions, possibilities or chances of development as persons developing correctly. Even though suitable legal provisions and rules exist, in practice these people are not treated equally with others.

The objective of the article is the presentation of effects of activities experienced by adults with deeper and deep intellectual disability, in most cases living at social nursing homes. One of the main effects of the mentioned activities is objectification. In the discussed case, objectification is the effect of simplified trust that may be a factor in manipulation. The study constitutes musings based upon the results of action research.²

their solution. This encourages bonds and increases mutual trust, and unifies the community doing the research and action, contributing to more democratic relations and mutual learning" – Maria Czerepaniak-Walczak, *Badanie w działaniu w kształceniu i doskonaleniu nauczycieli*, „Przegląd badań Edukacyjnych 2014, no. 2, p. 185.

² Referring to action research as a researcher engaged in action, in this study I will use this form of narrative in the first person; quoted from: P. Reason, W.R. Torbert: *Zwrot działaniowy. Ku transformacyjnej nauce społecznej*, [in:] H. Cervinkova, B.D. Gołębnik (ed.) *Badania w działaniu. Pedagogika i pedagogika zaangażowane*, Wydawnictwo Naukowe Dolnośląskiej Szkoły Wyższej, Wrocław 2010, pp. 136–147; B.D. Gołębnik: *Edukacyjne badania w działaniu – między akademicka legitymizacją a realizowanymi uproszczeniami*, [in:] H. Cervinkova, B.D. Gołębnik (ed.) *Edukacyjne badania w działaniu*, Wydawnictwo Naukowe Scholar, Warszawa 2013, pp. 54–55.

Action research means studying the social situation of the researcher, with the aim of improving it, meaning, honing the quality of one's activity during its course. This research is systemic gathering of information on phenomena causing certain changes, with the researcher instigating and actively participating in the events.

The adulthood of persons with deeper and deep intellectual disability

Persons with intellectual disability are frequently treated solely as a component of social policy, meaning, as a population suffering from mental disability that must only be provided with full care at every stage of the lives of the individuals.³ In political, social and economic lives, they want to be treated as social partners.

Persons with deeper intellectual disability require decidedly more aid and support. It must be stressed, however, that despite their disability, the majority of these is able to work on a much higher level than foreseen by stereotypical societal expectations. The most difficult situation is experienced by persons with deep intellectual disability, as they require not only aid, but care around the clock. Their lives always depend on another. Hence, society is responsible for these people, who are not able to function without any kind of support.

Irrespective of the level of intellectual disability, all persons experiencing it are able to develop, and function the better, the earlier they and their families are provided with suitable aid and support, such as: early development stimulation, suitable medical care, education adapted to their needs and diverse forms of activity, employment included. Studies on learning and motivation of persons with intellectual disability have shown that their development capacities were underrated. The systematic encouragement to development, a consequent system of requirements, leads to activation

Action research is done when the possibility is seen of changes for the better in a situation; one prepares the design for its improvement, implements it and watches what comes out of it all: Whether the improvement project brought about the expected results or not. If not, one can create a further one, correcting the shortcomings of the former, in order to reimplement it again"; I quote from: Tadeusz Pilch, Teresa Bauman, *Zasady badań pedagogicznych, strategie ilościowe i jakościowe*, Wydawnictwo Akademickie „Żak”, Warszawa 2010, p. 307.

³ Conf. K. Mrugalska, *Osoby z upośledzeniem umysłowym*, [in:] K. Mrugalska, *Osoby upośledzone fizycznie lub umysłowo*, op. cit., p. 55.

and development of the capacities of these people. Intellectual disability is not an illness that will pass if it is treated properly. Persons with deeper intellectual disability will never cease to be disabled, however, just like any other, they can develop and change according to their capacities. The perception and execution of the dynamic concept of reduced intellectual disability creates new, real chances of development and activation of the indicated group of people, their mastery of psycho-social functions that are useful for them and for the environment.⁴ This in turn creates for them chances at subjective treatment by other members of society during diverse activities.

From action to objectification

We influence others to a smaller or broader extent, for instance, the social group we are members of, but we also continue to submit to influence by it. We are members of diverse circles: family, social, societal and professional ones; we meet various people in the most diverse of situations, hence, we cannot avoid influencing others we are in contact with, and *vice versa* – we cannot avoid their influence on us. The sole presence of others, whom we need to take into account in some way, influences our choices, our behaviour. In many instances, we consider other alternatives ourselves.⁵

Participating in social life, we are constantly the object of influence that we either recognise or define in a certain way, or, perceiving it, we fail to understand its real objectives. Such activities may be referred to manipulation in particular. We are dealing with manipulation when we are not able to recognise the actual objectives of activity. Manipulation is a „certain mode of influence on the behaviour of others, one, the mechanism of which is to remain secret from the people being subjected to the influence, hence, not subject to

⁴ H. Borzyszkowska: *Upośledzenie – rewalidacja dzieci i młodzieży upośledzonych umysłowo*, [in:] *Encyklopedia pedagogiczna*, ed. by W. Pomykała, Warszawa 1993, p. 885.

⁵ A. Grzywa, *Potęga manipulacji*, Wydawnictwo Czelej, Lublin 2012, p. 1.

open and direct influence of their consciousness".⁶ Manipulation is influence or driving of others. Anyone being the subject of manipulation is in general not aware of their instrumentality. The thing is that manipulation generally aims at covert objectification of others.⁷

The basis for further considerations aimed at characterising manipulation is the assumption that it is a technique of influence, a type of social influence. This influence entails the sender, utilising their knowledge on the rules of peoples' behaviour, attempts to exert a specific kind of influence on a person or group of people in such a way so that they would not be aware of the fact that they are subjected to purposeful influence.⁸ Considered along these lines, manipulation strives to omit human consciousness in order to achieve a set objective.⁹ Objectives described by the manipulating party are visions of such conditions that they plan to achieve, irrespective of whether they apply to them or the person being manipulated. Referring back to definitions of manipulation functioning in object literature, it must be noted that we are dealing with such a mode of influence when:

"(...) the fundamental motive of the person utilising social manipulation is the maximisation of their own interests or the interests of a group or institution with which they identify"¹⁰; "(...) attempts made in course of manipulation always implement objectives outside of the scope of the person being their direct object. Manipulators always achieve their own objectives, or the objectives of their principals, their superiors".¹¹

⁶ Z. Ziemiński, *Wychowanie a manipulacja*, „Wykłady Inauguracyjne” no. 21, Wyd. Nauk. UAM, Poznań 1981, p. 6.

⁷ W. Łukaszewski, *Szanse rozwoju osobowości*, Książka i Wiedza, Warszawa 1984, p. 483.

⁸ Conf. C.W. Mills, *Elita władzy*, „Książka i Wiedza”, Warszawa 1961, p. 416.

⁹ Conf. R. Nawrat, *Czy można manipulować przechodniami na polskiej ulicy? Empiryczne badanie efektywności wybranych sekwencyjnych procedur zwiększania uległości*, „Przegląd Psychologiczny” 1989, vol. XXXII, no. 1, p. 205.

¹⁰ D. Doliński, *Inni ludzie w procesach motywacyjnych*, [in:] *Psychologia. Podręcznik akademicki*, vol. 2, ed. by J. Strelau, GWP, Gdańsk 2000.

¹¹ A. Lepa, *Świat manipulacji*, Wydawnictwo Tygodnika Katolickiego „Niedziela”, Częstochowa 1994, p. 135.

The research presented in this study shows that daily lives provide examples of such activity towards persons with intellectual disability, irrespective of whether these are actions of individuals or of the state. The subject of adulthood of persons with deeper and deep intellectual disability continues to be a difficult issue for many. Reality is very brutal; we consider persons with disabilities when we are promised financial aid for them. Such a perception may be related to the following quote:

“Is manipulation perhaps conditioned not as much on the instrumental treatment of people, but on objective treatment – meaning, in the sense that when it occurs, the objective of activity of the subject is the good of that person, however, implemented without consideration of their rights to make free decisions and to develop freely. In this concept, one can speak of manipulation in upbringing (both of youths as well as of society at large) when it is based on the behavioural concept of man, when a child or adult is controlled by so-called behavioural engineering... the system of prizes and punishments, acting on emotions instead of thoroughly informing and convincing”.¹² The quote indicates just how important our knowledge is – both in terms of individuals as well as the entire community. The indicated knowledge and, primarily, awareness in noticing threats, contributes to the objective handling of persons with deeper and deep intellectual disability. The lack of reflective thought, in turn, may support activities that objectify the mentioned persons.

The Dictionary of the Polish Language¹³ defines objectification as „assigning abstract concepts real presence”. We also have the term „to objectify” that primarily means „to reduce someone to the role of an object, a tool”, with the second meaning being „to provide something with a real shape”.¹⁴ What is important for me as a researcher, is an attempt at understanding, explaining both the issue

¹² J. Puzinina, *O pojęciu manipulacji*, [in:] *Nowomowa*, ed. by J. Rokoszowa, „Zeszyty Edukacji Narodowej”, Londyn 1985, p. 7.

¹³ The on-line Oxford Learner’s Dictionary defines *objectification* as *the act of treating people as if they are objects, without rights or feelings of their own* [translator’s note].

¹⁴ PWN Dictionary of the Polish Language, <<https://sjp.pwn.pl/slowniki/uprzedmiotowienie.html>> 2019.04.23.

itself, naming it, but also getting to know it and explaining the causes/ process/ progress of the phenomenon. This is important for me for reasons of better understanding, to suggest, better activity leading to social inclusion of the discussed group of people.¹⁵

Objectification is the lack of one's capacity to become aware of the fact of being subjected to changes and influence on these thanks to own more or less autonomous activity. An individual is somebody with a specific identity that discerns them from others; their own activity depends to a great extent on themselves. Objectification in turn is the removal of the capacity of an individual to become aware of the fact of being subjected to changes and the influence on these by their own more or less autonomous actions; a lack of their own identity taking into account individuality, the biological and life age. Objectification can be described as:

- primarily: lack of capacity to recognise one's own objective situation and to understand its individual components (category of seeming),
- secondly: lack of capacity to interpret and select inflowing stimuli due to the set task (category of power),
- thirdly: lack of internal organisation of the individual coupled with their limited position in the world, lack of bonds between them and their environment and the influence exerted upon them by their own activity (marginalisation of activity – exclusion).

The etymology of the concept indicates objective treatment of the person being manipulated. The removal of objectivity from the individual being manipulated gives rise to consequences reaching

¹⁵ Note on action research: „Action research is defined, as a research approach, by practicality, purposefulness, periodicity, collaboration, future orientation, situation orientation, transformation. In this context it is worth noting that, as stated by Andrew Brown and Paul Dowling, action research is a concept used for projects, in which practitioners seek efficient transformation in their own practical work”; I quote from: Maria Szymańska, *Badania w działaniu*, [in:] (ed. by) M. Ciechowska, M. Szymańska, *Wybrane metody jakościowe w badaniach pedagogicznych część 1*, Wydawnictwo Naukowe Akademii Ignatianium w Krakowie, Kraków 2018, pp. 234–235.

into the area of their freedom. This is a reduction of the space available for their free choice. The excess reduction of freedom is entering the area of manipulation. The person being manipulated wrongly believes that they are in control of their activity. They are not aware that they are merely a tool at the hands of an actual perpetrator, only serving the achievement of objectives of importance for them.¹⁶ The effect of manipulation is objectification of persons with deeper and deep intellectual disability. On the basis of the mentioned activity, categories were derived that are presented in the present article: of seeming, power and marginalisation of activity – exclusion.

Methodology and concept of own research

The objective of the article is the presentation of effects of activities experienced by adults with deeper and deep intellectual disability while inhabiting a social nursing home – the objectification of their adulthood. In the discussed case, the objectification is the effect of simplified trust that contributes to manipulation. The basic assessed group – the core of the conducted research – are female inhabitants of a nursing home¹⁷ and persons in contact with them in the common space.

The utilised method of so-called action research is defined, as a research approach, by practicality, purposefulness, periodicity, collaboration, future orientation, situation orientation, transformation.¹⁸ In this context it is worth noting that, as stated by Andrew

¹⁶ A. Wróbel, *Wychowanie a manipulacja*, Oficyna Wydawnicza „Impuls”, Kraków 2006, p. 18.

¹⁷ A social nursing home for children and youths with intellectual disability is operated by an order in one of the counties of the Silesian voivodeship in Poland. There are 89 residents in total, 59 with deep intellectual disability, 22 with deeper intellectual disability and eight with minor intellectual disability. The majority are elderly persons, there are only thirty residents under the age of 25, and they participate in education, re-validation or rehabilitation classes at a special school.

¹⁸ See R. Phelps, S. Hase, *Complexity and action research: exploring the theoretical and methodological connections*, op. cit.; P. Jarvinen, *Action research as an approach in*

Brown and Paul Dowling, action research is a concept used for projects, in which practitioners seek efficient transformation in their own practical work.¹⁹

The research material used in the present study constitutes personal experiences gained during work with persons with deeper and deep intellectual disability, their caretakers, parents and other specialists working with them, gained through participation in various activities/ projects aimed at them. Free, narrative discussions as well as focused discussions were conducted with representatives of the indicated groups (save for persons with deep, and in certain cases, significant intellectual disability). The analysis of the research material was conducted according to the action research methodology.²⁰

During regular observations as part of action research, I experience as a participating researcher certain activities that refer to the objectification of persons with intellectual disability; I also witness situations related to processes of manipulation of the discussed group.

The study shall present categories of objectification derived from action research and the category of manipulation.²¹ Depending on

design science, op. cit.; M. Szymańska, *Transformative creativity in teacher formation: a pedagogical approach*, op. cit. Quoted from Maria Szymańska, *Badania w działaniu*, [in:] (ed. by) M. Ciechowska, M. Szymańska, *Wybrane metody jakościowe w badaniach pedagogicznych część 1*, Wydawnictwo Naukowe Akademii Ignatianium w Krakowie, Kraków 2018, p. 234.

¹⁹ A. Brown, P. Dowling, *Doing research/reading research: A mode of interrogation for teaching*. Routledge Falmer, London 2001, p. 152. Quoted from: Maria Szymańska, *Badania w działaniu*, [in:] (ed. by) M. Ciechowska, M. Szymańska, *Wybrane metody jakościowe w badaniach pedagogicznych część 1*, Wydawnictwo Naukowe Akademii Ignatianium w Krakowie, Kraków 2018, pp. 234–235.

²⁰ During the construction of the research, the spiral model of research phases in action research was used, entailing common reflection on observation results to identify the research problem, through planning and implementation of activity, concluded with renewed reflection and the planning of further research; quoted from: Kurt Lewin „*Badania w działaniu a problemy mniejszości*, [in:] (ed.) H. Cervinkova; B.D. Gołębiak, *Badania w działaniu: Pedagogika i antropologia zaangażowane*, Wydawnictwo Naukowe DSW. Wrocław 2010, pp. 5–18.

²¹ A. Wróbel, citing M. Karwat, lists three examples of objectification. The first is using somebody as a tool of their activity, at the same time excluding them from

the assumed interpretation formula, they can take on the following forms:

- linear, when they emerge as a relationship of results, e.g. infantilisation, learned helplessness or “territoriality” or seeming, power and marginalisation of actions/ exclusion (this shall be discussed in more detail in course of the article), etc.
- metaphorical – e.g. verbal – related to activity, or nominal – related to the status/ condition.
- “a complex map construct” – the established category frequently leads to something or stems from something, remaining in coordination, subordination, superordination with other categories.

The categories referred to below were derived from the action research. On their basis, and on the basis of their mutual relationship, a theoretical construct is established that reflects reality. The linear version is used in the current article.

I identified in course of action research the following categories of objectification, as the effects and results of infantilisation of adults with deeper and deep intellectual disability:

- infantilisation ...
- “learned helplessness” ...
- territoriality – range ...
- “piece of furniture” ...
- (un)recognised adulthood ...
- “activation of adulthood” ...
- marginalisation of activity/ exclusion...
- power ...
- seeming ...

The proposed categories make up the daily reality of the indicated group of people. At the same time, they lead to rejection of

activity, marginalising it. Second: If leaders at a certain level make decisions in the name of the entire organisation. Third: Intervening in people’s consciousness and influencing their attitudes and behaviour using their own consciousness, conf. A. Wróbel, *Wychowanie a manipulacja*, Oficyna Wydawnicza „Impuls”, Kraków 2006, pp. 38–39.

recognition of their adulthood. As a consequence, this leads to a reduced reality.²²

Due to the unconstructive character of the utilised research techniques, and the broader scope of the conducted research, exceeding the issues described in the present article, the analysed notions were very diverse, however, concentrated around the fundamental research problem of objectification of adulthood of persons with deeper and deep intellectual disability. Hence, the presented study shall describe three examples of objectification that are linear in form, hence, they originate from each other linearly. The listed systems may take on diverse arrangements, depending on the time, place or position of the researcher.²³

As was already stated, certain actions cause the emergence of others or arise from them.

The category of seeming

The first situation, in which adults with deeper and deep intellectual disability experience objectification, is activity being seeming. As a result of their limitations, one can see in them the lack of ability to recognise their objective situation and to understand its individual components. "Society", meaning, fully able persons, is eager to show how the quality of life of persons with deeper and deep intellectual disability changed. They can participate in regular activities adapted to their capacities. Government entities and

²² "Reduced reality is reality that refers to specific social situations, in particular those, in which for some reasons somebody or something deliberately or unconsciously reduces or experiences an overly narrow, limited, hence, reduced role. Something paralysing, deforming a person's feelings, relations, capacities, capabilities. It hinders, sometimes even prevents, development in line with the expectations of the individual and/or reality"; quoted from: D. Prysak, *Zredukowana dorosłość osób głębiej niepełnosprawnych intelektualnie*, „Wychowanie Na Co Dzień”, no. 4(253), 2015, p. 27.

²³ Z. Gajdzica, *O pozycji badacza w poznawaniu świata osób niepełnosprawnych*, *Przegląd Badań Edukacyjnych*, no. 18 (1/2014), pp. 103-114.

NGOs offering broadly understood aid (from early support to vocational training) are mostly adapted to the discussed group. During daily activities, they feel, to a certain extent, equal to their peers. For many of their caretakers and parents, this is quite a lot of aid and support. They are very frequently presented as joyous and cheerful. "Within social space, one can also see activities entailing the integration in people's consciousness and the influence on their attitudes and behaviour via their own consciousness. However, the basis of control in this case is subversion, tricking of the recipient, etc. Hence, this is higher-order social manipulation, based on indirect objectification, which may use a facade of expression of respect towards the subjectivity of another, as in the case of flattery (...)"²⁴ They are treated as other citizens of our country.

However, this beautiful reality actually ends, in case of both discussed groups, at the stage of education. After this period, they are actually left to be dependent on their parents, caretakers, and the passion of their teachers who do not agree for years of their work with them to be wasted. The seeming of actions may be noted as present in financial aid as well. The family of a person with deeper and deep intellectual disability is eligible for all kinds of financial support in the form of benefits and aids for specialised equipment. The average citizen rarely considers, whether the amounts proposed by the state are sufficient. What kind of consequences can it have on us as a society? What happens, what is the fate of those adults, when their next of kin are gone? Who then actually cares for persons with deeper and deep intellectual disability? This is an example of "impression management"²⁵ by persons on whom the indicated group is dependent to a certain extent. This stems from the actual lack of capacity to check, or rather even to verify, whether the conveyed information are in line with the expectations of the interested individuals.

²⁴ A. Wróbel, *Wychowanie a manipulacja*, Oficyna Wydawnicza „Impuls”, Kraków 2006, p. 39.

²⁵ R. Keyes, *Czas prawdy, Nieszczerość i oszustwa w codziennym życiu*, Wydawnictwo PWN, Warszawa 2018, p. 62.

The category of power

The other situation, in which persons with deeper and deep intellectual ability experience objectification, refers to “power”. A particular type of objectification in manipulation is the case when the powers on a certain level make decisions in name of the entire organisation, without discussing with lowest-rank members:

“Regrettably, there are too few therapeutic day care centres for our – already – graduates, who attended our classes. It is sad to see them later in the street so sad, down, because all they are left with it sitting at home”.²⁶

The described group of people is characterised by the lack of capacity to interpret and select incoming stimuli on the basis of set tasks, which makes it difficult for them to understand decisions or actions of others. Such social manipulation ceases to influence attitudes and behaviour of people, and just becomes a form of activity of X (or of many X) undertaken by them in their own name and in the name of Y (or of many Y) without the knowledge of Y (of many Y). This is activity that is characterised by fraud, and exhibits objective treatment of people. These are significant factors of highest importance for the entire concept of manipulation of people in all its forms. The example given describes situations of influence on people and deciding about their fate without consideration for them, as if they were items, objects. This is objectification of people – of individuals, groups, communities (...) based on force, or on a feeling of superiority and impunity allowing the omission of human subjectivity. Utilisation of such a method of governance, management or leadership, is related to direct and almost literal objectification of one’s subjects²⁷:

²⁶ Statement by specialist in oligophrenopaedagogy with 29 years of work experience with persons with deep intellectual disability.

²⁷ Conf. A. Wróbel, *Wychowanie a manipulacja*, Oficyna Wydawnicza „Impuls”, Kraków 2016, p. 38.

“It would be good, if the government planned and included in some legal acts fixed financing e.g. for therapeutic day care centres for adults with deep intellectual disability, and right now we live in constant fear whether our project qualifies for financing. We go on from project to project like this. Sadly, we do not always get money for our activities and maintaining the day care centre itself”.²⁸

Frequently in our daily lives we see that the example comes from above. Suddenly, recent times have shown what power can do; sadly, it was not advantageous for people with intellectual disability. An example can be the the May 2018 protest in the Polish Sejm:

“The needs are enormous; this is reported by both the disabled and their parents; what does it matter if we even built such a round-the-clock care centre for our former attendees, the money would be there, parents want to give money, too, if it does not succeed. The state cannot be counted on for aid and help. In truth, everything goes to children, the most is provided for them, and the adults and elderly disabled are left to be forgotten; sad, isn't it?”.²⁹

Signs of marginalisation and exclusion of disabled persons are visible both on the personal, institutional, cultural as well as the social level, and they are an indication of discrimination against this group. Discrimination against the disabled may be referred to as a sort of social repression that has its source in the conviction that the disabled must be made to submit due to their disability.³⁰

Marginalisation of activity – exclusion

A result of the two examples of objectification named earlier is the “marginalisation of activity”, leading in consequence to the

²⁸ Statement by general manager of an NGO from the Cieszyn county in the Silesian Voivodeship, with 25 years of professional experience.

²⁹ Statement by general manager of an NGO with 35 years of professional experience.

³⁰ B. Colin, Mercer Geod, *Niepełnosprawność*, Wydawnictwo Sic!, Warszawa 2008, p. 29.

exclusion of the group. Mirosław Karwat concludes that “both a person subjected to open, clear influence, for instance, due to persuasion, as well as the victim of indirect or direct compulsion can become tools used to achieve the objectives of others. He also believes that own own profit may be achieved not only using someone as a tool of one’s own activity, but also by way of excluding them from activity, marginalising their work or involving them in something else”.³¹ Hence, in characterising manipulation, it is better to speak of objectification of others than of instrumentalisation.

“(…) we always wait for invitations, because we go where we are invited; we always wait for these two invitations, because only you invite us”.³²

The quoted statement confirms, how the discussed group may be consciously or unconsciously excluded from daily activities aimed at society in general. The low number of suggested concrete activities leads to systematic removal of the social group that is made up of persons with deeper and deep intellectual activity from the main stream of daily life, and is also related to the disadvantageous financial situation, exclusion from the subdivision of work, institutional segregation and deprivation of civil rights.³³

The lack of concrete proposals of activity for adults with deeper and deep intellectual disability makes them participate less and less in daily life. If they do not participate, then others get used to their absence from common space. They do not see their daily issues, the difficulties they experience, their needs. Unheard are their voices, but also the voices of their caretakers, parents, specialists. In reality, they do not have the right to indicate their needs. This take place very gently, it is veiled. One could say that they are sill there, but

³¹ A. Wróbel, *Wychowanie a manipulacja*, Oficyna Wydawnicza „Impuls”, Kraków 2016, p. 39.

³² Statement by specialist in oligophrenopaedagogy with 20 years of work experience with persons with deep intellectual disability.

³³ B. Colin, Mercer Geod, *Niepełnosprawność*, Wydawnictwo Siel, Warszawa 2008, p. 30.

somewhat invisible. One does not need to be directly told that they are unwelcome, due to their looks, behaviour, lack of communication, even uselessness³⁴:

(...) after all, they won't contribute to the GDP (gross domestic product)

All it takes is to omit them, failing to invite them to common activity in social life. The lack of fixed options and financing by the legislator of e.g. therapeutic day care centres, a larger number of occupational therapy workshops or other solutions causes the slow reduction of their participation in daily lives. Instead of including them in life by integration of fully able and disabled persons, we gradually exclude them. Showing, supporting work aimed only at a certain age group, e.g. little children, we unconsciously or consciously exclude the adulthood of these people. Failing to note at early stages of education that these children will one day grow up, we in actuality do not educate society about themselves.

It is easier to be charmed by children who even have compounded intellectual disabilities. But when we face the same person when they are grown up, we sometimes experience fear, shock, even abhorrence:

such people scare me; when I saw them so close, I feared that they might do something to me; they said something, but I didn't understand. I definitely prefer little children (...).³⁵

Conclusion

Considering the context of the conducted action research, the above description constitutes a sort of reflection on daily practices in meeting adults with deeper and deep intellectual disability. They are thoughts both about their future, described solely by stays in

³⁴ Statement by local government member from the county of Cieszyn of 2018.10.21.

³⁵ Statement by full-time first-degree female student, 2019.01.28.

social nursing homes after their next of kin are gone, as well as our future as society that will care for the described group. As a result, the following questions emerge: First of all, will we be able to maintain their quality of life that the legislator-dreamer described? Second of all, considering the estimates of professional stratification of labour, will such work be undertaken by future graduates of paedagogical studies as their professional lives related to the mentioned group? I am aware that there are more questions, and that they will keep coming back. The problematisation, the description of this reality is but a vantage point for activity that will contribute to further scientific research.

Bibliography

- [1] Borzyszkowska H., *Upośledzenie –rewalidacja dzieci i młodzieży upośledzonych umysłowo*, [in:] *Encyklopedia pedagogiczna*, ed. by W. Pomykało, Warszawa 1993, p. 885.
- [2] Barnes Colin, Mercer Geod, *Niepełnosprawność*, Wydawnictwo Sic!, Warszawa 2008.
- [3] Czerepaniak-Walczak M., *Badanie w działaniu w kształceniu i doskonaleniu nauczycieli*, „Przegląd badań Edukacyjnych” 2014, no. 2.
- [4] Doliński D., *Inni ludzie w procesach motywacyjnych*, [in:] *Psychologia. Podręcznik akademicki*, vol. 2, ed. by J. Strelau, GWP, Gdańsk 2000.
- [5] Gajdzica Z., *O pozycji badacza w poznawaniu świata osób niepełnosprawnych*, „Przegląd Badań Edukacyjnych”, no. 18 (1/2014).
- [6] Gołębiak B.D., *Edukacyjne badania w działaniu – między akademicka legitymizacją a realizowanymi uproszczeniami*, [in:] H. Cervinkova, B.D. Gołębiak (ed.) *Edukacyjne badania w działaniu*, Wydawnictwo Naukowe Scholar, Warszawa 2013.
- [7] Grzywa A., *Potęga manipulacji*, Wydawnictwo Czelej, Lublin 2012.
- [8] Prysak D., *Zredukowana dorosłość osób głębiej niepełnosprawnych intelektualnie*, „Wychowanie Na Co Dzień”, no. 4(253), 2015.
- [9] Keyes R., *Czas prawdy, Nieszczerość i oszustwa w codziennym życiu*, Wydawnictwo PWN, Warszawa 2018.
- [10] Lepa A., *Świat manipulacji*, Wydawnictwo Tygodnika Katolickiego „Niedziela”, Częstochowa 1994.
- [11] Lewin K., *Badania w działaniu a problemy mniejszości*, [in:] (ed.) H. Cervinkova, B.D. Gołębiak, *Badania w działaniu: Pedagogika i antropologia zaangażowane*, Wydawnictwo Naukowe DSW, Wrocław 2010.

- [12] Reason P., Torbert W.R., *Zwrot działaniowy. Ku transformacyjnej nauce społecznej*, [in:] H. Cervinkova, B.D. Gołębniak (ed.) *Badania w działaniu. Pedagogika i pedagogika zaangażowane*, Wydawnictwo Naukowe Dolnośląskiej Szkoły Wyższej, Wrocław 2010.
- [13] Mrugalska K. (ed.), *Osoby upośledzone fizycznie lub umysłowo*, Warszawa 1996.
- [14] Nawrat R., *Czy można manipulować przechodniami na polskiej ulicy? Empiryczne badanie efektywności wybranych sekwencyjnych procedur zwiększania uległości*, „Przeгляд Psychologiczny” 1989, vol. XXXII, no. 1.
- [15] Puzinina J., *O pojęciu manipulacji*, [in:] Nowomowa, ed. by J. Rokoszowa, „Zeszyty Edukacji Narodowej”, Londyn 1985.
- [16] Szymańska M., *Badania w działaniu*, [in:] (ed. by) M. Ciechowska, M. Szymańska, *Wybrane metody jakościowe w badaniach pedagogicznych część 1*, Wydawnictwo Naukowe Akademii Ignatianium w Krakowie, Kraków, 2018.
- [17] Ziemiński Z., *Wychowanie a manipulacja*, „Wykłady Inauguracyjne” no. 21, Wydawnictwo Naukowe UAM, Poznań 1981.
- [18] PWN Dictionary of the Polish Language, <https://sjp.pwn.pl/slowniki/uprzedmiotowanie.html> 2019.04.23.
- [19] Wróbel A., *Wychowanie a manipulacja*, Wydawnictwo Impuls, Kraków 2006.



DIANA AKSAMIT, BARBARA MARCINKOWSKA

The Maria Grzegorzewska University, Warsaw

My adult son, my adult daughter – reflections of mothers of children with profound intellectual disabilities

ABSTRACT: Diana Aksamit, Barbara Marcinkowska, *My adult son, my adult daughter – reflections of mothers of children with profound intellectual disabilities*. Interdisciplinary Contexts of Special Pedagogy, no. 26, Poznań 2019. Pp. 255–269. Adam Mickiewicz University Press. ISSN 2300-391X. DOI: <https://doi.org/10.14746/ikps.2019.25.12>

Everyone has the right to participate in society, regardless of his or her current personal situation, level of psychosocial functioning or experience. No reason can justify marginalisation or exclusion of people from social life at any stage of their lives. The aim of the article is an attempt to characterise the adulthood of people with profound intellectual disabilities on the basis of subjective assessment of their mothers. The methodology applied was that of a qualitative research, where the main research technique was narrative interviews. The results of the research demonstrate that adulthood is the stage of life when people with profound intellectual disabilities and their caregivers require special support in mental, spiritual, social, societal and educational dimensions.

KEY WORDS: person, adult, society, profound intellectual disability

Introduction

Discussion over the adulthood of the people with intellectual disabilities have only recently appeared in the literature¹, the adult-

¹ J. Lausch-Żuk, *Terapia czy wychowanie?*, [in:] *Wczesna diagnoza i terapia dzieci z utrudnieniami w rozwoju. Interdyscyplinarne problemy*, ed. J. Kruk-Lasocka, M. Seku-

hood of the people with profound intellectual disabilities being rather seldom the subject matter of scientific research.² Marginalisation or even exclusion from scientific and social discourse of the group of adults with profound intellectual disabilities can be caused, for instance, by: (1) small group size (thus incurring low interest); (2) inhomogeneity of the group (coexistence of other disabilities, giving rise to a new often unique individual requiring an individual approach); (3) difficulty in understanding specific characteristics of development and its consequences demonstrated by a particular psychosocial functioning of such person (social stereotype of an *adult – eternal child*); (4) difficulty in conducting research resulting from the necessity to apply an individual approach to every person (lack of proper techniques and research tools) and time-consuming nature. It should be emphasized that the adulthood of the people with profound intellectual disabilities is the result of the development process, influenced by both internal and external factors (see diagram 1). Peculiarity of functioning of adults with profound intellectual disabilities is demonstrated, for instance, in a considerable diversity of their functioning in various areas: intellectual (attention, memory, thinking, perception); social (establishing interactions, maintaining interactions, relations); emotional (express-

łowicz, Dolnośląska Szkoła Wyższa Edukacji Towarzystwa Wiedzy Powszechnej, Wrocław 2004, pp. 422–423; I. Lindyberg, *O jednym z kontekstów dorosłości osób z głębszą niepełnosprawnością intelektualną, czyli w poszukiwaniu sposobu „wyjścia z szafy”*, [in:] *Dorosłość, niepełnosprawność, czas współczesny. Na pograniczach pedagogiki specjalnej*, ed. K.D. Rzedzicka, A. Kobyłańska, Oficyna Wydawnicza „Impuls”, Kraków 2003, pp. 279–284; K. Wiater, B. Basa, *Losy uczniów warszawskich „szkół życia”*, „Szkoła Specjalna” 1981, No. 1, pp. 52–57.

² D. Kopeć, *Rzeczywistość (nie)edukacyjna osoby z głęboką niepełnosprawnością intelektualną. Zbiorowe instrumentalne studium przypadku*, Wydawnictwo Naukowe Uniwersytetu im. Adama Mickiewicza, Poznań 2003; B. Marcinkowska, *Model kompetencji komunikacyjnych osób z głębszą niepełnosprawnością intelektualną – poszukiwaniu wzajemności i współpracy*, Wydawnictwo Akademii Pedagogiki Specjalnej, Warszawa 2013, pp. 59–64; D. Wolska, *Stymulowanie rozwoju psychofizycznego osób dorosłych z głęboką wieloraką niepełnosprawnością*, [in:] *Annales Universitatis Paedagogicae Cracoviensis, Studia Paedagogica II*, ed. D. Wolska, A. Mikrut, Wydawnictwo Naukowe Uniwersytetu Pedagogicznego, Kraków 2012, pp. 392–399.

ing and controlling emotions); physical (controlling one's body) – as follows from the research it was quite significant in the process of shaping motherhood of the female respondents (mothers of the adult people with profound intellectual disabilities) over the years. Such people often reach physical maturity (including sexual one), whereas their intellectual and social functioning is comparable to the functioning of: 2–3 and 4–5 –years old child³ respectively – which quite frequently conditions the social reception of the adulthood period of individuals with profound intellectual disabilities.

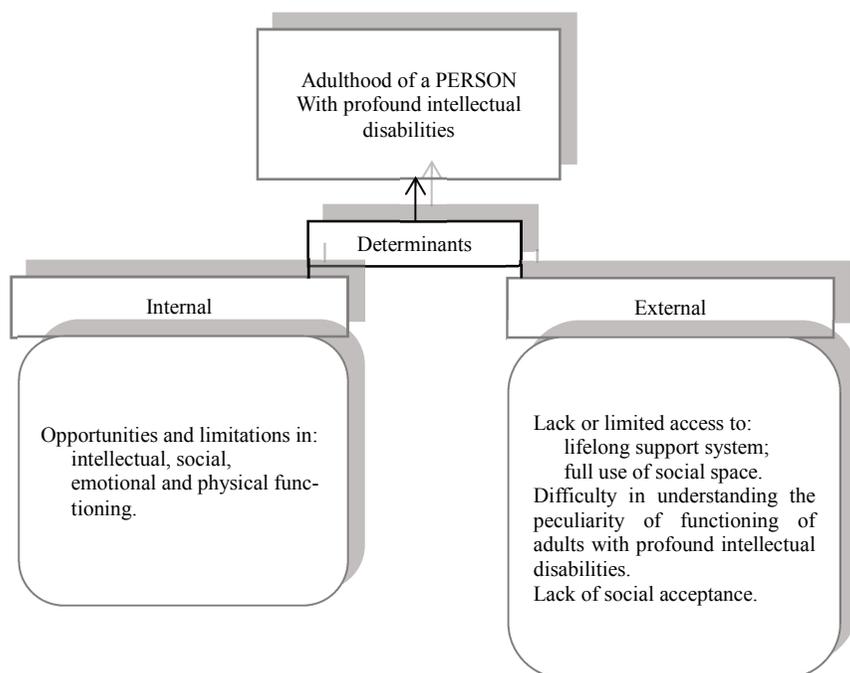


Diagram 1. Determinants of adulthood of people with profound intellectual disabilities

Source: own elaboration.

³ J. Kostrzewski, *Charakterystyka osób upośledzonych umysłowo*, [in:] *Upośledzenie umysłowe. Pedagogika*, red. K. Kirejczyk, Wydawnictwo Naukowe PWN, Warszawa 1981, pp. 110–114.

Living within a society is based on reciprocity and requires cooperation of numerous individuals. Development of a person takes place within the context of his/her mutual relationship with the environment.⁴ A human being is not only influenced by the environment, but also exercises some impact on it. The adoption of such a thesis leads to a reflection on the role of particular individuals (including people with profound intellectual disabilities) in creating a social space that is accessible to everyone. It should be assumed that every human being is part of a complex social system. He/she is a participant in social life and a co-creator of it at the same time. Basic elements that constitute such system are: the person, his/her close and distant relatives, peer environment and local environment, as well as the state and its policy.⁵ It seems appropriate to undertake theoretical and empirical research and analyses, covering the issues of the process of shaping adulthood of people with profound intellectual disabilities and its internal and external determinants (see diagram 1). The results of such analyses can be used to construct effective support systems for people with this type and degree of disability.

⁴ Ecological concepts of development and education indicate the relationships between social environments (ecosystems). (Bronfenbrenner, 1979 as cited in: A. Brzezińska, *Spoleczna psychologia rozwoju*, Wydawnictwo Naukowe Scholar, Warszawa 2007, pp. 187–188). In ecological concepts, the social development environment is understood as a system of interdependent systems, in which every human being will find his or her special place, regardless of abilities, prowess or limitations.

⁵ J. Głodkowska, *Przestrzeń rehabilitacyjna w otoczeniu osób z niepełnosprawnością intelektualną – ujęcie koncepcyjne*, „Ruch Pedagogiczny”, 2005, No. 5/6, pp. 7–23; B. Marcinkowska, A. Wołowicz, *Wielospecjalistyczna ocena poziomu funkcjonowania i konstruowanie programów dla osób z głębszą niepełnosprawnością intelektualną*, Wydawnictwo Akademii Pedagogiki Specjalnej, Warszawa 2010, p. 9; O. Speck, *Niepełnosprawni w społeczeństwie. Podstawy ortopedagogiki*, tłum. W. Seidler, A. Skrzypek, D. Gącza, D. Szarkowicz, Gdańskie Wydawnictwo Psychologiczne, Gdańsk 2005, pp. 271–308.

Selected prospects of adulthood with respect to profound intellectual disabilities – theoretical findings

As a conceptual category, *adulthood* can be analysed from different perspectives: (1) biological – age, specific physical appearance: weight, height, completion of development of somatic systems; (2) psychological – in other words, “maturity of an individual” characterized by self-determination, autonomy, shaped view of the world; (3) social – fulfilling certain social roles, observance of social norms, participation in social life; (4) cultural – understanding culture and participation in it⁶; (5) medical – taking into account the level of functioning of the individual.⁷ In people whose development is harmonious, individual areas of their functioning are correlated at a similar level. An adult person has specific rights, but also social expectations are formulated towards him/her. In people with profound intellectual disabilities, the development of particular spheres of functioning has different characteristics than in people with proper development.

One of the most common criteria in the definition of adulthood is age – the biological perspective of adulthood considerations.⁸ As an example, we can cite Robert Havighurst’s concept of three stages of adulthood: early adulthood (18–35 years), middle age (35–60 years), late adulthood (60–65 years).⁹ Each of these stages is attributed to expectations, achievements, and a certain image of man is constructed. We note here the connection between the following crite-

⁶ B. Cytowska, *Rodzice wobec dorosłości swoich dzieci z niepełnosprawnością intelektualną*, [in:] *Wychowanie w rodzinie. Rodzin o specjalnych potrzebach*. T. 4, eds, S. Walasek, B. Winczura, Karkonoska Wydawnictwo Państwowej Szkoły Wyższej, Jelenia Góra 2011, pp. 87–107.

⁷ B. Jordan, G. Dunlap, *Construction of Adulthood and Disability*, “Mental Retardation”, 2001, No. 39/4, pp. 286–296.

⁸ O. Czerniawska, *Trendy rozwojowe w zachowaniu ludzi dorosłych*, [in:] *Wprowadzenie do andragogiki*, ed. T. Wujek, Wydawnictwo Naukowe Instytutu Technologii Eksploatacji, Warszawa 1996, pp. 36–46.

⁹ R.J. Havighurst, *Developmental tasks and education*, New York-London, Longman, 1981, as cited in: A. Brzezińska, *Spółeczna psychologia rozwoju*, Wydawnictwo Naukowe Scholar, Warszawa 2000, pp. 231–236.

ria: legal (18 years of age), biological (ability to start a family, procreation), mental and social (a person is mentally mature enough to meet social expectations, has specific rights but also obligations with regard to society and takes responsibility for his/her actions and therefore is considered to be an “adult”).

Therefore, it should be assumed that adulthood of a person with profound intellectual disabilities has a unique characteristics. The consequence of adopting such a thesis is a specific approach to the process of supporting people with profound intellectual disabilities. The process of developing a support procedure should be guided not only by developmental age, but also by life age.¹⁰ An important problem in the support process is the recognition of the right of a person with profound intellectual disabilities (at various stages of development) to autonomy, expressed in the exercise of the right to self-determination. The ability to function independently on a daily basis, as Deborah Smith puts it¹¹, depends on the activities learned and the type of support provided. The problem we face in our reality is the social conviction that there is a need for “continuous and ongoing support” or care. Moreover, this conviction is present not only in public opinion, but also in the conduct of parents and therapists. The most common mistakes made by parents, which can be related to individuals with profound intellectual disabilities, include: lack of conditions and situations to take various actions,

¹⁰ It should be mentioned here that there is a certain “trap” – developmental age is a determinant in the treatment of children with disabilities, it is a point of reference in the selection of forms, methods and means for work, but very often developmental age dominates over the chronological age of people with profound intellectual disabilities. This is also indicated by Jolanta Lausch. – (J. Lausch-Żuk, *Terapia czy wychowanie?*, [in:] *Wczesna diagnoza i terapia dzieci z utrudnieniami w rozwoju. Interdyscyplinarne problemy*, eds. J. Kruk-Lasocka, M. Sekułowicz, Dolnośląska Szkoła Wyższa Edukacji Towarzystwa Wiedzy Powszechnej, Wrocław 2004, pp. 422–423), who mentions: too much emphasis on words, using typical childhood concepts or using diminutive elements in communication with adults with disabilities.

¹¹ D.D. Smith, *Pedagogika specjalna. Podręcznik akademicki*, T. 1, trans. T. Hołówka, A.P. Zakrzewski, Wydawnictwo APS, Wydawnictwo Naukowe PWN, Warszawa 2008, pp. 226–228.

lack of access to people, places; interference in all actions taken; nannying.¹²

Adulthood of people with intellectual disabilities is defined by Stanisław Kowalik as a “lost development zone”.¹³ According to the author, “adulthood is a very long time of a person’s life, in which nothing interesting happens. There are no new skills, mental processes have reached their peak, social relationships in which people function are fully stabilized”.¹⁴ It is reflected in the situation of people with profound intellectual disabilities, who, having attained the age of 25, are no longer obliged to attend remedial classes and thus no longer able to do so. At this point the question arises: what next? This is due to the fact that there is still a shortage of places in institutions such as community self-help homes, while in other institutions such people are not accepted because of their health status. Adulthood of such person is locked in the home and motherhood or fatherhood return to the starting point, to the situation from years ago.

Towards adulthood of people with profound intellectual disabilities – methodological findings

The aim of the research was theoretical, empirical and practical analysis of various aspects of experiencing motherhood in single mothers of adult children with profound intellectual disabilities. The analysis of the research results presented in the text was carried out in accordance with the following research problems:

- (1) How do mothers bringing up children with profound intellectual disabilities perceive their adulthood? Another re-

¹² A. Twardowski, *Oddziaływania rodziców blokujące rozwój autonomii u dzieci upośledzonych umysłowo*, [in:] *Spółczesność wobec autonomii osób niepełnosprawnych. Od diagnozy do prognoz i do działań*, ed. W. Dykcik, Wydawnictwo Eruditus, Poznań 1996, pp. 147–151.

¹³ S. Kowalik, *Dorosłość osób niepełnosprawnych w świetle koncepcji strefy utraconego rozwoju*, [in:] *Dorosłość, niepełnosprawność, czas współczesny. Na pograniczach pedagogiki specjalnej*, eds. K.D. Rzedzicka, A. Kobylańska, Oficyna Wydawnicza „Impuls”, Kraków 2003, pp. 61–78.

¹⁴ *Ibidem*, 2003, p. 61.

search problem was formulated on the basis of the theoretical assumptions presented in Diagram 1.

- (2) What is the significance of internal and external factors in the course and creation of the image of adulthood of people with profound intellectual disabilities in the opinion of their mothers (see Diagram 1)?

34 women from all over Poland were interviewed. The group of respondents included single mothers raising adult children with profound intellectual disabilities (children aged over 25). Out of 34 respondents, only three lived in a full family.

Other characteristic features of the research group are:

- age of women: 55–78 years;
- place of residence – due to the small size of the group of people with profound intellectual disabilities, women from all over Poland were included in the research;
- education – vocational, secondary, rarely tertiary; in the sample group there were both working and non-working women – more of the latter (including retired women). The number of qualitative surveys does not prove the accuracy, unlike in the quantitative methodology. The reliability of qualitative research is confirmed by the uniqueness of each interviewed person.

The research lasted from October 2015 to January 2018. The snowball method applied lead from one woman to others, also through state institutions, charities (foundations, associations), blogs and websites. The basic research technique was individual narrative interview. The respondents were asked to tell a fragment of their life or history of their entire life in the context of experiencing motherhood. The interviews were recorded on a recorder, then transcribed, and the recording procedure made it possible to listen to them repeatedly. The obtained information was analysed within the analytical procedures proposed in the well-established theory (MTU)¹⁵

¹⁵ B.G. Glaser, A.L. Strauss A.L., *The Discovery of Grounded Theory: Strategies for Qualitative Research*, Aldine Publishing, New York 1967. (Polish edition: 2009, *Odkrywanie teorii ugruntowanej: Strategie badania jakościowego*, Kraków, Zakład Wydawniczy Nomos, trans. M. Gorzko).

methodology, taking into account selected definitions of adulthood and disability cited in the theoretical part of the article.

Adult maturity – the perspective of the possibility or „coming full circle” – in the light of the results of own research

Age is one of the most common categories used to formulate a definition of adulthood, which is also demonstrated in the interviews. Mothers very often referred to the age of their children, emphasizing it as one of the important factors of their motherhood and determinants of their children's adulthood.

She's 38 years old, and I keep thinking how it went. She's grown up now, even though it is what it is [Ms Barbara]

She's 39 years old, not particularly independent, to be honest, dressing, washing... well, everything. But she is 39 years old and she is unlikely to learn more. But I don't force many things anymore, I let it go, because she's already grown up. I can see that she is also getting older, she is getting more and more tired and she doesn't feel like doing this or that, just like all of us. There is no verbal contact with her, but now that she is 39 years old, she can show what she wants. [Ms Agnieszka]

She's 40 years old and we threw her a real 40th birthday party... Because I wanted to invite her friends first of all. They came from all over Poland. [Ms Iza]

It is the age that determined the course of action and care. It encouraged women to notice and recognise the needs and choices of their children. This has a significant impact on the psychological and social functioning of people with profound intellectual disabilities. For years, the issue of adulthood of people with intellectual disabilities has been ignored or limited to solutions for young children: for pre-school and school age groups. The question arises:

what proposals do we have today for rehabilitation and education of adults with profound intellectual disabilities? Such dilemmas have appeared in the statements of women.

In the past, everyone cut themselves off from small children, from our children... And we didn't know what to do with them, because they didn't go to kindergarten, didn't go to school... Today it's different again. There are a lot of different therapies for children, even kindergartens, schools, and again there is nothing for adults. Just as for us, there is nothing. Maybe somewhere in Warsaw or in another big city... but there's nothing here... You know, as if we've come full circle. [Ms Agnieszka]

There is simply no life for our kids... Because the school ends and it seems like we start from scratch... Because once we lived a normal life, kids used to go to kindergarten, I used to go to work, but with time diseases started to appear, seizures, emotional problems, which most centres do not cope with. [Ms Zofia]

The concept of Stanislaw Kowalik's adulthood as a "zone of lost development"¹⁶ is reflected in the reality in which adults with profound intellectual disabilities function. As mothers emphasize, childhood is a period when a parent can benefit from many proposals of the educational and care sector. However, adulthood is a period when they have to return to their starting point, when what has been developed is subject to degradation.

The older he gets, the more trouble you get. I will not hide it. [Ms Nela]

If she doesn't want something, there is aggression. I learned how to deal with it, but now it's different. She is an adult, she has more strength, and sometimes I get the impression that I'm getting weaker and weaker. [Ms Agnieszka]

He's a grown man, it's not like Antoś would stay with his grandmother anymore. Now his grandmother is simply afraid of him sometimes, because he is quite strong. [Ms Jolanta]

¹⁶ S. Kowalik, op. cit., 2003, pp. 61-78.

I can't go out, because if she has a seizure, you have to give her medication, and not everyone is allowed and can do it properly, and she doesn't always accept it. [Ms Zofia]

Women emphasized that during the adulthood of their children, they experience different difficulties than before when they were younger. They pointed to the need for a different kind of support from what is available and offered to them.

I used to go out more, I had friends... But now, since my daughter doesn't go to the centre, I know that I've closed myself in. But I don't feel like it anymore, and so the two of us are getting older. [Ms Renata]

I still need support, I need it myself, even though I support these young women every day... Every mother with such a child, she doesn't need to hear: What are you saying? She won't walk? or that this child of yours is a child all her life „... I don't need pity, I just need something positive. [Ms Margaret]

Therefore, it should be concluded that the analysed adulthood requires special support and transforms the functioning of the family. It requires solutions that take into account not only the individuals with intellectual disabilities themselves, but also their carers. In one of her articles, Iwona Lindyberg¹⁷ mentions Stephen Schoen's "Psychotherapy as a sacred area" study¹⁸, in which the author uses the term "presence" written in Las Vegas inside the casino: "You must be present to win." This understanding applies to people with profound intellectual disabilities, especially their carers. This is due to a certain dependence caused by the specificity of profound intellectual disability (see Diagram 1), but it does not exclude the possibility of being treated with the same rights as others at every stage of life – something mothers in particular "fight for" every day. An attempt to analyse the two concepts: adulthood and profound intel-

¹⁷ I. Lindyberg, op. cit., 2003, pp. 279–284.

¹⁸ S. Schoen, *Psychoterapia jako obszar święty*, „Gestalt” 1992, No. 5, pp. 114–125.

lectual disability can be controversial and give rise to dilemmas. This may be due to the way in which these concepts are interpreted. The women respondents place them in a continuum consisting of three approaches: person – adulthood – disability.

She always has a choice, here she has coffee, here she has tea... But I always ask her: coffee or tea? [Ms Małgosia]

My daughter says one word: Mom. Oh, no, she's also argues with me. But lately she has been saying: 'ne you', which means she doesn't want to. [Ms Maria]

Apart from the above mentioned aspects determining adulthood and the factors that constitute it, mothers pointed to the personality traits of their children and included them in a continuum of terms: person-adults-disabilities.

Here's my little girl [...], namely [...] I don't think I should say that, because she's a grown-up woman. [Ms Małgosia]

I used to read to her, but now I prefer to talk to her, we like watching TV, she has her favourite shows, that he likes. [Ms Agnieszka]

She senses a lot, and with age, despite her condition, I know that she feels more and more in her own way. [Ms Jolanta]

As she gets older, she gets more and more huffy, she doesn't notice me if something doesn't go her way, even if I leave her in the best care and I have to leave, then when I come back, I see that she's in a huff with me. [Ms Maria]

It is difficult for people with profound intellectual disabilities to function as adults or to create their own adulthood because of the medical conditions that women have faced over the years.

I always have to be there, because if my daughter gets an epilepsy attack, not everyone knows what to do. But nobody wants to stay, although at the beginning I explained what to do... Because I wouldn't do anything else in such a situation. [Ms Agnieszka]

My daughter has to be monitored all the time, because she bites, pinches, now even throws different objects, sometimes it all gets thrown in the air. [Ms Agnieszka]

Apart from the medical aspects that determine the image of adulthood of people with profound intellectual disabilities, women speakers pointed to conditions resulting from social attitudes and opinions.

Even now I can hear: you better place her [in some institution], you've been toiling all your life. [Ms Grażyna]

I have a son who's 36 years old. But they don't always look at him as if he were a man of his age. Sometimes they talk to him like to a child, he gets nervous then, and so do I. [Ms Barbara]

People always feel sorry for me... I'm a mother, but my child is an adult. It's different, too. [Ms Aleksandra]

Adulthood of people with profound disabilities is a complex concept, conditioned and created by their carers, environment, culture in which they function.

Summary

On the way to respecting the adulthood of people with profound intellectual disabilities, there are many changes ahead of us, not only in the legal and guardianship system, but also in the social awareness. Based on the analysis of the interviews conducted so far, we can conclude that adulthood of people with profound intellectual disabilities in both subjective and objective dimensions (social opinion) is determined by the nature and level of support provided (social, psychological, information). It should be stressed that the (un)received expected support determines the psychological and spiritual condition of mothers as the only carers of adults with profound intellectual disabilities and has an impact on the quality of their lives. Adulthood of people with profound intellectual disabili-

ties in the opinion of their mothers should be considered in two dimensions: individual and community, which are interdependent and conditioned by each other. *Adulthood is a stage available to all people, regardless of the level of support they require. It is created and shaped by their carers, social attitudes, and then by themselves because of the opportunities they have. It is a concept entangled in negative stereotypes, implanted by the medical perception of disability and the medical model of therapy as well as the broadly understood rehabilitation directed to this group of people for years.*

Bibliography

- [1] Jordan B., Dunlap G., *Construction of Adulthood and Disability*, "Mental Retardation" 2001, No. 39/4, pp. 286–296.
- [2] Brzezińska A., *Spoleczna Psychologia Rozwoju*, Wydawnictwo Naukowe Scholar, Warszawa 2007.
- [3] Cytowska B., *Rodzice wobec dorosłości swoich dzieci z niepełnosprawnością intelektualną*, [in:] „Wychowanie w rodzinie. Rodzin o specjalnych potrzebach”, vol. 4, eds. S. Walasek, B. Winczura, Wydawnictwo Karkonoskiej Państwowej Szkoły Wyższej, Jelenia Góra 2011, pp. 87–107.
- [4] Czerniawska O., *Trendy rozwojowe w zachowaniu ludzi dorosłych*, [in:] *Wprowadzenie do andragogiki*, ed. T. Wujek, Wydawnictwo Naukowe Instytutu Technologii Eksploatacji, Warszawa 1996, pp. 36–46.
- [5] Glaser B.G., Strauss A.L., *The Discovery of Grounded Theory: Strategies for Qualitative Research*, Aldine Publishing, New York 1967. (Polish edition: 2009, *Odkrywanie teorii ugruntowanej: Strategie badania jakościowego*, Kraków, Zakład Wydawniczy Nomos, trans. M. Gorzko).
- [6] Havighurst R.J., *Developmental tasks and education*, New York–London, Longman 1981.
- [7] Głodkowska J., *Przestrzeń rehabilitacyjna w otoczeniu osób z niepełnosprawnością intelektualną – ujęcie koncepcyjne*, „Ruch Pedagogiczny” 2005, No. 5/6.
- [8] Wiater K., Basa B., *Losy uczniów warszawskich „szkół życia”*, „Szkoła Specjalna” 1981, No. 1, pp. 279–284.
- [9] Kopeć D., *Rzeczywistość (nie)edukacyjna osoby z głęboką niepełnosprawnością intelektualną. Zbiоровe instrumentalne studium przypadku*, Wydawnictwo Naukowe Uniwersytetu Adama Mickiewicza, Poznań 2003.
- [10] Kostrzewski J., *Charakterystyka osób upośledzonych umysłowo*, [in:] *Upośledzenie umysłowe. Pedagogika*, red. K. Kirejczyk, Wydawnictwo Naukowe PWN, Warszawa 1981, s. 110–114.

- [11] Kowalik S., *Dorosłość osób niepełnosprawnych w świetle koncepcji strefy utraconego rozwoju*, [in:] *Dorosłość, niepełnosprawność, czas współczesny. Na pograniczach pedagogiki specjalnej*, red. K.D. Rzedzicka, A. Kobyłańska, Oficyna Wydawnicza „Impuls”, Kraków 2003, pp. 61–78.
- [12] Lausch-Żuk J., *Terapia czy wychowanie?*, [in:] *Wczesna diagnoza i terapia dzieci z utrudnieniami w rozwoju. Interdyscyplinarne problem*, eds. J. Kruk-Lasocka, M. Sekułowicz, Wydawnictwo Dolnośląskiej Szkoły Wyższej Edukacji Towarzystwa Wiedzy Powszechniej, Wrocław 2004, pp. 422–423.
- [13] Lindyberg I., *O jednym z kontekstów dorosłości osób z głębszą niepełnosprawnością intelektualną, czyli w poszukiwaniu sposobu „wyjścia z szafy”*, [w:] *Dorosłość, niepełnosprawność, czas współczesny. Na pograniczach pedagogiki specjalnej*, eds. K.D. Rzedzicka, A. Kobyłańska, Oficyna Wydawnicza „Impuls”, Kraków 2003, pp. 279–284.
- [14] Marcinkowska B., *Model kompetencji komunikacyjnych osób z głębszą niepełnosprawnością intelektualną – poszukiwaniu wzajemności i współpracy*, Wydawnictwo Akademii Pedagogiki Specjalnej, Warszawa 2013.
- [15] Marcinkowska B., Wołowicz A., *Wielospecjalistyczna ocena poziomu funkcjonowania i konstruowanie programów dla osób z głębszą niepełnosprawnością intelektualną*, Wydawnictwo Akademii Pedagogiki Specjalnej, Warszawa 2010.
- [16] Schoen S., *Psychoterapia jako obszar święty*, „Gestalt” 1992, No. 5, pp. 114–125.
- [17] Smith D.D., *Pedagogika specjalna. Podręcznik akademicki, T. 1*, trans. T. Hołówka, A.P. Zakrzewski, Wydawnictwo Akademii Pedagogiki Specjalnej, Wydawnictwo Naukowe PWN, Warszawa 2008.
- [18] Speck O., *Niepełnosprawni w społeczeństwie. Podstawy ortopedagogiki*, trans. W. Seidler, A. Skrzypek, D. Gącza, D. Szarkowicz, Gdańskie Wydawnictwo Psychologiczne, Gdańsk 2005.
- [19] Twardowski A., *Oddziaływania rodziców blokujące rozwój autonomii u dzieci upośledzonych umysłowo*, [in:] *Spółczeństwo wobec autonomii osób niepełnosprawnych. Od diagnoz do prognoz i do działań*, ed. W. Dykcik, Wydawnictwo Eruditus, Poznań 1996, pp. 147–151.
- [20] Wolska D., *Stymulowanie rozwoju psychofizycznego osób dorosłych z głęboką wieloraką niepełnosprawnością*, [in:] *Annales Universitatis Paedagogicae Cracoviensis, Studia Paedagogica II*, eds. D. Wolska, A. Mikrut, Wydawnictwo Naukowe Uniwersytetu Pedagogicznego, Kraków 2012, pp. 392–399.



Doing and undoing gender by women with intellectual disabilities

ABSTRACT: Edyta Zierkiewicz, Beata Cytowska, *Doing and undoing gender by women with intellectual disabilities*. Interdisciplinary Contexts of Special Pedagogy, no. 26, Poznań 2019. Pp. 271–293. Adam Mickiewicz University Press. ISSN 2300-391X. DOI: <https://doi.org/10.14746/ikps.2019.25.13>

The aim of this article is to present socio-cultural processes of doing gender categories in women with intellectual disabilities and to identify barriers and limitations which they face on the way of „becoming women”.

The study and its analysis are based on the critical approach.

The method of data collection was a participant observation conducted during three proprietary workshops on femininity organized for 17 women with moderate to severe intellectual disabilities (5–6 people in a group), attending an occupational therapy workshop. The aim of our workshops was the empowerment of one’s own femininity and strengthening of processes of doing gender by the participants.

The analysis of collected material revealed that the process of shaping gender identities of women with intellectual disability is a subject of social control of the local community. Participants of the workshops are well aware that they are adult women and they strive for the realization of cultural patterns of femininity. In their case, however, these patterns are socially regulated and the women themselves internalize certain limitations imposed by the society during the socialization process. They instinctively “know” what they are allowed to do, and what they cannot gain as women with intellectual disabilities.

KEY WORDS: woman, intellectual disability, (un)doing gender, femininity, workshops, critical approach

Introduction

The subject of the analysis presented herein comprises processes of doing gender by women with intellectual disability, or rather barriers and limitations encountered by them in “becoming women”. This issue remains, in principle, outside the area of interests of disability researchers. In scientific publications, usually only “a student”, “a graduate”, “an adult”, “an employee” etc. or “a person” with intellectual disability is discussed as if they functioned in a utopian post-gender world, where gender no longer has any meaning. Perhaps, the researchers rather assume that other topics are more important and urgent to discuss than common, obvious issues of gender. We adopt a different position, in compliance with which, we understand gender as a social institution¹ and a structure of social relations.² “Personal identities, patterns of gendered embodiment, intimate contacts – all of these »close-up« experiential issues, which are usually the topic of discussion on gender – are constituted in the structure of gendered relations. This structure always comprises men and women and assumes different forms of masculinity and femininity”.³ Those patterns are adopted, reproduced and negotiated/transformed in social relations, where individuals and groups function.⁴ Furthermore, the quoted author explains that “gender refers to the manner in which the society copes with the human body and the reproduction process, as well as numerous consequences of this »coping« in our personal and social life”.⁵

¹ J. Lorber, *Believing is Seeing: Biology as Ideology*, “Gender and Society”, 1993, no. 7(4), pp. 568–581.

² R. Connell, *Advancing Gender Reform in Large-scale Organizations: A New Approach for Practitioners and Researchers*, “Policy and Society” 2005, no. 24(4), pp. 5–24.

³ R. Connell, *Advancing Gender Reform in Large-scale Organizations: A New Approach for Practitioners and Researchers*, “Policy and Society” 2005, no. 24(4), p. 6.

⁴ R. Connell, *Gender: In World Perspective (Socjologia płci. Płeć w ujęciu globalnym)*, transl. O. Siara, PWN, Warsaw 2013, p. 30.

⁵ R. Connell, *Gender: In World Perspective (Socjologia płci. Płeć w ujęciu globalnym)*, transl. O. Siara, PWN, Warsaw 2013, p. 31.

In the further part of the text we would like to present, how gender “works” as a social structure in the case of women with intellectual disability, that is, how it shapes (including: how it blocks) their functioning, as well as how it is perceived and doing by them. We believe, similarly to, Connell, that gender is multidimensional, liquid and can be produced by us in various ways, e.g. depending on the social context. We will present our considerations on the grounds of the data collected during three educational workshops with participation of women with intellectual disability. However, first of all, we will briefly explain the concept, which is key for our considerations.

Gender as regulatory fiction – the theoretical basis of the analysis

The concept of doing gender⁶ is usually explained as recreating by women the dominant model of femininity (and model of masculinity by men), in compliance with social expectations, however, as if it was a natural phenomenon not requiring thought or specific skills (here: gender competences⁷). The reality is different; becoming and then, “being” a woman (or a man) is a process in which the individual becomes engaged as soon as they are born and which continues throughout their life.

Many people believe that roles of women and men are not socially played, but rather biologically conditioned and therefore, universal, obvious and ahistorical. Biology, which only as of the end of the 19th century “has explained” gender differences⁸, as a science

⁶ Cf. C. West, D.H. Zimmerman, *Doing Gender*, “Gender and Society” 1987, no. 1(2), pp. 125–151.

⁷ R. Connell, *Gender: In World Perspective (Socjologia płci. Płeć w ujęciu globalnym)*, transl. O. Siara, PWN, Warsaw 2013, p. 170.

⁸ Previously, this issue was discussed mainly by theologians, according to whom “God created a man and a woman for different purposes”. Therefore, first, social inequalities constituted the adopted effect of the “Divine Law”, and when “biological differences between women and men were recognised as a scientific fact (...),

is perceived, not only by laypersons, as functioning above suspicion of any bias; it is believed to be an axiom that it simply describes natural facts. Nevertheless, as noticed by, among others, Judith Lorber, "Western ideology treats biology as the cause and the social behaviour and positions as the effect, then, it constructs biological dichotomies to justify »naturalness« of gendered behaviours and gendered social statuses. Thus, we believe what we see: two sexes produce two genders. However, this process happens inversely: the gender constructs social bodies so that they are different and unequal"⁹. Critical reflections presented by Lorber or e.g. Richard Lewontin (1996) lead to the observation that such binary understanding of the issue of sex (female/male) and gender (women/men) is an arbitrary procedure that remains in contrast to both, biological¹⁰, as well as socio-cultural reality.

Despite popularised scientific discoveries and anthropological analyses, people still, in majority thoughtlessly, refer to the strongly rooted in the western culture belief that gender is a derivative of sex that "its meanings inscribed in anatomically diversified bodies are characterised with a certain determinism, whereas, the bodies only passively wait for the implacable law to work".¹¹ The quoted author

[then,] all attempts at objection against (...) discrimination of women [proved to be] a violation of the »laws of nature«" (M. Kimmel, *The Gendered Society (Społeczeństwo genderowe)*, transl. A. Kłonkowska, GWP, Gdansk 2015, pp. 42–43).

⁹ J. Lorber, *Believing is Seeing: Biology as Ideology, "Gender and Society"*, 1993, no. 7(4), p. 568. The fact that the language of biology is biased was proved by many authors, among others, Emily Martin, who, on the grounds of the analysis of ways of describing oocyte and sperm in academic textbooks, demonstrated that the language of the scientific – seemingly neutral – description is soaked with gender stereotypes (cf. E. Martin, *The Egg and the Sperm: How Science Has Constructed a Romance Based on Stereotypical Male-Female Roles. (Jajo i plemnik. Naukowy romans)*, transl. J. Włodarczyk, [in:] „Gender. Perspektywa antropologiczna”, ed. R. Hryciuk, A. Kościńska, Warsaw 2007.).

¹⁰ E.g. M. Kimmel, *The Gendered Society (Społeczeństwo genderowe)*, transl. A. Kłonkowska, GWP, Gdansk 2015, pp. 41–88.

¹¹ J. Butler, *Gender Trouble: Feminism and The Subversion of Identity (Uwikłani w płęć. Feminizm i polityka tożsamości)*, transl. K. Krasuska, „Krytyka Polityczna”, Warsaw 2008, p. 54.

underlines that this customary manner of understanding gender constitutes a function of the discourse, which "is based on binary structures, which appear as the language of universal rationality". The fact that, until recently we could not imagine that there are more than two sexes or two genders (or that we still feel resistance thereto) results from the limitations, which are "already built-in in the notion of cultural sphere of gender allowed by language".¹² The seemingly obvious observation that sex is binary (which is supposed to be proved by primary sex features) leads to the conclusion that "»men« are (...) an addition to biologically male bodies or that »women« constitute an interpretation of solely female bodies".¹³ Therefore, for many it can be even more difficult to accept the following analytical conclusion: that "sex is always defined as gender".¹⁴ However, the author accurately explains which measures and tools are used so that the "apparatus of production and establishing sex"¹⁵ works effectively and thus, invisibly. She indicates, among others, the binarism underlining the discursive ordering of the world, including the establishment of apparent opposites: strong will – determinism, mind/soul – body, culture – nature, gender – sex, etc. The relation in this dichotomous system to some extent assumes that one element constitutes a reverse of the other, therefore, if one results from intentional intervention, the other exists independently of social action, is more primary. Stability of the biological construction of sex is guaranteed by inscribing it in

¹² J. Butler, *Gender Trouble: Feminism and The Subversion of Identity (Uwikłani w płęć. Feminizm i polityka tożsamości)*, transl. K. Krasuska, „Krytyka Polityczna”, Warsaw 2008, p. 56.

¹³ J. Butler, *Gender Trouble: Feminism and The Subversion of Identity (Uwikłani w płęć. Feminizm i polityka tożsamości)*, transl. K. Krasuska, „Krytyka Polityczna”, Warsaw 2008, p. 51.

¹⁴ J. Butler, *Gender Trouble: Feminism and The Subversion of Identity (Uwikłani w płęć. Feminizm i polityka tożsamości)*, transl. K. Krasuska, „Krytyka Polityczna”, Warsaw 2008, p. 55.

¹⁵ J. Butler, *Gender Trouble: Feminism and The Subversion of Identity (Uwikłani w płęć. Feminizm i polityka tożsamości)*, transl. K. Krasuska, „Krytyka Polityczna”, Warsaw 2008, p. 52.

the pre-discourse sphere and, therefore, in consequence, people come to believe that it is natural, inalienable and gender constitutes a specific opposite thereto.¹⁶ The power apparatus blurring traces of discursive creation of such feeling constitutes the “comprehensibility matrix”, which defines sex as “substance, being identical as self”, whereas, it hides the fact that “»being« sex or gender if fundamentally impossible”.¹⁷ Nevertheless, the majority of us thoughtlessly state that we are “a woman/feminine” (or “a man/masculine”), not noticing in this gesture the limiting activity of hegemonic discourse using the binary regulation of sexuality.¹⁸ Effectiveness of the discourse is reinforced with the presence of other fundamental belief in our culture: concerning the substantial, psychological person (“real, inner Me”). This person is “disclosed” in the statement “I am a woman” (“I am a man”) expressing the wish to be a causative subject (i.e. “being a cause for own thoughts”) and simultaneously transforming “fictitious wholes, which at the beginning had only linguistic reality” in substance.¹⁹ And thus, there is a significant shift in discourse, which leads to the conclusion that “a person is a gender in culture and that it is so due to own sex, mental feeling of self and various manners of expressing own psychological »me«, out of which the most noticeable is sexual desire”.²⁰

¹⁶ J. Butler, *Gender Trouble: Feminism and The Subversion of Identity* (*Uwikłani w płęć. Feminizm i polityka tożsamości*), transl. K. Krasuska, „Krytyka Polityczna”, Warsaw 2008, p. 53.

¹⁷ J. Butler, *Gender Trouble: Feminism and The Subversion of Identity* (*Uwikłani w płęć. Feminizm i polityka tożsamości*), transl. K. Krasuska, „Krytyka Polityczna”, Warsaw 2008, pp. 70–71.

¹⁸ J. Butler, *Gender Trouble: Feminism and The Subversion of Identity* (*Uwikłani w płęć. Feminizm i polityka tożsamości*), transl. K. Krasuska, „Krytyka Polityczna”, Warsaw 2008, p. 71.

¹⁹ J. Butler, *Gender Trouble: Feminism and The Subversion of Identity* (*Uwikłani w płęć. Feminizm i polityka tożsamości*), transl. K. Krasuska, „Krytyka Polityczna”, Warsaw 2008, pp. 74–75.

²⁰ J. Butler, *Gender Trouble: Feminism and The Subversion of Identity* (*Uwikłani w płęć. Feminizm i polityka tożsamości*), transl. K. Krasuska, „Krytyka Polityczna”, Warsaw 2008, p. 76.

A cultural requirement that all of us are subjected to (and which we are negotiating or trying to oppose) constitutes having a stable, unequivocal and, preferably, “correspondent” to our sex, identity (including: gender identity). In psychology – e.g. in Erik Erikson’s conception²¹ – it is assumed that an individual in their development process should undertake the task of self-formation (i.e. of own identity) at the relatively early stage, i.e. in the adolescence period, at approx. 16 years old. Currently, this task, as many other previously limiting adulthood, is postponed in time (memorandum), yet, still the majority of people lack the awareness that the “postulate of identity is a cultural limitation – a principle introducing order and hierarchy, in short: regulatory fiction”.²² “Women” and “men” continue to be understood as permanent substances, yet, this “substantial effect of gender is performatively created and becomes obligatory by regulatory practices of its coherence. (...) [G]ender is always an activity, however, not the activity of an individual that would proceed their action”.²³ In short, the author of the *Gender Trouble* (*Uwikłani w płęć*) states: “Gender constitutes a repeated body stylisation, a collection of acts repeated in exceptionally rigid regulatory framework, which solidify with time, creating an appearance of substance, an appearance of a certain type of natural being”.²⁴

Biological features of women and men considered as key and varied in quality, for many centuries enabled unequivocal classification of people to one of two separate social categories. In contemporary Western societies this mechanism “gets stuck”, since ideologi-

²¹ E. Erikson, *Identity and the Life Cycle* (*Tożsamość a cykl życia*), transl. M. Żywicki, Zysk i S-ka, Poznań 2004, pp. 84–90.

²² J. Butler, *Gender Trouble: Feminism and The Subversion of Identity* (*Uwikłani w płęć. Feminizm i polityka tożsamości*), transl. K. Krasuska, „Krytyka Polityczna”, Warsaw 2008, p. 79.

²³ J. Butler, *Gender Trouble: Feminism and The Subversion of Identity* (*Uwikłani w płęć. Feminizm i polityka tożsamości*), transl. K. Krasuska, „Krytyka Polityczna”, Warsaw 2008, p. 80.

²⁴ J. Butler, *Gender Trouble: Feminism and The Subversion of Identity* (*Uwikłani w płęć. Feminizm i polityka tożsamości*), transl. K. Krasuska, „Krytyka Polityczna”, Warsaw 2008, p. 94.

cal beliefs legitimising its functioning are disclosed, discussed and questioned, as well as various subversive practices with regard to the heteronormative order are undertaken. More and more people come across journalistic debates and scientific considerations regarding, whether gender is achieved, done and (in various ways) implemented and not “authoritatively” assigned. It seems that nowadays, gender is more and more often perceived as “a task to perform”, or rather a manner to express inner Me, or desirable stylisation of own body.

The explanations referred above should help us present the phenomenon of performative gender creation, i.e. the activity of regulatory fiction constituting gender with regard to persons, who are often excluded from population of “real women” or function at its margin.

Methodology

The main objective of our research, as has already been mentioned, constituted the analysis of the phenomenon of doing gender (creating gender identity), in which women with intellectual disability are engaged. The research was situated in a critical paradigm. In compliance with the critical approach, the researcher’s task is to uncover linguistic violence and hidden power relations. Women with intellectual disability encounter numerous limitations in the process of creating gender identity or even rejection in this regard from their environment. In this text we want to answer the question, how, in the case of women with intellectual disability, the process of socialising to gender roles attributed to females occurs or does not occur. Therefore, we will strive to identify moments when the mechanism of regulatory fiction usually acting through “the unambiguity of sex, internal cultural coherence of gender and binary frameworks of sex and gender”²⁵ is “stuck”.

²⁵ J. Butler, *Gender Trouble: Feminism and The Subversion of Identity* (*Uwikłani w płęć. Feminizm i polityka tożsamości*), transl. K. Krasuska, „Krytyka Polityczna”, Warsaw 2008, p. 94.

The presented research has been conducted during educational workshops aimed at supporting the process of empowering participants – women with more severe intellectual disability. While establishing the organisation of workshops, we conducted several focus interviews to distinguish areas important for adult women with intellectual disability²⁶. One of the conclusions from conducted focuses, which we would like to refer here, harmonised with findings of our researchers and it concerned numerous barriers blocking emancipatory efforts undertaken by persons with intellectual disability.²⁷ Moreover, a category of gender as “an element” repeated many times during interviews was also strongly distinguished in our results. As a result of conducted analyses, gender proved to be a meta-issue entering into “interactions” with each distinguished topic. Therefore, the interviews implied that the research participants, despite considering themselves as females, are not deemed as real women in the social context and experience many limitations in performing life roles typical for women. Due to recognising one of the most arduous and unclear for the focus interviewees’ difficulties, we decided to devote the educational workshops to the issue of femininity and thus, the identity, which they “aspire” to achieve.

To conduct the workshop (in three different groups) we had invited a professional with many years of experience in working with persons with intellectual disability, a psychologist, supported employment coach, who proprietarily selected methods and detailed contents to the topic stipulated beforehand. Our participation in the workshop consisted in observing (participant observation) and registering its course, however, we sometimes helped participants if

²⁶ B. Cytowska, E. Zierkiewicz, *Conversations about health – sharing the personal experiences of women with intellectual disabilities*, “Journal of Applied Research in Intellectual Disabilities”), 2020.

²⁷ Cf. B. Cytowska, *Difficult Ways of Adaptation. Emancipation Themes in the Analysis of the Situation of Adults with Intellectual Disabilities in the Contemporary Polish Society. (Trudne drogi adaptacji. Wątki emancypacyjne w analizie sytuacji dorosłych osób z niepełnosprawnością intelektualną we współczesnym społeczeństwie polskim)*, Oficyna Wydawnicza „Impuls”, Kraków 2012.

directly requested e.g. in drawing a picture they came up with or writing down a specific phrase on paper.

The workshop was participated by a total of 17 women with more severe intellectual disability aged 24–48 years old (3 groups of 5–6 persons), living in various environments and attending two Lower Silesian Occupational Therapy Workshops.

Each workshop lasted approx. 3–4 hours with half-an-hour break. Participation was voluntary and all participants had been asked individually, if they agreed to being recorded during workshops. Furthermore, all women had been ensured that the information would be used anonymously and the information identifying them would be omitted. Moreover, we agreed that at any moment of the project they could resign from participation in classes.

After completion, each workshop was described in details and statements given by the trainer and participants were transcribed.

Workshops for women with intellectual disability as social space for community definition of female identity

In compliance with our assumptions, the process of constructing gender identity has a relational character and is executed with specific social activities and practices, in which the entity, in the given context, engages (and is engaged). Our position is contrary to the still popular belief that femininity is a highly abstract concept category, which can be understood solely by achieving a specific level of cognitive development (i.e. formal thinking exceeding the concrete and experience, characterised with the ability to generalise, deduct and conclude).²⁸ Moreover, understanding own femininity would supposedly naturally stem from the “inside” of the individual, who, by achieving a specific level of maturity, can disclose and express this truth about oneself. In reality, since birth we participate

²⁸ Cf. J. Piaget, Inhelder B., *The Psychology of the Child (Psychologia dziecka)*, transl. Z. Zakrzewska, Siedmióróg, Wrocław 1996, p. 120.

in processes of doing gender and we acquire certain gender competences quite early, which allow us to find ourselves in the world popularised by, so to say, two separate groups: women and men.

Such dichotomous thinking of gender is still widespread in common beliefs and intensively supported by media images, and even scientific works, e.g. psychological.²⁹ Of course, there are many more social powers pressuring the individual to “properly” create their gender identity. Additionally, persons with intellectual disability are pressured to “create disability”, that is, impose on them specific beliefs regarding their ability and various, presumably protective, limitations. Analysis of the material collected during workshops allowed noticing three of such pressures, which were disclosed in the approach, beliefs and behaviours of the psychologist conducting the workshop, as the person organising and ordering the social space of the meeting and representing the institutional power. By indicating the phenomenon of “forming” objects of activity in compliance with the previously adopted vision, we do not want to criticise the person conducting the workshop, who completed the training task very well, but to draw attention to the fact that taking a certain role (here: the teacher, the trainer of the group, the organiser of the workshop etc.) entails unconsciously exercising certain pressures related to the functioning of given regimes, among others, institutional and gender. Noticing this entanglement is extremely difficult.

Therefore, first of all, our analysis disclosed the meaning of the trainer’s beliefs on cognitive and emotional functioning of participants of classes as persons with intellectual disability. These beliefs were not communicated directly but were manifested with a surprise at a lack of expected reactivity of participants of the first workshop and by changes introduced in exercises with two following groups. Secondly, the source of pressure also consisted in the professional experience of the trainer establishing her beliefs. Years of professional work enable workers to establish and main-

²⁹ Cf. R. Connell, *Gender: In World Perspective (Socjologia płci. Płeć w ujęciu globalnym)*, transl. O. Siara, PWN, Warsaw 2013, p. 110 and next.

tain contact with supported persons, but, at the same time, result in the former internalising norms and rules of the institution, which they later enforce from the latter. The third type of pressure disclosed in the analysis should be connected with the topic of workshops, i.e. defining femininity and undertaking actions with regard to biographical gender designs.³⁰

The psychologist conducting the workshop quite quickly gained "an idea" regarding cognitive abilities and limitations of participants of the first workshop (she familiarised herself with this group effectively, since she knew some of those persons earlier and she met them in her work). As, at the beginning her questions regarding who a woman is and what femininity is were not elaborated on by the participants, the trainer did not go into reasons for silence and she reached for props: dialogue cards presenting females often in unreal or symbolic manner (e.g. as a matryoshka, with a house on the head, with butterflies on the head, with a teddy bear in the belly). The exercise to which women had been invited, consisted in selecting one image from a pack of 30 cards and describing it to a colleague sitting next to them. Work in pairs was also welcomed quite reluctantly, therefore, the trainer changed the form of the exercise to work in a group. She asked participants to present their card to the others and explain their choice; to facilitate the task, the participants were asked to answer the question, what they liked about the picture (or what they did not like). Yet another time the trainer faced resistance from the group; this time, a little smaller. As it seems, participants started to get accustomed to the situation and undertook the task describing elements observed in the image to others. They mainly used simple, very precise terms, such as: "I have a lady dancing on water and she dances like this, moves her leg and hand like this. Here, she has a dress, here she has a scarf tied, here she has shoes and I like that she is dancing nicely". Other constructed this statement: "I see a woman leaning, she is watching something", without giving reasons for selecting the card. "I can

³⁰ R. Connell, *Gender: In World Perspective (Socjologia płci. Płeć w ujęciu globalnym)*, transl. O. Siara, PWN, Warsaw 2013, p. 172.

try... But I do not know, what to say. She has something on her head, I do not know, a castle. (...) Because I liked this card. Because she has something on her head, she holds something”.



Photo no. 1

The trainer did not comment behaviours and statements made by participants, she did not lecture them; she tried to adjust to them (or rather to her interpretation of their intellectual and social abilities at a given moment). However, it seems she assumed that the proposed exercises are too difficult for women and they showed a low level of language constructions and complete misunderstanding of symbolism in the pictures, since in two consecutive workshop groups the trainer changed the use of cards significantly. In the modified task, the participants could, instead of forming own opinions, use definitions signed on prepared cards (photo no. 1). The majority of studied individuals participating in all three workshops could read and those who did not manage with reading were

helped by the trainer, who gave them several propositions to choose from. Some of those were metaphorical or abstract, yet, women matched them to the selected card correctly.

The first exercise in unmodified version (group 1) and in modified version (groups 2 and 3) – allowed participants to get used to the unusual situation, relax and engage in further parts of the workshop. Women showed openness, they expressed their opinions more willingly and, if they did not hear or understand the request, they were not afraid to ask for repetition or explanation. They also started helping each other or asked the psychologist for support. In that way e.g. new terms were learned or less frequently used terms were repeated, such as: *subtlety*, *fulfilment*, *passion*, *concentration*, *longing* and similar concepts were differentiated: *love* and *infatuation*, *admiration* and *joy*.

After this part of workshops, the trainer asked all participants what they understand by femininity. The manner of giving answers varied: persons from group 1 who did not have hints in a form of cards with ready statements, used descriptive phrases, where practices and gendered activities were underlined: “A woman is pregnant”, “She has to feed, she has boobs”, “Put make-up on, get dressed”, “Taking care of personal hygiene”, “Dying hair”, “Painting nails”, “Puts lipstick on”, “A woman wears earrings”, “She is in love”, “Yes, she loves her man”. Apart from the above, the participants recalled associations with appearance, indicating the process of “creating” feminine image with the use of various cosmetics (related to makeup). It could be stated that their statements to some extent indicated the beautification regime domineering in culture, as the “natural capital” of women (gender capital, aesthetic capital³¹), and simultaneously “deciphering” that femininity is a kind of disguise³², or, as we have already written, it is “doing” in repeated behaviours, stylised gestures etc.

³¹ See. K. Huppertz, *Reworking Bourdieu's 'Capital': Feminine and Female Capitals in the Field of Paid Caring Work*, “Sociology” 2009, no. 43(1).

³² *Womanliness as Masquerade* by J. Riviere, cf. as cited in: G. Gajewska, *Masquerade of Gender, that is, Non-woman Pretending to be a Woman (Maskarada płci, czyli nie-*

In contact with two other groups, where the trainer decided to interfere in the group work to “improve” it, a significant phenomenon of relative construction of femininity and “helpful” use of regulatory fiction is observed. Participants from groups 2 and 3 in their statements on the meaning of the concept of femininity did not use phrases referring to social performance, but to psychological, internal “nature” of women. These definitions (and depictions) became available to them by: a) previously prepared cards with terms referring to personality-related feminine features, b) vocabulary suggested to them during the exercise by the trainer, and c) by own agreements made during the group discussion. Therefore, mainly two dimensions of gender regime appeared in the conversations held by participants of groups 2 and 3, called by Connell the dimension of emotions and human relations³³ (e.g. indicating that women are characterised with sensitivity, protectiveness) and the dimension of gender ideology (here: mainly the roles “assigned” to women: a mother and a wife).

Biological, but not cultural determinism? Social limitations of the possibility to “implement” gender identity by women with intellectual disability

As we have already mentioned, the majority of people do not reflect deeply on the essence of gender identity and mechanisms of creating it. It is still commonly believed that gender roles and gender result directly from primary sex features: female or male genitalia (unambiguous cases, e.g. androgyny, are “invalidated” surgically). Sex is considered to be primary and unequivocal. However, this common sense approach to women and men is difficult in use, since

kobieta udająca kobietę), “Miscellanea Anthropologica et Sociologica” 2017, no. 18(2), p. 59.

³³ R. Connell, *Advancing Gender Reform in Large-scale Organizations: A New Approach for Practitioners and Researchers*, “Policy and Society” 2005.

we meet nude persons in social situations extremely rarely – and only in this way we can state their sex. Therefore, every day we “identify” others only on the grounds of their appearance and behaviour, which can result in misunderstandings in contacts with them.³⁴ Avoiding social faux pas, difficulties or more serious problems (resulting from e.g. social ostracism due to the non-adherence to gender norms), people usually send quite clear signals regarding sex, which has been assigned to them and/or with which they identify. In the direct and indirect, via media, living environment of contemporary people, since early childhood they are presented with ideal and, much less frequently, alternative models of gender behaviours, which they should copy. Expectations regarding fulfilment of relevant roles (or rather roles corresponding with their sex) are being constantly formulated etc.

The process of doing gender happens to some extent unnoticed or not fully consciously and, in majority of cases it happens efficiently and effectively. Trajectories of gender development cease to proceed collision-free, among others, when gender designs are not or cannot be coherent with the model of femininity (or masculinity) available in the culture.³⁵ Admittedly, in the contemporary world we do observe relaxation of gender regimes and individualisation of the approach to construct gender identities, however, this case extremely rarely concerns persons with intellectual disability. What is interesting, those are the persons who are at the disposal of a considerable “subversive potential” exceeding narrow and rigid models of femininity (or masculinity). However, the use of this “arsenal” by persons with intellectual disability is objected by basically all of their social environment: parents, carers, teachers, pedagogues, psychologists, friends, neighbours and others. Therefore, they are subjected to intensified and very special social control

³⁴ M. Kimmel, *The Gendered Society (Społeczeństwo genderowe)*, transl. A. Klonkowska, GWP, Gdansk 2015, pp. 168-169.

³⁵ R. Connell, *Gender: In World Perspective (Socjologia płci. Płeć w ujęciu globalnym)*, transl. O. Siara, PWN, Warsaw 2013, p. 172.

aimed at (and resulting from) doing gender in compliance with their sex and simultaneously limiting or hindering it, that is, undoing gender.

Women with intellectual disability are identified by, among others, medical personnel or own parents, as women, because they have female genitalia. Thus, they are socialised and brought up in compliance with the binding model of femininity, however, they are more often and more intensively than their typical peers subjected to control interventions, presented to them as undertaken for their own good, for their safety, hygiene and care. Whereas, such treatments above all violate their privacy and intimacy, infringe their individual rights (including to experience their sexuality), biological functions of their bodies are subjected to stigmatisation and embarrassment. In consequence, thus repressed individuals, despite their bodies biologically maturing, almost never, in social sense, become adult women (i.e. their environment still often does not give them such status); they do not "receive" the right to enter into relations with intimate partners (the more so, to get married and start families), the right to make life choices independently and often, even to purchase basic clothes (they receive T-shirts, bras or even underpants from their mothers). And despite the fact that majority of them are not legally incapacitated, to some extent they are socially and politically made a non-person (dependent, non-adult, irresponsible) - culturally disabled. Paradoxically, or rather contrary to the assurances made by the environment (among others, parents) such hindrance or blocking (in social and political context) gender identity implementation and limiting it to physiological and sexual functions of body (especially, to the "nuisance" with menstruation, "danger" of getting pregnant, "horror" of starting sexual life) is executed due to the interest of all of the other persons apart from the woman with intellectual disability.

We refer to the important and uncomfortable for many social entities, issue, since it shows how complex the matter of creating gender by persons with intellectual disability is. The physiological aspect of their functioning is so deeply "naturalised" that they be-

come to some extent “biology of their organism”, that is, females, who – for many never – should not become cultural individuals: women. What for typical persons is only a starting point, for them is to be the ending point. Of course, it is not possible to implement such dystopian postulate, therefore, women with intellectual disability have a considerate subversive potential, as they create other, different, exceptional, marginal, alternative etc. gender identities significantly different from the dominant model and thus, they show that this model is only a certain cultural construction and not a biological and cultural destiny of each female.

The objective of our workshops was to start a conversation with women with intellectual disability on the topic of their possibilities in doing gender and mutually explore factors blocking such processes. Therefore, the next task proposed by the trainer consisted in, generally speaking, the participants situating themselves as a woman in social reality and more accurately: in social roles.

The psychologist asked women from group 1 to draw themselves and then to draw persons with whom they have close relations and at the end to write their characteristic features in the drawing (persons who had difficulties with writing dictated the text to the trainer). This task was not successfully completed by the group; one woman refused drawing, the other wanted to destroy the picture, because she was not happy with it (“I look like a tramp”), and the other stated that it did not look like she wanted, although, after a moment she found similarity to her mother in the self-portrait. While observing drawing women, one paradoxical phenomenon was noticed: on the one hand, they were in general happy with the drawing; however, on the other hand, in various ways, they expressed disappointment with the results or rather, they communicated dislike to themselves and low self-esteem. This situation is only seemingly contradictory and atypical. In fact, a majority of women do not accept their appearance; cultural ideals of feminine beauty are very difficult to achieve and in comparison to such models one should refer while assessing own image. Participants of this training expressed these cultural mandates they regu-

larly come across in the mass media and not only. To some extent, they even played with this dissatisfaction, as if they performed for themselves and their friends.



Photo no. 2

Despite undertaking the activity of drawing, the subjects from group 1 did not want to talk about themselves or to write down their characteristic features, therefore, the person conducting the workshop had to change this formula and proposed that the participants wrote down attributes admired and appreciated in their colleagues in the group (photo no. 2). This task was performed by the participants more willingly. They described their colleagues only with positive features: “she is polite, cheerful”, “she is smiling, laughing”, “kind”, “nice”, “she is pretty”, “lovely”, “she is a good colleague”, “a woman”, “friendly”. When features enumerated by their colleagues were read out, the described participants were visibly happy – they had been openly appreciated.

turned directly to the particular person. They did not refer to the category of femininity as key to characterise themselves or their social relations. The situation was completely different in groups 2 and 3, where a story was made up about an imagined, single female as if symbolising the whole population of women. This type of exercise reinforces the gender regime and refers to certain perceptions concerning social expectations formulated with regard to women. However, participants of both groups evidently used their own resources, therefore, doctors appear among important persons with whom they have relations. "Facilitating" or perhaps "enabling" work with workshops' participants, the trainer clearly directed them to cultural socialisation strategies and reinforced gender regimes.

Summary

When a child is born, in common perception, in fact, a girl (future woman) or a boy (future man) is born. From the very beginning, parents and other persons from the child's environment undertake actions that will create proper, in terms of gender, environment, among others, they buy specific toys (dolls or cars), they dress her/him in clothes adjusted to sex (skirts or trousers), pay attention that they use proper grammatical forms, as well as daydream with the child about his/her adult life: occupation, family (of course, heterosexual) and children that will be born from this relationship: a girl or a boy. The whole process is smooth and almost unnoticed, however, only if "everything is fine" the child, or rather it is able to adjust to the existing normative order. However, if the child is "different" e.g. homosexual, transgender or has intellectual disability, this process "gets stuck" and is distorted and particular stages of socialisation are not automatic, they are even blocked by carers as undesirable.

Special "others" do not have social consent to, among others, get married and have children (and if the latter happens, then, as in the case of women with intellectual disability, children are taken from them and given up for adoption). They are not allowed to routinely

undergo the “natural” social process; nevertheless, they do undergo this process, yet, differently. Thus, their presence in the society discloses existence of the cultural socialisation mechanism, which results in effectively engaging social entities in “gender doing” processes and therefore, in responding to the call to embody and internalise gender norms. Nevertheless, it seems that in majority, carers of persons with intellectual disability concentrate so much on controlling their behaviours or desires that they do not notice the potential of persons under their care, which is revolutionary with regard to the social order. Besides, it is not something desirable for them and for the whole environment. However, they cannot allow to completely ban their disabled children from forming gender identity, since our whole life is lived within the gender system, which operates through images, language, relations, behaviour, appearance etc.

At the same time, in the case of women with intellectual disability, being recognised as women is often an aspirational objective they link with adulthood, freedom of choice, independence and full rights. However, due to considering them as persons with intellectual disability they are refused to “be” (“real”) women. Therefore, usually, they acquire only a certain scope of gender competences, so as to make it possible to recognise, where the social barrier between “being” a woman and “being” a disabled (woman) was set. Paradoxically, our workshops allowed disclosing both of these processes: doing gender in compliance with the dominant models of femininity, which was actively participated by the psychologist conducting the training and undoing gender, which constituted participants’ response to reaching the invisible barrier separating them from implementing the call imposed on (almost) all women.

Bibliography

- [1] Butler J., *Uwikłani w płęć. Feminizm i polityka tożsamości*, transl. K. Krasuska, Krytyka Polityczna, Warsaw 2008.
- [2] Connell R., *Advancing Gender Reform in Large-scale Organizations: A New Approach for Practitioners and Researchers*, “Policy and Society” 2005, no. 24(4), pp. 5–24.

- [3] Connell R., *Socjologia płci. Płeć w ujęciu globalnym*, transl. O. Siara, PWN, Warsaw 2013.
- [4] Cytowska B., Zierkiewicz E., *Conversations about health – sharing the personal experiences of women with intellectual disabilities*, “Journal of Applied Research in Intellectual Disabilities”, (in review)
- [5] Cytowska B., *Trudne drogi adaptacji. Wątki emancypacyjne w analizie sytuacji dorosłych osób z niepełnosprawnością intelektualną we współczesnym społeczeństwie polskim*, Oficyna Wydawnicza „Impuls”, Kraków 2012.
- [6] Erikson E., *Tożsamość a cykl życia*, transl. M. Żywicki, Zysk i S-ka, Poznan 2004.
- [7] Gajewska G., *Maskarada płci, czyli nie-kobieta udająca kobietę*, “Miscellanea Anthropologica et Sociologica” 2017, no. 18(2), pp. 53–64.
- [8] Huppatz K., *Reworking Bourdieu’s ‘Capital’: Feminine and Female Capitals in the Field of Paid Caring Work*, “Sociology” 2009, no. 43(1), pp. 45–66.
- [9] Kimmel M., *Spółczesność genderowe*, transl. Anna Klonkowska, Gdańskie Wydawnictwo Pedagogiczne, Gdansk 2015.
- [10] Lorber J., *Believing is Seeing: Biology as Ideology*, “Gender and Society” 1993, no. 7(4), pp. 568–581.
- [11] Martin E., *Jajo i plemnik. Naukowy romans*, transl. J. Włodarczyk, [in:] *Gender. Perspektywa antropologiczna*, ed. R. Hryciuk, A. Kościańska, V. 2, Warsaw 2007, pp. 33–49.
- [12] Piaget J., Inhelder B., *Psychologia dziecka*, transl. Z. Zakrzewska, Siedmioróg, Wrocław 1996.
- [13] West C., Zimmerman D.H., *Doing Gender*, “Gender and Society” 1987, no. 1(2), pp. 125–151.



Children and adolescents with a chronic condition in the public school space – in search of an effective model of psychopedagogical support

ABSTRACT: Hanna Krauze-Sikorska, *Children and adolescents with a chronic condition in the public school space – in search of an effective model of psy-chopedagogical support*. Interdisciplinary Contexts of Special Pedagogy, no. 26, Poznań 2019. Pp. 205-318. Adam Mickiewicz University Press. ISSN 2300-391X. DOI: <https://doi.org/10.14746/ikps.2019.25.14>

Chronic condition may, in time, become a specific kind of „stigma” that determines the formation of a specific “conveyor belt” which determines the trajectories of the fate of children and adolescents. Analysing the functioning of children and adolescents with a chronic condition, for which the school should provide (as for other students) the conditions of learning, both in the cognitive and in the directional aspects, one may indicate not only the imperfections of educational activities, but also a myth of noble ideas inscribed in the function of school, as a place of universal development of every student. The article is a proposal of employing, within the process of educating children and adolescents with a chronic condition, an eclectic model of activities, based on their complexity and sequentiality. The model refers to models proposed by Frederick C. Thorne, or Richard James, used in situations of crisis intervention: the equilibrium model, the cognitive model, and the social change model.

KEY WORDS: chronic condition, psychosocial issues of students with a chronic condition, the model of supporting children and adolescents with a chronic condition in the educational and social space of the school

Introduction

A chronic condition, is one of the most traumatic experiences, both for a child and an adolescent. It may become a sort of a “stigma” that determines the constitution of a specific “conveyor belt” (one issue makes way for other issues), which determines the trajectories of the fates of the children and the adolescents.

For many years, schools have struggled in search of effective educational solutions, however, the issues related to the necessity of an effective support for children and adolescents with a chronic condition, not always echo in these activities, that would enable these students to fulfil themselves as fully-fledged participants of the process of learning – teaching, as well as, would allow to gather experiences, that would allow for a feeling, that they are not simply members of peer groups, but also of the school community.

Empirical studies indicate, that for many students with a chronic condition, the problem is not related solely to receiving optimal support in a given phase of education, but it also includes receiving proper support while traversing from one educational phase to the other. The lack of efficient support is a barrier for a progressive, versatile development, as the chronic condition, by excluding the student from the school community, turns the return to school to a constant re-adaptation, that helps neither the realisation of the possessed cognitive potential, nor “being among others, with others, and for others”. Unfortunately, the transition often contributes to the generation of subsequent issues of essential significance regarding the psychophysical well-being of children and adolescents with a chronic condition.

Therefore, maybe the teachers and the experts, that support the student in school, should search for the answers to questions regarding issues such as, *“To what degree, in school, is the basic right of the student with a chronic condition respected, not only to learn, but primarily, to learn with others, according to the principles of respecting others, being responsible for performed tasks, and developing own self?”*, *“Can the student with a chronic condition, experience the systemic sup-*

port?", "To what degree can the student with a chronic condition, experience friendliness, efficiency, and the modern character of the forms of support?", and "Does he really have a feeling, that school is a place, where he takes an important place, is among others, however, with retaining his original self?". Unfortunately, these questions appear as if contrary to the theoretical premises of integration, inclusive education, and social inclusion¹, as well as, to legal acts. However, the answer to these questions, creates an opportunity to build the grounds for such a model of school education, that would aid the learning and the self-accomplishment of students with a chronic condition, resulting in creating a school that is favourable to such students.

“Lebenswelt” and sub-universes – on the multi-dimensional nature of the “lifeworld” of children and adolescents with a chronic disease

The term “Lebenswelt” was introduced by Edmund Husserl, who indicated, that each man has his “Lifeworld”, that he assumes as something obvious.² Expanding the semantic range of the term, Alfred Schütz indicates, that the basis of the interpretation of the world is the personal and social experiences, which serve as a scheme of reference. The knowledge of the world, respectively, to the development phase of the human, and the specifics of his psychophysical functioning, is, of course, diverse; limited, fragmentary,

¹ The analysis of terms: “integration”, inclusion, or inclusive education, used not only in pedagogy, allows to notice their diverse definitions, and the abundance of often co-occurring instances (e.g. social inclusion, educational integration, social integration, partial integration), that fail to help using these terms in practice. M. Bowen and J. Thompson e.g. note, that the terms educational, or social integration in relations to the actions aimed at the integration of persons with disorders with able-bodied persons, should be used with great care, as it suggests, that the individuals, that it refers to, are different, worse, and already excluded from the general system of educational services (2000, s. 66).

² E. Husserl, *Kryzys nauk europejskich*, Wyd. S. Rolewski, Toruń 1999, p. 53.

scantly coherent, often characterised by the common sense attitude, or wishful thinking about the world that is in us, and the world that surrounds us.

However, despite these differences, the world, both the physical and the social, does not cease to be an inter-subjective world, and our knowledge about it was learned through the process of socialisation. According to Alfred Schütz, the common existence in the world allows us to perceive the Other, not as an organism, but as a "fellow-man", and his "(...) its overt behavior not as an occurrence in the space-time world, but as our fellow-man's action (...)"³ Additionally, Schütz believes that "(...) we normally 'know' what the Other does, for what reason he does it, why he does it at this particular time and in these particular circumstances. That means that we experience our fellow-man's action in terms of his motives and goals"⁴ Their understanding, such as the understanding of all types of actions, demands, that we look at them from the perspective of a particular individual's biography, and the subjective meanings, ascribed by the individual to choices, motives, and the goals of actions. Additionally, such approach, related to the understanding of the Other, demands an insight into areas of reality, different than the "Lebenswelt", with every area having its own specifics. *Sub-universes*⁵ are spheres defined by way of perceiving objects, different for every individual. Each of the sub-universes; the world of health and diseases, the world of ideal relationships, the world of individual views and fantasies, however, also the world of science, religion, or myth, are sub-universes that should be coherent and compatible,

³ A. Schütz, *O wielości światów. Szkice z socjologii fenomenologicznej*, Wyd. NOMOS, Kraków, 2008, p. 9.

⁴ Ibidem.

⁵ A. Schütz uses the *sub-universes* term referring to W. James' conclusions, who indicated that, depending on the ways of experiencing the surroundings, a number of spheres of reality may constitute, characterised by a specific, different from the others, way of existing, determined by the different way of perceiving them by the individual, and the actions, that are initiated by the "actor" that functions in these sub-universes.

however, at times, they function in a separate way. They constitute both the stage, and the object of actions, and of the interactions of the individual – the actor. The actor may change the sub-universes/sub-universe, however, the sub-universe may also change him.

Here, one should highlight, that the way the children and the adolescents, for whom a condition **is not** an inherent element of their everyday lives, understand the concept of a condition, as well as, the state that they are currently in, depends on the level of their development, and on their experiences; along with age, their content range expands, the information is organised in a coherent structure, and their character, from being particular, turns increasingly abstract.⁶ Between ages 2 and 7, a condition is usually perceived as a phenomenon that exists outside of the body, that can enter it, or as a result of contracting illnesses, that exist in close proximity to the body and may attack just before the condition appears. When speaking of a condition, little children refer to their previous experiences, and identify its cause in cold air, germs, simultaneously, rejecting bad behaviour as the cause of a condition⁷, which also results in the child's way of thinking about the treatment process. In this case, from the viewpoint of a child, during the period of early and moderate childhood, it is imperative to create certain rituals, related, e.g. with frequent washing, or ventilating rooms.

Between ages 7 and 11, the condition is increasingly defined as something, that may be contracted, however, also that something be treated; the condition "leaves", when the medicine is taken, or certain prescriptions are followed. Children at this age often perceive a condition as a reversible phenomenon. During the period between ages 10–11, children begin to differentiate the somatic and the psychological conditions clearly, indicating that people with somatic conditions should be treated medically, while people with psycho-

⁶ R.J. Thompson, K.E. Gustafson, *Adaptation to Chronic Childhood Illness*. American Psychological Association, Washington DC. 1999.

⁷ Zob. np. M.C. Roberts, W.B. Beidleman, S.K. Wurtele, *Children's perceptions of medical and psychological disorders in their peers*, "Journal of clinical child psychology" June 1981, 10(2), pp. 76–78.

logical issues should receive different kind of help. However, a condition as an internal process of psychophysical nature, is not recognised until age 11.

The studies, dedicated to health and illness, conducted by M. John-Borys, on a group of 120 adolescents, between ages 12 and 14, indicate that the majority of youth in the period of early adolescence, not only is capable of explaining the concept of a condition, in accordance with its scientific meaning, but also can indicate its diverse symptoms, including: somatic and pain conditions, vital exhaustion, sadness, depression, the lack of interest in other people, changes in external features, as well as, anxiety and insecurity.⁸

Analysing the perception of health and illness by children and adolescents, one must always consider its complexity and multi-dimensional nature, as they are affected by both internal and external determinants.

To summarise this aspect of inquiries, it is advisable to studies indicating that:

- (1) younger children, consider themselves healthy or sick, when someone tells them about it, or, when they recognise symptoms, that occurred before; they also list symptoms related to the physical aspect of health, to a much higher degree, than older children; and the concepts of health and illness themselves, they define on the basis of own experience (they do it much more often, than older children and adults);
- (2) older children define the concept of health with more precision; they also consider its various aspects, which is related to their increased knowledge; however, their communicational competencies are of significance as well;
- (3) children more often understand health, not as a “lack of illness”, but as a “well-being”;

⁸ M. John-Borys, 2002, cyt. za: H. Krauze- Sikorska, *Dorośli w świecie dziecka chorego terminalnie*, [in:] *Świat małego dziecka. Przestrzeń instytucji, cyberprzestrzeń i inne przestrzenie dzieciństwa*, red. H. Krauze-Sikorska, M. Klichowski, Wyd. Naukowe UAM, Poznań, 2017, pp. 143-154.

- (4) while describing the concept of health, adolescents refer to well-being, the ability to perform various activities, but also to various emotional states. Creating subjective concepts of health and illness, they indicate physical and energetic (body, the organism, the dynamics of action), psychological (emotions, experiences, feelings), and social (interpersonal and task-oriented) components;
- (5) the older the child, the more the concept of health is identified with the concept of the mother's health.⁹

The studies regarding the concepts of health and illness, evolving with age, allow us – adults – to understand the essence of the perception and the definition of these phenomena, by children and adolescents. However, one should realise the fact, that we are entering an area that is enormously difficult to study, as, for people who did not have long-term health issues, these concepts are but a small piece of their knowledge about the Self and the world, while in terms of children with a chronic condition, these concepts become one of the most important life issues. The concept of illness is strictly related to how they perceive their own condition; a cognitive structure is created, which some authors refer to as, not only an image of own condition, but its theory.¹⁰

Richard Lau and Karen Hartmann indicate, that within the structure of representation of own condition, one may distinguish five elements: (1) the identification of a condition, i.e. a name (label) given to the condition and its symptoms by the person with the

⁹ R. Kalnis, *Love Children's concept of health and illness – and implications for health education*, "Health Education Quarterly" no 2-3, 1982, pp. 104-115; M. John-Borys, *Koncepcja zdrowia i choroby u dorastających*. Wydawnictwo Uniwersytetu Śląskiego, Katowice 2002; B. Wojnarowska, J. Mazur, A. Kowalewska, H. Kołoto, A. Małkowska, *Zachowania zdrowotne i postrzeganie szkoły przez młodzież w Polsce w 2002 r. Raport techniczny z badań*. Wydział Pedagogiczny Uniwersytetu Warszawskiego, Warszawa 2012.

¹⁰ E.D. Hale, G.J. Treharne, G.D. Kitas, *The Common-Sense Model of self-regulation of health and illness: how can we use it to understand and respond to our patients' needs?* "Rheumatology", Volume 46, Issue 6, June 2007, ss. 904-906, <<https://doi.org/10.1093/rheumatology/kem060>> [access: 11.04.2019].

condition; (2) the beliefs regarding its causes (hereditary, internal, external); (3) the expectations regarding the duration and the course of the condition; (4) the expected results and the consequences of the condition; (5) the belief regarding the possibility of curing and /or controlling the condition.¹¹

John Weinman, Keith Petrie, Rona Moss-Morris, and Rob Horne, while discussing the essential aspects of a condition, that determine the perception of it, list the severity of the condition, its dependency on the behaviour of the individual with the condition, the ability to affect its course, the estimated time of its duration, and thinking of the condition in a coherent and logical way.¹²

In the case of children and adolescents, many of the aforementioned aspects may be deformed by the cognitive, emotional, and behavioural components, affecting the behaviour initiated in situations of experiencing illness and discomfort.

In cases of many individuals with a chronic condition, their progression is multi-stage; the condition may be a result of disorders appearing during the prenatal, or perinatal phase; they may also occur in the postnatal phase, e.g. due to the organism's prior vulnerability to pathogenic factors. In the last case, a significant meaning may be ascribed to the law of "clearing pathway" ("torowanie drogi"), and the law of „background" ("tło")¹³, while in other cases,

¹¹ R.R. Lau, K.A. Hartman, *Common sense representations of common illnesses*, "Health Psychology" 1983, 2(2), s. 167–185, <<http://dx.doi.org/10.1037/0278-6133.2.2.167.pdf>> [access: 5.03.2019].

¹² J. Weinman, K. Petrie, R. Moss-Morris, R. Horne, *The Illness Perception Questionnaire: A New Method For Assessing The Cognitive Representation Of Illness*, "Psychology and Health" 1996, 11(3): 431–445 <https://www.researchgate.net/publication/251957846_The_Illness_Perception_Questionnaire_A_New_Method_For_Assessing_The_Cognitive_Representation_Of_Illness> [access: 3.03.2019].

¹³ The law of *clearing pathway*, is related to the decrease of the immunity of the nervous system under the influence of a prior "clearing" occurrence of unfavourable factors. E.g. respiratory disorders are much more dangerous to children from pregnancies with complications. It is, because the defensive and compensatory mechanisms, weakened by the factors that damage the CNS, break down under the pressure of subsequent pathogenic factors. The other regularity, referred to as the

it manifests “unexpectedly” in the later period of life, however, with its determining factors possibly appearing much earlier. In the second case, the signals coming from the body, are not perceived properly, neither by the young people, neither by the parents. Instead, wishful thinking appears, referring to various aspects, indicated by the example sayings of adults and adolescents: “I am just having a bad day”, “I have been doing great so far, it is just a temporary issue”, “It will go away”, “You have never had any health issues”, “I do not understand why you feel so bad today, everything was fine yesterday, so it is probably nothing big”.¹⁴

Additionally, the child’s feeling of being unwell is often referred to school issues that appear (in various aspects), and often, they are considered to be the primary factor of the child/student’s malaise (“are you simply not trying to get away from school, this condition of yours happens a bit too often”).

Even when the parents/guardians decide for a medical diagnosis, they do not always receive information that would allow them to direct further actions, and look for professional support from experts. A significant diagnostic difficulty, not only of medical nature, may be the phenomenon, occurring in numerous chronic conditions, known as “waxing-waning”¹⁵; the increase and decrease of symptoms. The symptoms of the condition, may gradually increase, some of them decline, or “withdraw”, being replaced by others. The phenomenon of the amplitude of the amount and the intensity of particular symptoms, prevents diagnosis, as well as, taking effective action.

However, always, health issues that gradually limit the physical activity, influence not only the cognitive, emotional, social, or motivational processes, but also the self-image.

law of background, indicates the unfavourable influence of the pathogenic factors that occur simultaneously with the primary factor; they enhance its strength.

¹⁴ All the mentioned statements come from the author’s own study.

¹⁵ Zob. np. H.U. Wittchen, R. Lieb, H. Pfister, P. Schuster, *The waxing and waning of mental disorders: evaluating the stability of syndromes of mental disorders in the population*. “Comprehensive Psychiatry”, 2000 Mar-Apr; 41(2 Suppl 1), pp. 122-132.

Student with a chronic condition in school – expectations and needs, and the possibilities of their realisation

Education, focusing the concepts of learning, education, and teaching, is a process, which Zbigniew Kwieciński defines as a general assortment of activities related to leading the other person, allowing him to develop, to make use of his potential, which helps shape his identity, and become a member of various communities, e.g. social, national, cultural. Analysing the functioning of children and adolescents with a chronic condition, for whom the school (as for other children) should provide the conditions for learning, both in the cognitive and the directional aspect, one may indicate not only the imperfections of educational activities, but also the myth of noble ideas inscribed in the function of school¹⁶, as a place of universal development of every student.

Polish school has a problem with the tolerance regarding all forms of diversity, and difference between pupils¹⁷, which translates significantly both to the didactic issues of children and adolescents with a chronic condition, who have difficulties not only in meeting expected standards, but also in experiencing the acceptance of their *alterity*, by their peers.

The negative effects of the experiences, and the accompanying feeling of failure, regardless of the discipline, to which they refer, significantly determine the functioning of these students, not only “here and now”, but also in the subsequent phases of life and education; they influence the entirety of their development and may, in time lead to developing the *adaptive decompensation syndrome*.¹⁸

¹⁶ Z. Kwieciński, *Socjopatologia edukacji*, Wyd. Trans Humana, Olecko 1995, p. 14.

¹⁷ M. Dudzikowa, *Mit o szkole, jako miejscu wszechstronnego rozwoju ucznia. Eseje etnopedagogiczne*, Oficyna Wydawnicza „Impuls”, Kraków 2001.

¹⁸ Zob. H. Krauze-Sikorska, *Wsparcie społeczne w sytuacji wystąpienia Syndromu Adaptacyjnej Dekompensacji u dzieci i młodzieży z niepowodzeniami szkolnymi*, [in:] M. Piorunek (ed.), *Pomoc – wsparcie społeczne – poradnictwo. Od teorii do praktyki*, wyd. Adam Marszałek, Toruń 2010, pp. 407–427.

Unfortunately, the studies yield no optimism. The overview of the school reality, after conducting a study within a group of 50 children of early school age, and 50 children of school age, with asthma and/or atopic dermatitis¹⁹, indicated numerous unfavourable areas of school functioning, that had essential impact on the choices of the aforementioned students regarding educational and social challenges.

In the studies²⁰, which encompassed two phases, the quantitative-qualitative approach was applied. In phase one, due to the interviews with the teachers of the examined children, and the observations of their lessons, it was possible to gather information regarding the teachers' working strategy. In this phase, abundant material was provided by the observation of students with asthma and/or atopic dermatitis during their stay at school (in various educational and social situations). Phase two of the studies, allowed to evaluate the educational and social situations, from the perspective of a student with a chronic condition.

In the analysis presented below, I focus primarily on this element of the studies, which indicates the experiences of the students, and their viewpoint regarding school.

The below average school achievements are experienced by 25 children of early school age, 37 children speak of being significantly overburdened by studying; 35 students declare difficulties in studying, 25 declare a high level of fatigue from studying, the lack

¹⁹ According to WHO data, there are c. 300 million people with asthma, and the number is increasing, to reach 400 million by 2025. The condition affects people of all races, both sexes, and people of all age. In Poland, according to ECAP estimates, the condition affects 4 million people, being the most common chronic condition of children and people up to the age of 30. See. P. Dąbrowiecki, I. Kupryś-Lipińska. D. Łęcka, *Raport, Astma ciężka. Sytuacja pacjentów w Polsce POCHP*, Wyd. Novartis, 2015, <https://www.astma-alergia-pochp.pl/download/Raport_Astma_Ciezka_maj%202015.pdf> [access: 19.05.2019].

²⁰ The study was conducted in 2017–2018 in public elementary schools, in urban and country environments: both the selection of the groups of students, and the groups of teachers, was intentional – the teachers were working with persons affected by asthma and/or atopic dermatitis.

of acceptance from peers (isolation within the group) is indicated by the experiences of 18 persons, the cases of bullying was experienced by 10 children, while the lack of interest “with me as a Person”, on the teachers’ part, by 17 children.

The values increase respectively to the age of the students. The below average school achievements are a problem of 37 students between 12 and 15 years of age. 40 students declare being overburdened with work, 41 persons experience difficulties in studying, 40 students indicate fatigue from studying. Additionally, one may note an increase of indications related to the lack of acceptance from peers - 32 students, experiencing peer violence - 17, or the lack of interest in the student as a Person, on the teachers’ side, felt by the youth - 28.

These factors determine secondary issues. Difficulties appear, in the transition between educational phases (from the early school phase, to the school phase), in the adaptation to the new environment, and in perceiving the school space as a place that is friendly to students with a chronic condition. As stated by Kasia “(...) *I like to study, but I’m not sure if I like school (...) no, I have no friends, but I get sick a lot, that is probably it (...) the teacher is nice, but she is the only one saying ‘look, Kasia is back, we will all help her, so that she feels nice with us... I don’t want to be nice, because the kids will not understand anyway, and Zosia said, that I don’t bother them, but they still won’t play with me, and when we have a workout, or they dance, I stand in the corner (...) but, you know, I have asthma (...)*” [age 8]

The student’s satisfaction drawn from learning, is always related to the fact, that he is learning reflectively, that he is looking for a sense, and the understanding of the surrounding world, sharing his new knowledge with others, and using dispersed knowledge. In reality, it often turns out just as Jarek says “*Im sick often, and I have to learn by myself (...) sometimes my mum helps me, and sometimes my tutor (...) in general, I am not doing too bad...*

My teacher says that I must involve myself in various activities in the classroom (...) wonder how? Even, if I am in a group, the guys say, that I am working too slow (...) once I made a poster (you know, it turned out

nice, my mum helped me find a lot of materials), still no one could pick it up from me, and I was sick again. So tell me yourself 'what for'?!"

[Jarek, age 9, asthma, immunological issues, he is often excluded from school life]

Just by analysing the given examples of the children's statements, one may notice the overlapping, in the case of a condition, crisis situations resulting in the fact that: (1) school situations get out of control quicker; (2) new blockades in learning cause the appearance of masks, stiffness and superficial behaviour; (3) the student receives and sends many false messages; (4) he does not cope well with polarised emotions; (5) the complicated nature of his relations to the environment increase.

Here, Tomasz Szkudlarek²¹ speaks of a peculiar "incompatibility of the student with the school", however, it seems that one must clearly highlight the specific biofeedback; the student has difficulties in finding himself in the school space, but the school does little in order to change the situation.

However, (1) ignoring the difference between students by being blind to them; (2) the lack of the individualisation of educational activities; (3) didactic work focused on those, who follow the curriculum at a normal pace; (4) the silent treatment - marginalising the increasing irregularities in the student - student, student - teacher relations, and expecting nothing but obedience in the classroom; (5) stigmatising and discrimination - labelling students and dooming them to fail; (6) *suggesting* children with a chronic condition, to take up individual education, quickly leads, within this group of students, to the feeling of learned helplessness.

To this last point, one may refer the official statement of the Ombudsman for Children (Rzecznik Praw Dziecka), who, in reference to the Convention on the Rights of the Child, ratified by Poland, notes, that ascribing a child's education to a particular place results in: (1) the violation of the right of the child to live in condi-

²¹ T. Szkudlarek, *Pedagogika krytyczna*, [in:] Z. Kwieciński, B. Śliwowski (eds.), *Pedagogika*, vol. 1. Wyd. Naukowe PWN, Warszawa 2003, s. 370-374.

tions that guarantee dignity, allow to achieve independence, and aid in the active participation in the life of the society; (2) the lack of help provided to the child; help exercised in a way leading to achieving the highest degree of integration with the society, as well as, ensuring the child's personal development.²²

Within this background, the studies of Barbara Olszewska are situated²³, who studied the opinions of teachers regarding the educational situation of children with asthma (the analysis addressed their knowledge regarding the health and social problems, related to this group of students). The study was conducted on a group of 150 teachers employed in elementary and middle schools in the Łódź Voivodeship. Based on the information from the respondents, one may notice, that the teachers did not participate in training, or courses, that would bring them closer to the issues that are occur most frequently in cases of children with chronic conditions, including asthma. In the group examined by Olszewska, 63% of respondents does not now, or "is not sure", whether there are students with asthma among their pupils. The majority of them could list the right, and most frequent symptoms of the condition, that occur in cases of children, however, they worried, that their "overheard"

²² According to a PKPD entry, there is a possibility of the participation of a child in the school environment, as paragraph 9 states, that the "Children and adolescents within the individual pre-school education, or individual teaching, whose state of health severely handicaps their presence in pre-school or school, for the purpose of their integration with the environment and providing them with comprehensive personal development, the principal, within his capabilities, considering the prescriptions included in the opinion, and the current health, organises various forms of participation in the life of pre-school and school, in particular, allows the participation in extracurricular activities, celebrations, and school events. Cf. The Statement of the National Association of Management Staff in Education on the organisation of the individual education of children and adolescents (Stanowisko Ogólnopolskiego Stowarzyszenia Kadry Kierowniczej Oświaty w sprawie organizacji nauczania indywidualnego dzieci i młodzieży); <www.oskko.edu.pl> [access: 01.02.2019].

²³ B. Olszewska, *Uczeń z chorobą przewlekłą – zakres świadomości i odpowiedzialności działań edukacyjnych*, „Kultura i Wychowanie” 2011, 1, pp. 234-244.

knowledge was not sufficient. In response to the question: "Why do they not display involvement in providing help to students with a chronic condition?", they indicated, i.a. that they fear the responsibility for the condition of the child, and the problem lies with the parents, that do not report any issues (therefore, they presume, that the child manages well); they also raised a point, that "the child's condition is an embarrassing subject", and so, if a parent doesn't report any problems, the teacher won't create one.

Therefore, considering the factors that determine the issues regarding the student-school environment mutual compatibility, it is advisable to seek for efficient solutions, however it will not be made possible without an agreement between the teachers, the parents of children with a chronic condition, and experts, an agreement based on competencies, mutual trust, and the open attitude towards activities, allowing to determine the scale of the health, and non-health issues of children and adolescents.

The (Un)Realness of the effective support for a student with a chronic condition, in a school reality

According to, not only theoretical principles, or solutions prescribed in the Salamanca Statement²⁴, but also to the records of the Polish educational acts, or the educational core curricula, school should create such conditions for each student, that will allow children and adolescents with various experiences and biographies, to achieve educational success. Among the many records regarding educational priorities, still remain the statements about the necessity of supporting development and learning, both in the instrumental and the directional spheres, of students with "different development", with "developmental difficulties", or with "special educational needs".

²⁴ Deklaracja z Salamanki oraz wytyczne dla działań w zakresie specjalnych potrzeb edukacyjnych przyjęte przez Światową Konferencję Dotyczącą Specjalnych Potrzeb Edukacyjnych: *Dostęp i Jakość*, Salamanka, Hiszpania 7-10 czerwca 1994 r., UNESCO 1994.

The basic, primary aims include, such support of the development of these students, that will enable them to use their potential in a way that will allow them to satisfy their needs, develop their own talents, shape their cognitive, emotional, and social processes, as well as, build motivation to act in a way that will allow each of them to become an active member of the school as a learning organisation.²⁵

However, within this context, it seems that the process of education of children and adolescents with a chronic condition, allowing to care for them²⁶, and support their learning and socialisation, is not just a matter of complying with regulations²⁷, but rather, a specific challenge for each teacher, pedagogue/school psychologist, and other experts working in school, related to building a strategy based on the understanding of the principles of individuation, and of the social participation in life.

When we speak of the process of supporting children and adolescents with a chronic condition, it is advisable to refer to the basic principles, that should be considered; (1) grasping the problems of children and adolescents in a holistic and multi-aspect way; (2) using the organism ability to compensate; (3) discovering and developing the potential, therefore, these individual capabilities, and „Archimedean” (strong) traits, that may serve as the basis for the optimisation of educational, preventive, and therapeutic activities;

²⁵ H. Krauze-Sikorska, *Praca z dziećmi o specjalnych potrzebach edukacyjnych i jej implikacje dla ich rozwoju*, [in:] *Dziecko w szkolnej rzeczywistości. Założony a rzeczywisty obraz edukacji elementarnej*, (ed.) H. Sowińska, Wyd. Naukowe UAM, 2011, pp. 479-534.

²⁶ None of the acts defines the details of the guardianship function of the teacher. The term “guardianship” is primarily a legal term, and the teacher does not provide guardianship in a legal meaning of the Family and Guardianship Codex (Kodeks rodzinny i opiekuńczy), therefore the guardianship role in regard a child with a chronic condition, may be interpreted freely.

²⁷ The right is highlighted by the Karta Nauczyciela (Teacher’s Ledger), which obligates the teacher to the earnest execution of his tasks related to his position, and the primary functions of school: didactic, educational, and guardianship function, including the tasks regarding ensuring the safety of the students (art. 6 sec. 1), as well as, supporting each student in his development oraz (art. 6 sec. 2).

(4) creating conditions that aid the adaptation of children and adolescents to the situation determined by their health; (5) creating a space of their physical and social life (family, school, outside of school), with the consideration of their needs, the realistic nature of expectations, but also their own activity.

We may speak of the effectiveness of support perceived as such, only if:

- creating new habits of learning, will be at the basis of the new principles of the reconstruction related to the physical and motor aspect.
- in the process of psychological adaptation the child/adolescent will be supported in transitioning through subsequent phases of coping with the experience of “being a sick person” – the shock, the hope for recovery, resignation, and feeling sorry for self. The support is also related to situations. The support is also related to situations, in which non-adaptive defence mechanisms appear, that are of significance for the actual evaluation of own capabilities, the adaptation to the limitations enforced by the condition, and creating relations with others (and, when an opportunity arises, also for others),
- within the process of learning social roles, due to the possibility of an occurring and progressing social alienation related to, e.g. withdrawal from the previous role, identification with a new role, developing within the framework of a new role, and integration of this role with the entirety of the previous roles, it is essential to support both the parents and the peers, often serving as the basis for creating a “new” image of the Self, and the process of self-actualisation, which is an accidental result of the intentional nature of the life of each human. Its essence is reflected fully in Karl Jaspers’ words, “Was der Mensch ist, das ist er zur seinen mach” (“A man is, whom he had become by his own doing”).

In the case of children and adolescents with a chronic condition, one must also consider other factors that modify the image of the self: the duration of the condition, the type of the condition, the

severity, and the difficulties that the condition causes, the circumstances, in which the condition had appeared, the level of intellectual development, and of the own activity of children and adolescents.

In creating a support process, it is advisable to refer to the proposal of coping in the face of a chronic condition, by Rudolf Moos²⁸, indicating, that in a situation of a chronic condition, if an individual manages well, he executes tasks related directly to the condition, as well as, the general tasks.

Within the context of psychopedagogical activities, undertaken in school, the first ones should be dedicated to: (1) supporting the child in coping with the consequences of the condition, particularly, with symptoms and the reappearing loss of psychophysical efficiency, (2) supporting the child in adaptation and re-adaptation, regarding the school environment; and (3) allowing the student with a chronic condition, to build and maintain positive interpersonal relations. The general tasks are related to: (1) maintaining emotional balance; (2) maintaining a coherent feeling of Self, particularly, within the area of competencies and the feeling of effectiveness; (3) maintaining good relations with family and peers in the classroom.

Successful coping in a school educational and social space seems real, if, in educational activities, we consider the complexity and the sequentiality of activities, taking into account, e.g. the eclectic approach model, proposed by Frederick C. Thorne²⁹, or Richarda James³⁰, being a hybrid based on the integration of the basic models used in the situations of a crisis intervention: the equilibrium model, the cognitive model, and the model of social change. Here, it is important to: (1) identify and verify the elements of each system, and to integrate them into an internally coherent whole matching the behavioural data, that is to be explained; (2) analyse everything that refers to the problem – the theories, methods, standards of evalua-

²⁸ R.H. Moos, J.A. Schaefer, *The crisis of physical illness*, [in:] R. Moos (ed.), *Coping with physical illness* New York. Plenum Press, 1984, pp. 3–26.

²⁹ F.C. Thorne, *Principles of Personality Counseling – An Eclectic Viewpoint* by Publisher: Ind Press, 2011.

³⁰ R.K. James, *Crisis Intervention Strategies*, Cengage Learning, 2016.

tion and clinical data; according to the latest state of knowledge; (3) apply unbiased evaluation, without the “artificial” bending of the evaluation for the purpose of a particular theory, and remaining an open mind, that aids searching for such strategies and approaches, that yield the best results. An important aspect of the activities, is to remember about their multi-phase nature:

Phase 1 is the definition and the understanding of the problem from the student’s viewpoint (with the basis being the systemic diagnosis).³¹

Phase 2 is to minimise the physical and the psychological threats, i.e. providing the student with the feeling of safety.

Phase 3 is the unconditional acceptance towards the student; ensuring him, that he is a person, about which we care, and that we see and appreciate his effort.

Phase 4 is to recognise, together with the student, his capabilities, finding efficient solutions, and indicating that some choices may be better than others (choices must be appropriate and realistic). The activity is based on situational support; parents and peers may be the source of support. It is important to develop, with the student, the means to cope with difficulties (activities, behaviour, environmental assets), and the modification of looking at the issue; creating models of positive, constructive thinking.

Phase 5 encompasses the planning of activities that aid the reinstating of emotional homeostasis. Here, the identification of the sources of emotional support is necessary (home, school), providing a means of coping with difficulties, motivating the student to take up certain activities that are possible, therefore, based on the available assets; the essence is to understand the sense of activities and accepting them; the student must have a feeling of independence, and remain in control over the activities.

Phase 6 is the result of the realisation of the premises from the previous phase, therefore, developing the student’s feeling of au-

³¹ H. Krauze-Sikorska, *Mikro- i makrokontekst w procesie systemowej diagnozy psychopedagogicznej dzieci i młodzieży z trudnościami w uczeniu się*, Studia Edukacyjne, 2014, np. 33, pp. 19-34.

tonomy, and control over the performed activities, remains the basis. This phase is not just the support of a student in his activities, ensuring his feeling of safety, but also cooperation, still allowing him to build his self-efficacy.

The analysis of the particular phases, allows to sketch out a model of an activity, that could efficiently support and aid students with a chronic condition, during the process of school education (fig. 1).

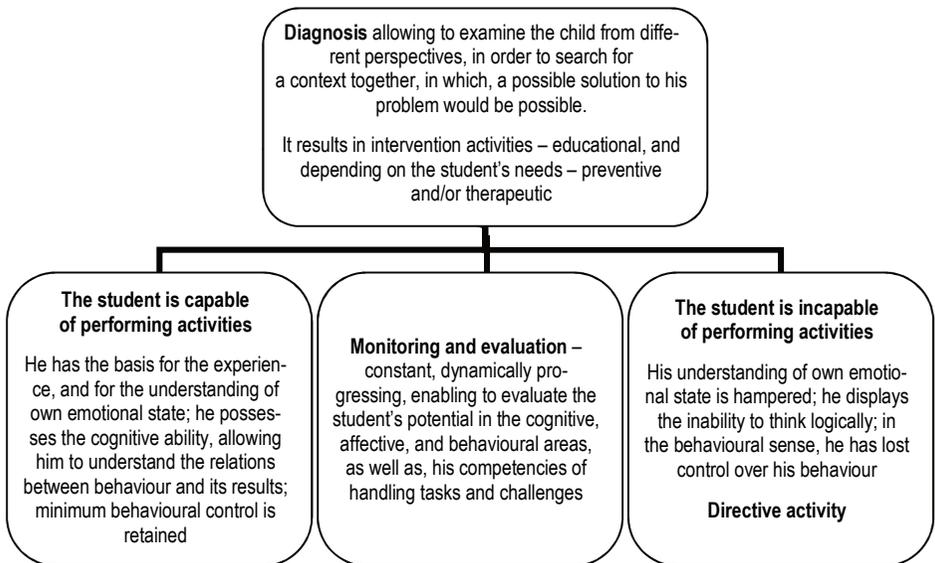


Fig. 1. The proposal of a model of supporting and aiding students with a chronic condition

Source: own research.

The application of the above proposal, would, in my opinion, be justified also in building optimising activities for the aid for children/students from different risk groups regarding educational and social setbacks, as the model includes the necessity of a holistic look at the student, along with his biography, and various experiences.

Conclusion

The occurrence of difficulties and setbacks in learning, and in social relations, that, exceptionally often, seems to encompass children and adolescents with a chronic condition³², limits not only their choices in subsequent phases of schooling that determines their educational, and professional profile, but also, their opportunity to achieve a position within the social structure, the adult life.

One of the essential risk factors of setbacks, is probably the fact, that the school period, in which the need to become competent becomes essential, which is related to the psychosocial crisis; feeling of competence vs the feeling of inadequacy.³³ When the child begins the systematic acquisition of knowledge, and studying becomes an essential form of activity, a time comes, to realise developmental tasks, the aim of which is to meet the expectations of the school, and of the parents. Erik Erikson describes this period of life as the age of industry or inferiority. It is related to the shaping of the feeling of competence, and of efficiency, in activities, that are the result of the intentional activity of an individual, as well as, of intensive learning. All success leads to the development of the feeling of competence, and of the belief regarding own efficiency.³⁴

Thereby, one of the aspects of activities taken up during the process of education, that links the processes of learning – education and teaching, should be assisting students in achieving self-actualisation, as the danger, existing in this phase of development, of the appearance of the feeling of inferiority, related to the lack of success in learning, in both the instrumental and the directional spheres, usually carries over constraints and irregularities in the development of the entire personality. Already, more than fifty years ago, Stefan Szuman noted, that "(...) Without developing own knowledge

³² J. Bąbka, *Nie integrować nadmiernie*, Edukacja i Dialog 2002, no 1, pp. 3–11; B. Jachimczak, *Dydaktyczne i pozadydaktyczne uwarunkowania efektów nauczania indywidualnego dzieci przewlekle chorych*, Oficyna Wydawnicza „Impuls”, Kraków 2011.

³³ E. Erikson, *Dzieciństwo i społeczeństwo*, Wyd. Rebis, Poznań 2000, pp. 269–272.

³⁴ *Ibidem*.

of the world properly, the child cannot acquire a broader and indispensable orientation in own environment; without acquiring this orientation, necessary at a given age, the child cannot act intentionally; if the child is not sufficiently active, he or she does not acquire experience necessary for developing own mind; if the child secludes self from people and other children, does not recognise them, and has no opportunity to test own strength and capabilities against them; if the child is emotionally unstable, he or she cannot achieve balance; if the child is explosive, he or she falls in conflict with the environment and becomes neurotic (...)"³⁵

However, in the realisation of tasks, that may be defined as pro-developmental, children and adolescents with a chronic condition, need educational and life success, determined by the cooperation with others, a community of aims, based on the analogy of the systems of value of the students with a chronic condition, their parents, teachers, experts, as well as, peers, among whom they function. In the specific case of a condition, when it "excludes" from the school life for a period of time, maintaining contact with others becomes a problem. In such conditions, it is difficult, not only to develop cognitive, or emotional competencies, to learn how to be with, and for others, but also, to design own future. These challenges may create another area of difficulties, primarily related to the reevaluation of the attitude towards life, and accepting life as it is, in its a priori mutability.

However, the efficiency of, how children and adolescents with a chronic condition, will handle the challenges ahead of them, will depend not only on their personal assets, but also, activities within the school environment. This last element, is strictly tied to the creation of a model of such support – theory is its basis, however, its principles should result in pedagogical practice.

The model shows, that in school, due to the atmosphere that ensures the feeling of safety, the student can "leave" the role of a "sick child" and no longer be perceived through the prism of own condi-

³⁵ S. Szuman, *O dojrzałości szkolnej dzieci siedmioletnich*, Nowa szkoła, 1962, no 6.

tion. It is important, to reinstate the child's value as a Person, possessing strong and weak points, own interests and dreams, that learns achieving success and coping with setbacks, that every person experiences.

Bibliography

- [1] Bąbka J., *Nie integrować nadmiernie*, „Edukacja i Dialog” 2002, no 1, pp. 3-10.
- [2] Bowen M., Thomson J., *Nie wystarczy tam tylko być*, [in:] *Integracja dzieci o specjalnych potrzebach edukacyjnych. Wybrane zagadnienia etyczne*, (ed.) G. Fairbairn, S. Fairbairn. Warszawa, CMPP-P, 2000.
- [3] Dąbrowiecki P., Kupryś-Lipińska I., Łęcka D., *Raport, Astma ciężka. Sytuacja pacjentów w Polsce POCHP*, Wyd. Novartis; 2015, <https://www.astma-alergia-pochp.pl/download/Raport_Astma_Ciezka_maj%202015.pdf> [access: 19.05.2019].
- [4] *Deklaracja z Salamanki oraz wytyczne dla działań w zakresie specjalnych potrzeb edukacyjnych przyjęte przez Światową Konferencję Dotyczącą Specjalnych Potrzeb Edukacyjnych: Dostęp i Jakość*, Salamanka, Hiszpania 7-10 czerwca 1994 r., UNESCO 1994.
- [5] Dudzikowa M., *Mit o szkole, jako miejscu wszechstronnego rozwoju ucznia. Eseje etnopedagogiczne*, Oficyna Wydawnicza „Impuls”, Kraków 2001.
- [6] Erikson E., *Dzieciństwo i społeczeństwo*, Wyd. Rebis, Poznań 2000.
- [7] Hale E.D., Treharne G.J., Kitas G.D., *The Common-Sense Model of self-regulation of health and illness: how can we use it to understand and respond to our patients' needs? "Rheumatology"*, June 2007, Vol. 46, Issue 6, pp. 904-906
- [8] Jachimczak B., *Dydaktyczne i pozadydaktyczne uwarunkowania efektów nauczania indywidualnego dzieci przewlekle chorych*, Oficyna Wydawnicza „Impuls”, Kraków 2011.
- [9] James R.K., *Crisis Intervention Strategies*, Cengage Learning, 2016.
- [10] John-Borys M., *Koncepcje zdrowia i choroby u dorastających*, Wyd. Uniwersytetu Śląskiego, Katowice 2002.
- [11] Kalnis R. *Love Children's concept of health and illness – and implications for health education*, „Health Education Quarterly” 1982, 9(2-3), pp. 104-115.
- [12] Krauze-Sikorska H., *Dorosły w świecie dziecka chorego terminalnie*, (in:) *Świat małego dziecka. Przestrzeń instytucji, cyberprzestrzeń i inne przestrzenie dzieciństwa*, (ed.) H. Krauze- Sikorska, M. Klichowski, Wyd. Naukowe UAM, Poznań 2017, pp. 143-154.
- [13] Krauze-Sikorska H., *Praca z dziećmi o specjalnych potrzebach edukacyjnych i jej implikacje dla ich rozwoju*, [in:] *Dziecko w szkolnej rzeczywistości. Założony a rzeczywisty obraz edukacji elementarnej*, (ed.) H. Sowińska, Wyd. Naukowe UAM, 2011, pp. 479-534.

- [14] Krauze-Sikorska H., *Wsparcie społeczne w sytuacji wystąpienia Syndromu Adaptacyjnej Dekompensacji u dzieci i młodzieży z niepowodzeniami szkolnymi*, [in:] M. Piórunek (ed.), *Pomoc – wsparcie społeczne – poradnictwo. Od teorii do praktyki*, wyd. Adam Marszałek, Toruń, 2010, pp. 407–427.
- [15] Krauze-Sikorska H., *Mikro- i makrokontekst w procesie systemowej diagnozy psychopedagogicznej dzieci i młodzieży z trudnościami w uczeniu się*, *Studia Edukacyjne*, 2014, no 33, pp. 19–33.
- [16] Kwieciński Z., *Socjopatologia edukacji*, Wydawnictwo Trans Humana, Olecko, 1995
- [17] Lau R.R., Hartman K.A., *Common sense representations of common illnesses*, "Health Psychology", 1983,2(2),s. 167–185 <http://dx.doi.org/10.1037/0278-6133.2.2.167> (pdf).
- [18] Moos R.H., Schaefer J.A., *The crisis of physical illness*, [in:] *Coping with physical illness*, (red.) R. Moos New York: Plenum Press, 1984, pp. 3–25.
- [19] Olszewska B., *Uczeń z chorobą przewlekłą – zakres świadomości i odpowiedzialności działań edukacyjnych*, *Kultura i Wychowanie* 2011, 1, pp. 234–344.
- [20] Roberts M.C., Beidleman W.B., Wurtele S.K., *Children's perceptions of medical and psychological disorders in their peers*, "Journal of clinical child psychology" 10(2) June 1981, pp. 76–78.
- [21] Schütz A., *O wielości światów. Szkice z socjologii fenomenologicznej*, NOMOS, Kraków 2008.
- [22] Szkudlarek T., *Pedagogika krytyczna*, [in:] *Pedagogika*, vol. 1 (ed.), Z. Kwieciński, B. Śliwerski Wyd. Naukowe PWN, Warszawa 2003, pp. 363–377.
- [23] Szuman S., *O dojrzałości szkolnej dzieci siedmioletnich*, „Nowa szkoła” 1962, no 6.
- [24] Thompson R.J., Gustafson K.E., *Adaptation to Chronic Childhood Illness*, American Psychological Association, Washington DC., 1999.
- [25] Thorne F.C., *Principles of Personality Counseling – An Eclectic Viewpoint* by Publisher: Ind Press, 2011.
- [26] Woynarowska B., Mazur J., Kowalewska A., Kołosa H., Małkowska A., *Zachowania zdrowotne i postrzeganie szkoły przez młodzież w Polsce w 2002 r. Raport techniczny z badań*. Wydział Pedagogiczny Uniwersytetu Warszawskiego, Warszawa 2012.
- [27] Weinman J., Petrie K., Moss-Morris R., Horne R., *The Illness Perception Questionnaire: A New Method For Assessing The Cognitive Representation Of Illness*, *Psychology and Health* 1996, 11(3), pp. 431–445; <https://www.researchgate.net/publication/251957846_The_Illness_Perception_Questionnaire_A_New_Method_For_Assessing_The_Cognitive_Representation_Of_Illness> [access: 15.06.2018].
- [28] Wittchen H.U., Lieb R., Pfister H., Schuster P., *The waxing and waning of mental disorders: evaluating the stability of syndromes of mental disorders in the population*, "Comprehensive Psychiatry", 2000 Mar-Apr; 41 (2 Suppl 1), pp. 122–132.



The Competence of Teacher Assistants in the Context of Working with Visually Impaired Students. Needs of the Environment and the Vision of Change

ABSTRACT: Małgorzata Paplińska, *The Competence of Teacher Assistants in the Context of Working with Visually Im-paired Students. Needs of the Environment and the Vision of Change*. Interdisciplinary Contexts of Special Pedagogy, no. 26, Poznań 2019. Pp. 319–341. Adam Mickiewicz University Press. ISSN 2300-391X. DOI: <https://doi.org/10.14746/ikps.2019.25.15>

The text contains an analysis of the competence of a special education teacher, with particular emphasis on the competence of one working as a teacher assistant with blind and visually impaired students. It attempts to answer the question of what competence a teacher assistant should have. On the one hand, this competence must be a response to the current needs of students with visual impairments, their teachers and parents. In line with the current approach to inclusive education, the teacher assistant who works with visually impaired students should be equipped with a whole array of competences, especially a number of highly specialised ones. On the other hand, taking into account e.g. creative and ethical competences, universities educating future teachers of the kind are not able to equip graduates with full competences.

KEY WORDS: competencies, teacher of students with visual impairments, teacher assistant, blind students, visually impaired students

Introduction

Contemporary challenges, resulting from changes in various areas of life of people with disabilities, entail specific actions, and often the need to change views that must keep up with contemporary expectations and needs in the field of education and rehabilitation. These changes are visible in theoretical studies and research as well as in the modification of practitioners' activities, including specialists and teachers working with students with special educational needs.

Special pedagogy has long been the field for discussion on the model of education and support for people with disabilities, which has led theorists and practitioners to develop a systemic triad. It covers special (segregation) education, integration education and inclusive education.¹

The Convention on the Rights of Persons with Disabilities (2006, 2012) ensures the right of persons with disabilities to education under an inclusive education system at all levels of education, with the obligation of a rational support system directed to the individual possibilities and needs of students, without any exclusion.² Iwona Chrzanowska draws attention to item 4 of that article, emphasizing that this support is to include employing teachers with appropriate qualifications and skills, e.g. the use of alternative methods, forms, resources, techniques, and teaching materials relevant for working with people with disabilities.³

¹ M. Dycht, *Edukacja i wspieranie uczniów ze specjalnymi potrzebami edukacyjnymi i rozwojowymi w placówkach oświatowych w Polsce (Education and Support for Students with Special Educational and Developmental Needs in Educational Institutions in Poland)*, [in:] *Dzieci z trudnościami rozwojowymi w młodszym wieku. Indywidualne programy edukacyjno-terapeutyczne w procesie wspierania dzieci (Children with Developmental Handicaps at a Younger Age. Individual Educational and Therapeutic Programs in the Process of Supporting Children)*, ed. E. Śmiechowska-Petrovskij, Wydawnictwo Naukowe UKSW, Warszawa 2017, pp. 11-36.

² The UN Convention on the Rights of Persons with Disabilities, UN, New York 2006; The UN Convention on the Rights of Persons with Disabilities, Journal of Laws of 25 October 2012, item 1169.

³ I. Chrzanowska, *Nauczanie inkluzyjne w doświadczeniach polskich – podstawy prawne i społeczne uwarunkowania (Inclusive Teaching in the Polish Experience – Legal and Social Conditions)*, „Studia Edukacyjne” 2014, no 30, pp. 109-117.

While analyzing the importance of inclusive education, Zdzisława Janiszewska-Nieścioruk and Marzenna Zaorska pay attention to its possibilities and strengths, as well as weaknesses and areas requiring rapid corrective action.⁴

Modern education, therefore, forces a change in the role and tasks of the teacher, both in the overall teaching process and the placement of the teacher in the classroom. A new challenge in the teacher's work is the increasing diversity of the school population of students, resulting from both the different pace of development of individual children, developmental disorders and irregularities, as well as from cultural diversity.⁵ The teacher faces numerous educational challenges that require professional preparation for working with children with special educational needs. These are also the tasks related to the organization of an educational space in which the individual needs of students will be met. Danuta Wosik-Kawala and Teresa Zubrzycka-Maciąg, citing Wincenty Okoń, emphasize "there is no pedagogical system in the world that would disregard the role of the teacher in the education process. Although these systems differ so much, they agree that good education and upbringing can be the work of a good teacher-tutor".⁶

The effectiveness of education for blind and visually impaired students is determined by various factors. These factors include the

⁴ Z. Janiszewska-Nieścioruk, M. Zaorska, *Prowłączające zmiany w systemie polskiej edukacji - nowe możliwości, ograniczenia i wyzwania (Pro-integrative Changes in the Polish Educational System - New Opportunities, Limitations and Challenges)*, „Interdyscyplinarne konteksty pedagogiki specjalnej” 2014, no. 4, pp. 9-28.

⁵ M. Rutkowski, K. Bidziński, *Nauczyciele szkoły ogólnodostępnej - realizatorzy idei edukacji włączającej - w poszukiwaniu źródeł zawodowego wsparcia (Teachers of Public School - Implementers of the Idea of Inclusive Education - In Search of Sources of Professional Support)*, [in:] *Jest człowiek z niepełnosprawnością. Pola refleksji (A Person with a Disability. Fields of Reflection)*, eds. B. Antoszevska, I. Myśliwczuk, Wydawnictwo Naukowe SILVA RERUM, Poznań-Olsztyn 2017, pp. 167-186.

⁶ W. Okoń, *Wprowadzenie do dydaktyki ogólnej (Introduction to General Education)*. Żak, Warszawa, 1996, p. 423, after: *Kompetencje diagnostyczne i terapeutyczne nauczyciela (The Diagnostic and Therapeutic Competence of the Teacher)*, eds. D. Wosik-Kawala, T. Zubrzycka-Maciąg, Oficyna Wydawnicza „Impuls”, Kraków 2011, p. 7.

preparation of an educational space, including adaptation of the environment and didactic aids, as well as resources of competences and attitudes of regular teachers, teachers of students with visual impairments –teacher assistants and other specialists working with a student who has a visual disability. It is obvious that the negative characteristics of any of these factors will limit the learning outcomes.⁷

In the teachers' opinion, considering their experience with all groups of children with special educational needs, it is the work with a visually impaired student that is the most difficult.⁸ Perhaps it is associated with cognitive dissonance, which Iwona Chrzanowska points out. "According to Festinger's theory, the lack of reliable assessment of the situation, as a result of not having knowledge about the specifics of the functioning of people with disabilities, creates a sense of frustration, uncertainty and anxiety. (...) the appearance in the community of a person functioning differently can be perceived as a disturbance of the developed, cognitive assessment of reality".⁹

The question then arises, what competencies should be inherent in a teacher of students with visual impairments, who works as a teacher assistant? On the one hand, competences must be a re-

⁷ M. Rutkowski, *Kompetencje diagnostyczne, planistyczne, realizacyjne i ewaluacyjne w pracy z uczniami ze specjalnymi potrzebami edukacyjnymi – w ocenie własnej nauczycieli uczących w placówkach specjalnych oraz integracyjnych (Diagnostic, Planning, Implementation and Evaluation Competences in Working with Students with Special Educational Needs – The Own Assessment of Teachers in Special and Integrative Institutions)*, „Pedagogika. badania, dyskusje, otwarcia”. Dzieci i młodzież ze specjalnymi potrzebami edukacyjnymi. Implikacje dla teorii i praktyki (Children and Youth with Special Educational Needs. Implications for Theory and Practice), issue 3/2014, pp. 47–64.

⁸ D.Al. Khamisy, *Edukacja włączająca edukacją dialogu. W poszukiwaniu modelu edukacji ucznia ze specjalnymi potrzebami edukacyjnymi (Inclusive Education as the Education of Dialogue. In Search of a Model of Education for Students with Special Educational Needs)*. Wydawnictwo Akademii Pedagogiki Specjalnej, Warsaw 2013.

⁹ I. Chrzanowska, *Nauczanie inkluzyjne w doświadczeniach polskich – podstawy prawne i społeczne uwarunkowania (Inclusive Teaching in the Polish Experience – Legal and Social Conditions)*. „Studia Edukacyjne” 2014, no. 30, p. 113.

sponse to the contemporary needs of a student with a visual disability, his teachers, parents. On the other hand, universities educating future teacher of students with visual impairments are not able to equip their graduates with all the competences needed when working with blind and visually impaired students.

The spectrum of professional competences of a special educator

As Małgorzata Kupisiewicz points out, special pedagogy has long ceased to have the status of only special school pedagogy, at a time when its foundations were shaped by Maria Grzegorzewska.¹⁰ Therefore, the role and tasks of the special educator change. The teaching profession appears to be particularly difficult because it requires many qualifications (often very specialized ones), specific attitudes, both cultural, intellectual, as well as moral, social and psychological. At the same time, it requires highly developed teaching skills, supported by a wealth of individual information resources from various fields of science.¹¹

An expression of interest in teaching competences is the presence in literature on *pedeutology* of many classifications that attempt to create the image of desired skills that are to ensure teacher's effectiveness. A holistic approach to competences in the teacher's work includes knowledge in the field of his profession and related fields, practical skills, including diagnosis, pragmatism and evalua-

¹⁰ M. Kupisiewicz, *Pedagog specjalny – człowiek o wyjątkowych predyspozycjach osobowościowych, profesjonalista posiadający rozległą, interdyscyplinarną wiedzę i umiejętności* (Special Education Teacher – A Person with Exceptional Personality Traits, a Professional with Extensive, Interdisciplinary Knowledge and Skills), „Studia z teorii wychowania” 2016, vol. VII, no. 4(17), pp. 173–184.

¹¹ M. Konieczna-Kucharska, *Miękkie i twarde kompetencje nauczycieli* (Soft and Hard Competences of Teachers), „Zeszyty Naukowe Politechniki Częstochowskiej Zarządzanie” 2015, no. 19 pp. 229–241, <<http://www.zim.pcz.pl/znwz>> [access: 28.05.2019].

tion, as well as moral awareness, personal characteristics and predispositions.¹²

The term of *competences* is used in the context of behavioural (so-called soft) and functional (so-called hard) competences. The first group defines the way people should behave to do their job well. Therefore, this group of competences include, among others, personal skills, character and temperament traits, attitudes, social and communication skills. Thanks to them, it is primarily possible to manage yourself, your time and others, plan and anticipate, function in society, including the ability to work in a team, as well as motivate to act, both yourself and others, assertiveness, creativity and emotional intelligence. Hard competences relate to specific skills, qualifications and knowledge. This group of competences includes, among others, skills related to the adaptation of educational tasks, the pace of their implementation to the level of development, opportunities and learning style of students.¹³

The spectrum of competences of a special needs counsellor can be outlined by dividing them into seven main groups. The first group consists of substantive skills related to the implementation of the teaching and improvement process, including correction and compensation, as well as efficiency in the use of various therapeutic methods and techniques. The second group consists of didactic as well as psychological and pedagogical competences regarding didactic diagnosis, planning, organizing, controlling and evaluating the course and results of educational processes, with particular emphasis on the specific needs and functioning of individual students with special educational needs. An important group of competences are communication competences, which manifest themselves,

¹² M. Zaorska, *Rola i miejsce pedagoga specjalnego w kreowaniu działalności edukacyjno-terapeutycznej (The Role and Place of Special Needs Counselor in Creating Educational and Therapeutic Activity)*, "Acta Universitatis Nicolai Copernici Pedagogika" 2012, vol. XXVIII (405), pp. 13-23.

¹³ M. Konieczna-Kucharska, *Miękkie i twarde kompetencje nauczycieli (Soft and Hard Competences of Teachers)*, „Zeszyty Naukowe Politechniki Częstochowskiej Zarządzanie” 2015, no. 19 pp. 229-241, <<http://www.zim.pcz.pl/znwz>> [access: 28.05.2019].

among others in the scope of knowledge and communication skills using verbal as well as supportive and alternative methods of interpersonal communication. Cooperation competences are expressed in the form of pro-social behaviour, especially the skills to shape them in students, as well as skills in solving difficult and problem situations, also in the areas of integration activities.

Creative competences are extremely important in the context of seeking and creating methods, didactic and therapeutic techniques as well as developing materials and didactic aids, taking into account the individual needs and capabilities of students with special educational needs. It is impossible to function without technology in the modern world. Therefore, the broadly understood IT competences are those thanks to which a teacher or special needs counselor can effectively use modern technologies, acquiring information, communicating with students, preparing and adapting teaching materials.

Personality as well as moral and ethical competences are characterized by humanitarianism. It is expressed by the recognition of the student's subjectivity, regardless of the type and degree of his or her disability. It is also responsibility, honesty, empathy, perseverance and consistency, as well as self-criticism and the capability of an in-depth moral reflection.¹⁴ Ethical values, personal standards regarding behaviour in the work environment and performance of professional tasks, as well as individual predispositions fall within the area of soft competences resulting from deeply rooted personality structures. They are the potential and resources of a special educator to effectively work for the benefit of people with disabilities.¹⁵

¹⁴ M. Kupisiewicz, *Pedagog specjalny – człowiek o wyjątkowych predyspozycjach osobowościowych, profesjonalista posiadający rozległą, interdyscyplinarną wiedzę i umiejętności* (Special Education Teacher – A Person with Exceptional Personality Traits, a Professional with Extensive, Interdisciplinary Knowledge and Skills), „Studia z teorii wychowania” 2016, vol. VII, no. 4(17), „Studia z teorii wychowania” 2016, vol. VII, no. 4(17), pp. 173–184.

¹⁵ M. Wolan-Nowakowska, *Znaczenie kompetencji społecznych w pracy pedagoga specjalnego* (The Importance of Social Competence in the Work of a Special Needs Teacher), „Lubelski rocznik pedagogiczny” 2016, vol. XXXV, issue 3, pp. 153–163.

The multitude of teaching specialties prevents a comprehensive description of competences. This description allows, however, to selectively relate to competences resulting from the specifics of working with a unique group of students, as well as in an assumptive way, referring to the concept of human experience in the area of significant, basic categories.¹⁶

Teacher of students with visual impairments as a teacher assistant – competences and expectations

According to the current approach to inclusive education, and therefore in accordance with the needs of a generally accessible school, a teacher assistant (and in this role, a teacher of students with visual impairments) should possess a wide range of competences, especially highly specialised ones, which cannot possibly be acquired in the course of academic studies by any student majoring in teaching children with visual impairments (as regards full-time, part-time and postgraduate studies alike). As we examine substantive competences alone, we should note that it is expected that a teacher of students with visual impairments is expected to be able to work with a diverse group of students. Such a group will include blind children, as well as students with poor sight (those with a stable level of visual functioning, but also those who happen to be losing their sight quite rapidly or gradually as a result of visual system conditions). The support of a teacher of student with visual impairments is also granted to children with little or no sight, at the same time suffering from multiple disabilities, be it diagnosed or

¹⁶ S. Byra, Z. Kazanowski, *Postrzeżenie kompetencji zawodowych nauczyciela w edukacji inkluzyjnej – próba pomiaru (The Perception of Teacher's Professional Competence in Inclusive Education – An Attempt at Measurement)*, [in:] *W poszukiwaniu indywidualnych dróg wspierających wszechstronny rozwój osób z niepełnosprawnościami (In Search of Individual Approach to Support the Comprehensive Development of People with Disabilities)*, eds. B. Szczupał, A. Giryński, G. Szumski, Wydawnictwo Akademii Pedagogiki Specjalnej, Warsaw 2015, pp. 247-260.

not. It follows from practical observations that additional disabilities of a student with little or no sight, such as e.g. intellectual disabilities (especially mild ones), or autism spectrum disorders, are diagnosed in the course of school education. A group of children with multiple disabilities also includes students whose visual impairment results from brain damage, who suffer from chronic diseases, e.g. diabetes, epilepsy, as well as children whose visual impairment results from or coexists with a cancer. This refers e.g. to students with tumours of deep brain structures, whose visual impairments, epilepsy or intellectual disability are secondary consequences of the cancer.¹⁷ Therefore, the spectrum of co-morbidities and conditions coexisting with visual impairments or blindness is rather broad. Additionally, it should be emphasised that the methodology of working with students with visual impairments is completely different from working with a blind student, which is why the scope of knowledge and skills of a prospective teacher must be really wide.

When analysing the needs of blind students and the school environment in detail, it is expected that the teacher of students with visual impairments will possess highly specialised competences related to teaching the Braille tactile writing system, which in turn includes the preparation for tactile reading and the development of tactile perception, as well as the knowledge of advanced Braille notation: mathematical, physical, chemical, musical, or Polish Braille abbreviations. The awareness of the significance of graphic education of blind students is the starting point for the teaching methodology of tactile graphics¹⁸, which is why the teacher's knowledge and competences in this respect are vital.

¹⁷ M. Paplińska, M. Walkiewicz-Krutak, *Visual impairment as a consequence of brain tumour: difficulties experienced by the child in spatial orientation, and in the cognitive, social and communication areas*, „Człowiek-Niepełnosprawność-Społeczeństwo” 2018, no. 2(40), pp. 15–27.

¹⁸ M. Paplińska, *Edukacja graficzna uczniów z niepełnosprawnością wzroku odzwierciedlona w IPETach – ważny czy pomijany obszar wsparcia (Graphic Education of Students with Visual Impairment reflected in IPETs – Important or Omitted Areas of Support)*, [in:]

It's hard to imagine that a teacher assistant, who works with a blind student, doesn't understand the implications of blindness and cannot use compensation methods to support a child and help them understand certain notions, including spatial and surrogate notions, when teaching them to gain access to information with the use of special teaching aids. The ability to choose correct teaching aids, which are often prepared by the teachers themselves, and to adapt teaching materials to include Braille notation is one of the key competences in order to provide efficient support to a blind student.

It is also expected that a teacher of students with visual impairments as a teacher assistant will also educate the school environment and the community outside. This includes any activities aimed at popularising the awareness of people with visual impairments.¹⁹ Therefore, the most important competences and skills are those that will help the teacher boost social integration of visually impaired students with their healthy peers at school, by spreading knowledge about people with poor or no sight, their needs and abilities, as well as debunking myths and eliminating prejudice.

It is usually the case that except for schools and educational centres for children and youth with visual impairments, blind students do not have any classes in spatial orientation, moving around or everyday activities. Therefore, a teacher assistant is also expected to possess a full set of competences needed to teach the students how to move around and protect themselves. This includes moving around with a sighted guide and with a long white cane. Such

Jest człowiek z niepełnosprawnością. Pola refleksji (A Person with a Disability. Fields of Reflection), eds. B. Antoszewska, I. Myśliwczyk, Wydawnictwo Naukowe SILVA RERUM, Poznań-Olsztyn 2017, pp. 205–229.

¹⁹ M. Paplińska, J. Witczak-Nowotna, *Tyfloedukacja jako element budowania integracji społecznej uczniów niewidomych i słabowidzących w edukacji włączającej (Teaching Students with Visual Impairments as Part of Building Social Integration of Blind and Visually Impaired Students in Inclusive Education)*, [in:] *Tyflopedagogika wobec współczesnej przestrzeni edukacyjno-rehabilitacyjnej (Teaching Students with Visual Impairments Against the Background of Contemporary Educational and Rehabilitation Space)*, eds. K. Czerwińska, M. Paplińska, M. Walkiewicz-Krutak, Wydawnictwo Akademii Pedagogiki Specjalnej, Warsaw 2015, pp. 114–134.

needs also include basic rehabilitation skills, which the teacher of students with visual impairments should have.

While we remember that a vast majority of poorly sighted children attend inclusive education, which means they attend mainstream schools, there is a great demand for professional assistants – teachers of students with visual impairments – in such schools. When working with students with visual impairments, it is important to remember about the crucial set of competences related to the improvement of visual functioning. This area includes a choice of proper aids (optical and non-optical), as well as the ability to adapt teaching aids to individual needs, related to functional implications of specific visual conditions. Expectations related to teachers of students with visual impairments also include teaching spatial orientation, including the interpretation of available visual information and improving the sight. A teacher of students with visual impairments who is also qualified as a visual rehabilitation specialist will support students in developing advanced visual skills, which make it easier for him/her to access information, communicate and be independent.

People with visual impairments may effectively use modern technologies, especially educational assistive technologies, to compensate for the lack of or limited access to information, mainly visual, which is necessary to gain knowledge, communicate and move around.

It follows from the analysis of teachers' competences as regards the use of assistive technologies when working with people with visual impairments that teachers lack these competences. Although international studies with the participation of 38 subjects from 273 countries show that educational assistive technologies are usually included in the curriculum of candidates studying to become teachers of students with visual impairments, the teachers themselves claim their skills are poor in this respect. Among the most frequent reasons for this they quote: diverse groups and diverse needs of children with visual impairments, which requires particular effort and there may be not enough time to select new technologies and

support students in this process. Another argument is the lack of opportunities for developing the skills acquired during the studies, as technological solutions are subject to rapid changes.²⁰

The most difficult tasks faced by special education teachers are those related to a reliable, complex functional diagnosis of a student. Diagnostic competences of teachers working with blind students and those with visual impairments require a creative integration of knowledge and skills from a wide variety of areas. Diagnosing a blind or visually impaired student is a challenge, considering the diversity of the group of visually impaired children and a multitude of areas that require specialised, extensive knowledge. Plus, there are not enough reliable and available diagnostic tools. The awareness of functional conditions of the visual system as well as proper diagnosis of visual functioning of a visually impaired child is the foundation for the proper diagnosis of their needs as well as for the choice of appropriate optical, non-optical and electronic aids. In the case of a child who is blind or is losing their sight, the diagnosis of their functioning at school and at home includes: understanding notions, readiness to learn tactile reading, degree of familiarity with the Braille reading and writing system, including the use of Braille tools and devices, the ability to read and prepare tactile graphics, as well as the skills related to spatial orientation and moving around, and self-care activities corresponding to the child's needs, abilities and age.²¹ As Joanna Głodkowska em-

²⁰ E. Śmiechowska-Petrovskij, *Kompetencje nauczycieli uczniów niewidomych i słabowidzących w zakresie wspomagających technologii informacyjno-komunikacyjnych (Competences of Teachers of Blind and Partially Sighted Students with Respect to Assistive Information and Communication Technologies)*, „Niepełnosprawność. Dyskursy pedagogiki specjalnej”. Niepełnosprawności złożone i sprzężone – konteksty normalizacji oraz psychospołecznej aktywizacji (Complex and Interlinked Disability – Contexts of Standardisation and Psychosocial Activation), 2016, no. 21, Gdańsk, pp. 106–120.

²¹ M. Paplińska, J. Witczak-Nowotna, *Kompleksowa diagnoza dziecka niewidomego, jego sytuacji w domu i szkole – studium przypadku (Comprehensive Diagnosis of a Blind Child, Situation at Home and at School. A Case Study)*, [in:] *Diagnoza i metody wspomaganie rozwoju (Diagnosis and Methods of Development Assistance)*, eds. B. Antoszewska, M. Wójcik, Uniwersytet Warmińsko-Mazurski, Olsztyn 2015, pp. 71–89.

phasises, knowledge about a student is the basis for diagnosing and designing any further actions. It is important that the teacher is able to conduct a reliable, complex diagnosis and recognise various areas of functioning (comprehensive diagnosis). The teacher should be able to recognise not only disorders and difficulties, but also strengths and developmental advantages of a student (positive diagnosis). Teachers should be able to use appropriate measurement tools to define developmental profiles (profiling diagnosis). They should also focus on following the child's development and capturing any changes (dynamic diagnosis), and should be able to interpret the outcomes of a diagnosis in a conscientious and appropriate manner, so as to define the student's needs and abilities (prognostic diagnosis).²²

Considering the fact that diagnostic competences of a special education teacher are of key importance and the diagnosis itself requires special skills, it should be emphasised that the process of becoming a diagnostician and a teacher is constructive and cumulative. It is fully consistent with the idea of lifelong learning. It is impossible to equip prospective teachers with a complete set of skills needed to conduct a reliable, multifaceted diagnosis. This requires experience and certain internal personality traits.

Educating teachers of students with visual impairments – current status and potential changes

As Stefan Kwiatkowski emphasizes, “meeting the requirements set for modern school counsellors turns out to be a task that is incomparably more difficult than before. Only properly trained specialists can count on achieving professional success in schoolwork, who have successfully gone through the entire educational process, taking into account all the necessary elements”.²³

²² J. Głodkowska, *Dydaktyka specjalna. Od wzorca do interpretacji (Special Education. From Standard to Interpretation)*, PWN, Warsaw 2017, pp. 40–41.

²³ S.T. Kwiatkowski, *Znaczenie kształcenia społeczno-emocjonalnego w rozwijaniu kluczowych kompetencji współczesnych nauczycieli (The Significance of Socio-emotional*

Careful preparation of methodical and practical specialization classes serves the development of professional competences of future teachers of students with visual impairments at the Academy of Special Education in Warsaw. By experiencing in a simulated situation of blindness or impaired vision (headbands and simulators of impaired vision are used), students have the direct opportunity to perform various tasks and activities while facing cognitive, emotional and social difficulties. It is learning through experiencing and acting, once as a student, once as a teacher. This kind of experience stimulates reflection and allows us to better understand the difficulties faced by blind and visually impaired people. Through the personal involvement of future teachers of students with visual impairments, it also gives students the chance to develop their own didactic strategies. In addition, workshop-and-lecture classes allow students to be better prepared for apprenticeships and later for work.

The analysis of the professional activity of graduates of the teacher of students with visual impairments specialization showed that the majority of people after completing their studies improved their professional competences through courses and trainings as well as postgraduate studies, which proves that graduates of the studies to become a teacher of students with visual impairments play a great role in their professional development. This is desirable and corresponds to the model of an individualized career path.²⁴

Zdzisława Janiszewska-Nieścioruk and Marzenna Zaorska point out that acquiring the competences of future special education

Education in the Development of Key Competences of Contemporary Teachers, [in:] *Kompetencje interpersonalne w pracy współczesnego nauczyciela (Interpersonal Competences in a Modern Teacher Work)*, eds. S.T. Kwiatkowski, D. Walczak, Wydawnictwo Akademii Pedagogiki Specjalnej, Warsaw 2017, p. 133.

²⁴ K. Czerwińska, K. Miler-Zdanowska, *Tyflopedagog we współczesnej przestrzeni edukacyjnej (Teacher of Students with Visual Impairments in Contemporary Educational Space)*, [in:] *Tyflopedagogika wobec współczesnej przestrzeni edukacyjno-rehabilitacyjnej (Teaching Students with Visual Impairments Against the Background of Contemporary Educational and Rehabilitation Space)*, eds. K. Czerwińska, M. Paplińska, M. Walkiewicz-Krutak, Wydawnictwo Akademii Pedagogiki Specjalnej, Warsaw 2015, pp. 12–43.

counsellors in the course of two-cycle studies is ostensible in its character. The authors emphasize that “allowing full competence to work with students with disabilities and / or special needs to graduates after completing their first cycle of studies is highly inadequate and redundant, especially since they could have obtained them after completing two or even three specializations within just three years of study (...)”.²⁵

Therefore, a return from the 2019/2020 academic year to a five-year master’s course in special education will allow graduates of the programme for teachers of students with visual impairments (as part of the uniform study program) to obtain additional competences, including to work as an eye rehabilitator, teacher of spatial orientation or Braille teacher. Unfortunately, despite the fact that many teachers of students with visual impairments have full qualifications and competences, and what is more, they successfully work as sight rehabilitators with visually impaired people, or as teacher-instructors of spatial orientation and independent movement of blind and visually impaired people, none of these professions is included in the list of professions. Registration of new professions and giving them a formal character seems necessary, not least because the demand for the services of these specialists is relatively high.

When analyzing the development of Polish field of expertise among teachers of students with visual impairments, Marzenna Zaorska determined the categories of its successes and (un)successes. In addition to achievements, such as the emergence of courses for teachers of students with visual impairments established as a sub-discipline of academic and practical special pedagogy, or the implementation, improvement of the quality and effectiveness of highly humanistic activities for the subject and practice, the author draws attention to “making the domain of teachers of students with

²⁵ Z. Janiszewska-Nieścioruk, M. Zaorska, *Prowłaczające zmiany w systemie polskiej edukacji – nowe możliwości, ograniczenia i wyzwania (Pro-integrative Changes in the Polish Educational System – New Opportunities, Limitations and Challenges)*, „Interdyscyplinarne konteksty pedagogiki specjalnej” 2014, no. 4, p. 21.

visual impairments a specialization in pedagogy, which means broader and more purposeful education of specialists to work with people with visual disabilities, development of staff operating in academic and practical pedagogy for teachers of students with visual impairments".²⁶ Among the so-called (non)successes were the lack of preselection of candidates for the profession of a teacher of students with visual impairments and the lack or shortage of obligatory subjects in this field in pedagogical study programs, which entails negative consequences regarding knowledge, competences and skills related to work and educational and rehabilitation support of students with sight disabilities.

Competences are not a permanent feature. Their acquisition and development depend on the teacher, their commitment, skills, motivation and pursuit of self-development.²⁷ Therefore, it is impossible to determine when the teacher will be able to state that he or she has already mastered the full range of necessary knowledge, skills and competences.²⁸ It is worth emphasizing, however, that the apparent sense of achieving full competence may also become a trap

²⁶ M. Zaorska, *Tyflopedagogika wobec wyzwań rozwoju współczesnej nauki i cywilizacji (Teaching Students with Visual Impairments in the Face of the Developmental Challenges of Modern Science and Civilization)*, [in:] *Tyflopedagogika wobec różnorodności współczesnych wyzwań edukacyjno-rehabilitacyjnej (Teaching Students with Visual Impairments in the Face of the Diverse Challenges of Modern Education and Rehabilitation)*, eds. K. Czerwińska, K. Miler-Zdanowska, Wydawnictwo Akademii Pedagogiki Specjalnej, Warsaw 2017, p. 19.

²⁷ J. Gasik, *Pedagog specjalny w kształceniu uczniów ze specjalnymi potrzebami edukacyjnymi (Special Education Councillor in the Education of Students with Special Educational Needs)*, [in:] *Dydaktyka specjalna w przygotowaniu do kształcenia uczniów ze specjalnymi potrzebami edukacyjnymi (Special Education in Preparation for the Education of Students with Special Educational Needs)*, ed. J. Głodkowska, Wydawnictwo Akademii Pedagogiki Specjalnej, Warsaw 2010, pp. 250–273.

²⁸ S.T. Kwiatkowski, *Znaczenie kształcenia społeczno-emocjonalnego w rozwijaniu kluczowych kompetencji współczesnych nauczycieli (The Significance of Socio-emotional Education in the Development of Key Competences of Contemporary Teachers)*, [in:] *Kompetencje interpersonalne w pracy współczesnego nauczyciela (Interpersonal Competences in a Modern Teacher Work)*, eds. S.T. Kwiatkowski, D. Walczak, Wydawnictwo Akademii Pedagogiki Specjalnej, Warsaw 2017, pp. 125–158.

in which a special education teacher, especially an experienced specialist in narrow, highly specialized areas, is convinced of their omnipotence in the sphere of diagnosis, support for a child with disabilities. This, in turn, entails the phenomenon of positive and negative authority, described by researchers²⁹, with all its consequences, among others, for the teacher-student relationship. Especially when working with students with vision disabilities, in whom the diseases of the visual system are often progressive, and therefore the changes are dynamic and require adaptation to the new situation and different conditions, one cannot define a full knowledge of the pedagogy in the specialization of a teacher of students with visual impairments, concerning the future of the child. Resignation from controlling the student's development in support of their development requires the teacher to limit the attitude of the dictate in favour of dialogue in an attitude of self-reflection and openness.³⁰ It is important, however, that the teacher of students with visual im-

²⁹ Cf. B. Skalbania, *Nauczyciel jako aktor szkolnej codzienności – aspekty dramaturgii i władzy (Teacher as an Actor of Everyday School Life. Aspects of Drama and Power)*, [in:] *Nauczyciel we współczesnej edukacji. Diagnoza – Rozwój – Zmiana (Teacher in Modern Education. Diagnosis – Development – Change)*, eds. M. Kamińska, Z.P. Kruszewski, A. Gretkowski, B. Skalbania, Szkoła Wyższa im. Pawła Włodkowica in Płock, Płock-Warsaw 2016, pp. 139–347; S. Sadowska, *O władzy nauczycielskiej – jasne i ciemne strony władzy w kontekście integracji (On Teacher's Power – The Bright and Dark Sides of Power in the Context of Integration)*, [in:] *Od tradycjonalizmu do ponowoczesności (From Traditionalism to Postmodernity)*, eds. E. Górniewicz, A. Krause, Wydawnictwo UWM, Olsztyn 2002, pp. 289–298.

T. Żółkowska, *Normalizacja – niedokończona teoria praktyki (Standardisation – The Unfinished Theory of Practice)*, „Niepełnosprawność” 2011, no. 5, pp. 85–93, <<http://bazhum.muzych.pl/media/files/Niepelnosprawnos/Niepelnosprawnos-r2011-t-n5/Niepelnosprawnos-r2011-t-n5-s85-93/Niepelnosprawnos-r2011-t-n5-s85-93.pdf>>, [accesses: 28.05.2019].

³⁰ M. Rutkowski, K. Bidziński, *Nauczyciele szkoły ogólnodostępnej – realizatorzy idei edukacji włączającej – w poszukiwaniu źródeł zawodowego wsparcia (Teachers of Public School – Implementers of the Idea of Inclusive Education – In Search of Sources of Professional Support)*, [in:] *Jest człowiek z niepełnosprawnością. Pola refleksji (A Person with a Disability. Fields of Reflection)*, eds. B. Antoszewska, I. Myśliwczyk, Wydawnictwo Naukowe SILVA RERUM, Poznań-Olsztyn 2017, pp. 167–186.

pairments – a teacher assistant – is substantively and methodically prepared to respond to the current needs of a blind and visually impaired child. The teacher should be able to draw conclusions from practice and diverse experiences.

Building the awareness of pedagogical students that the initial stage of education is just the starting point for a continued education and professional development can counteract the future negative phenomena of power/authority and omnipotence of specialist teachers involved in the educational and rehabilitation process of children with special educational needs. Looking closely at one of the classification of competences of a special educator proposed by Zofia Szyrkowska³¹, one can reflect that the development of the so-called basic competences, i.e. the first and basic ones, which are broadly understood social, intellectual and moral skills, are beyond the scope of pedagogical universities, although opportunities for their development are and should be arranged during classes.

Summary

Social expectations towards teachers are often too steep and sometimes impossible to implement. Teachers are treated as a group for which specific personality traits are required, as well as meeting various professional tasks, and to have competences “immediately”.³² The profession of a special education counsellor belongs to the group of subject professions focused on working with another person, therefore, apart from theoretical and substantive preparation of

³¹ Z. Szyrkowska, *Program nauczania a kompetencje nauczyciela* (The Curriculum vs. Teacher Competence), [in:] *Kompetencje zawodowe nauczycieli a problemy reformy edukacyjnej* (Professional Competences of Teachers and Problems with Educational Reform), ed. E. Sałata, Wydawnictwo Politechniki Radomskiej, Radom 2001.

³² J. Giedyk-Miko, *Oczekiwania wobec nauczyciela oraz jego roli w środowisku wiejskim – w świetle wypowiedzi studentów pedagogiki urodzonych i wychowanych na wsi* (Expectations Towards the Teacher and His or Her Role in the Rural Environment – In the Light of the Statements by Students of Pedagogy Born and Raised in Rural Areas), „Rozprawy Społeczne” 2014, vol. VIII, no. 3, pp. 48–56.

interdisciplinary character, it requires numerous practical competences, as well as special internal predispositions – personal ones, including characterological and empathic, and deepened moral and ethical awareness.

Analyzing just the substantive competences of a teacher of students with visual impairments needed for effective and successful work with blind and visually impaired students, it can be argued that this is one of the special needs tutors equipped with the most specialist skills.

As Stefan T. Kwiatkowski emphasizes, “students of pedagogical sciences should be made clearly aware during their studies that the education obtained in their Alma Mater, even if the university occupies first place in prestigious rankings, will never be sufficient and is only the foundation necessary for continuous development of their potential and including new forms of problem solving in the arsenal of their behaviour resulting from the experience acquired in the course of professional work”.³³ In addition to this awareness among graduates of pedagogical faculties, it is also important to monitor the effects of changes in the model of preparing teachers to work with students with special educational needs. The teachers’ needs in the area of improving their professional competences should be translated, among others to training offer, post-graduate studies, etc.³⁴

³³ S.T. Kwiatkowski, *Znaczenie kształcenia społeczno-emocjonalnego w rozwijaniu kluczowych kompetencji współczesnych nauczycieli (The Significance of Socio-emotional Education in the Development of Key Competences of Contemporary Teachers)*, [in:] *Kompetencje interpersonalne w pracy współczesnego nauczyciela (Interpersonal Competences in a Modern Teacher Work)*, eds. S.T. Kwiatkowski, D. Walczak, Wydawnictwo Akademii Pedagogiki Specjalnej, Warsaw 2017, p. 130.

³⁴ S. Byra, Z. Kazanowski, *Postrzeganie kompetencji zawodowych nauczyciela w edukacji inkluzyjnej – próba pomiaru (The Perception of Teacher’s Professional Competence in Inclusive Education – An Attempt at Measurement)*, [in:] *W poszukiwaniu indywidualnych dróg wspierających wszechstronny rozwój osób z niepełnosprawnością (In Search of Individual Approach to Support the Comprehensive Development of People with Disabilities)*, eds. B. Szczupał, A. Giryński, G. Szumski, Wydawnictwo APS, Warszawa 2015, pp. 247–260.

Education for inclusion at school is an important dimension of teacher training today. For inclusive education not to be merely apparent, it is necessary to shape favourable social attitudes, prepare competent staff equipped with knowledge about the possibilities, needs and conditions that must be met in order for a child to participate effectively in education.³⁵

Bibliography

- [1] Al-Khamisy D., *Edukacja włączająca edukacją dialogu. W poszukiwaniu modelu edukacji ucznia ze specjalnymi potrzebami edukacyjnymi (Inclusive Education as the Education of Dialogue. In Search of a Model of Education for Students with Special Educational Needs)*, Wydawnictwo Akademii Pedagogiki Specjalnej, Warsaw 2013.
- [2] Byra S., Kazanowski Z., *Postrzeganie kompetencji zawodowych nauczyciela w edukacji inkluzyjnej – próba pomiaru (The Perception of Teacher's Professional Competence in Inclusive Education – An Attempt at Measurement)*, [in:] *W poszukiwaniu indywidualnych dróg wspierających wszechstronny rozwój osób z niepełnosprawnością (In Search of Individual Approaches to Support the Comprehensive Development of People with Disabilities)*, eds. B. Szczupał, A. Giryński, G. Szumski, Wydawnictwo APS, Warsaw 2015, pp. 247–260.
- [3] Chrzanowska I., *Nauczanie inkluzyjne w doświadczeniach polskich – podstawy prawne i społeczne uwarunkowania (Inclusive Teaching in the Polish Experience – Legal and Social Conditions)*, „*Studia Edukacyjne*” 2014, no. 30, pp. 109–117.
- [4] Czerwińska K., Miler-Zdanowska K., *Tyflopedagog we współczesnej przestrzeni edukacyjnej (Teacher of Students with Visual Impairments in Contemporary Educational Space)*, [in:] *Tyflopedagogika wobec współczesnej przestrzeni edukacyjno-rehabilitacyjnej (Teaching Students with Visual Impairments Against the Background of Contemporary Educational and Rehabilitation Space)*, eds. K. Czerwińska, M. Paplińska, M. Walkiewicz-Krutak, Wydawnictwo Akademii Pedagogiki Specjalnej, Warsaw 2015, pp. 12–43.
- [5] Dycht M., *Edukacja i wspieranie uczniów ze specjalnymi potrzebami edukacyjnymi i rozwojowymi w placówkach oświatowych w Polsce (Education and Support for Students with Special Educational and Developmental Needs in Educational Institutions*

³⁵ I. Chrzanowska, *Nauczanie inkluzyjne w doświadczeniach polskich – podstawy prawne i społeczne uwarunkowania (Inclusive Teaching in the Polish Experience – Legal and Social Conditions)*, „*Studia Edukacyjne*” 2014, no. 30, pp. 109–117.

- in Poland), [in:] *Dzieci z trudnościami rozwojowymi w młodszym wieku. Indywidualne programy edukacyjno-terapeutyczne w procesie wspierania dzieci (Children with Developmental Handicaps at a Younger Age. Individual Educational and Therapeutic Programs in the Process of Supporting Children)*, ed. E. Śmiechowska-Petrovskij, Wydawnictwo Naukowe UKSW, Warsaw, 2017, pp. 11–36.
- [6] Gasik J., *Pedagog specjalny w kształceniu uczniów ze specjalnymi potrzebami edukacyjnymi (Special Education Councillor in the Education of Students with Special Educational Needs)*, [in:] *Dydaktyka specjalna w przygotowaniu do kształcenia uczniów ze specjalnymi potrzebami edukacyjnymi (Special Education in Preparation for the Education of Students with Special Educational Needs)*, eds. J. Głodkowska, Wydawnictwo Akademii Pedagogiki Specjalnej, Warsaw 2010, pp. 250–273.
- [7] Giedyk-Miko J., *Oczekiwania wobec nauczyciela oraz jego roli w środowisku wiejskim – w świetle wypowiedzi studentów pedagogiki urodzonych i wychowanych na wsi Expectations Towards the Teacher and His or Her Role in the Rural Environment – In the Light of the Statements by Students of Pedagogy Born and Raised in Rural Areas*, „Rozprawy Społeczne” 2014, vol. VIII, no. 3, pp. 48–56.
- [8] Głodkowska J., *Dydaktyka specjalna. Od wzorca do interpretacji Special Education. From Standard to Interpretation*, PWN, Warsaw 2017, pp. 40–41.
- [9] Janiszewska-Nieścioruk Z., Zaorska M., *Prowłaczające zmiany w systemie polskiej edukacji – nowe możliwości, ograniczenia i wyzwania (Pro-integrative Changes in the Polish Educational System – New Opportunities, Limitations and Challenges)*. „Interdyscyplinarne konteksty pedagogiki specjalnej” 2014, no. 4, pp. 9–28.
- [10] Konieczna-Kucharska M., *Miękkie i twarde kompetencje nauczycieli (Soft and Hard Competences of Teachers)*, „Zeszyty Naukowe Politechniki Częstochowskiej. Zarządzanie” 2015, no. 19, pp. 229–241, <<http://www.zim.pcz.pl/znwz>> [access: 28.05.2019].
- [11] Kupisiewicz M., *Pedagog specjalny – człowiek o wyjątkowych predyspozycjach osobowościowych, profesjonalista posiadający rozległą, interdyscyplinarną wiedzę i umiejętności (Special Education Teacher – A Person with Exceptional Personality Traits, a Professional with Extensive, Interdisciplinary Knowledge and Skills)*, „Studia z teorii wychowania” 2016, vol. VII, no. 4(17), pp. 173–184.
- [12] Kwiatkowski S., *Znaczenie kształcenia społeczno-emocjonalnego w rozwijaniu kluczowych kompetencji współczesnych nauczycieli (The Significance of Socio-emotional Education in the Development of Key Competences of Contemporary Teachers)*, [in:] *Kompetencje interpersonalne w pracy współczesnego nauczyciela (Interpersonal Competences in a Modern Teacher Work)*, eds. S.T. Kwiatkowski, D. Walczak, Wydawnictwo Akademii Pedagogiki Specjalnej, Warsaw 2017, pp. 125–158.
- [13] Okoń W., *Wprowadzenie do dydaktyki ogólnej (Introduction to General Education)*. Żak, Warsaw 1996.
- [14] Papińska M., *Edukacja graficzna uczniów z niepełnosprawnością wzroku odzwierciedlona w IPETach – ważny czy pomijany obszar wsparcia (Graphic Education of*

- Students with Visual Impairment reflected in IPETs – Important or Omitted Areas of Support*), [in:] *Jest człowiek z niepełnosprawnością. Pola refleksji (A Person with a Disability. Fields of Reflection)*, eds. B. Antoszevska, I. Myśliwiczek, Wydawnictwo Naukowe SILVA RERUM, Poznań-Olsztyn 2017, pp. 205–229.
- [15] Paplińska M., Walkiewicz-Krutak M., *Visual impairment as a consequence of brain tumour: difficulties experienced by the child in spatial orientation, and in the cognitive, social and communication areas*, „Człowiek-Niepełnosprawność-Społeczeństwo” 2018, no. 2(40), pp. 15–27.
- [16] Paplińska M., Witczak-Nowotna J., *Kompleksowa diagnoza dziecka niewidomego, jego sytuacji w domu i szkole – studium przypadku (Comprehensive Diagnosis of a Blind Child, Situation at Home and at School. A Case Study)*, [in:] *Diagnoza i metody wspomagania rozwoju (Diagnosis and Methods of Development Assistance)*, eds. B. Antoszevska, M. Wójcik, Uniwersytet Warmiński-Mazurski, Olsztyn 2015, pp. 71–89.
- [17] Paplińska M., Witczak-Nowotna J., *Tyfloedukacja jako element budowania integracji społecznej uczniów niewidomych i słabowidzących w edukacji włączającej (Teaching Students with Visual Impairments as Part of Building Social Integration of Blind and Visually Impaired Students in Inclusive Education)*, [in:] *Tyflopedagogika wobec współczesnej przestrzeni edukacyjno-rehabilitacyjnej (Teaching Students with Visual Impairments Against the Background of Contemporary Educational and Rehabilitation Space)*, eds. K. Czerwińska, M. Paplińska, M. Walkiewicz-Krutak, Wydawnictwo Akademii Pedagogiki Specjalnej, Warsaw 2015, pp. 114–134.
- [18] Rutkowski M., *Kompetencje diagnostyczne, planistyczne, realizacyjne i ewaluacyjne w pracy z uczniami ze specjalnymi potrzebami edukacyjnymi – w ocenie własnej nauczycieli uczących w placówkach specjalnych oraz integracyjnych (Diagnostic, Planning, Implementation and Evaluation Competences in Working with Students with Special Educational Needs – The Own Assessment of Teachers in Special and Integrative Institutions)*, „Pedagogika. Badania, dyskusje, otwarcia”. Dzieci i młodzież ze specjalnymi potrzebami edukacyjnymi. Implikacje dla teorii i praktyki (Children and Youth with Special Educational Needs. Implications for Theory and Practice), issue 3/2014, pp. 47–64.
- [19] Rutkowski M., Bidziński K., *Nauczyciele szkoły ogólnodostępnej – realizatorzy idei edukacji włączającej – w poszukiwaniu źródeł zawodowego wsparcia (Teachers of Public School – Implementers of the Idea of Inclusive Education – In Search of Sources of Professional Support)*, [in:] *Jest człowiek z niepełnosprawnością. Pola refleksji (A Person with a Disability. Fields of Reflection)*, eds. B. Antoszevska, I. Myśliwiczek, Wydawnictwo Naukowe SILVA RERUM, Poznań-Olsztyn 2017, pp. 167–186.
- [20] Sadowska S., *O władzy nauczycielskiej – jasne i ciemne strony władzy w kontekście integracji (On Teacher's Power – The Bright and Dark Sides of Power in the Context of Integration)*, [in:] *Od tradycjonalizmu do ponowoczesności (From Traditionalism to Postmodernity)*, eds. E. Górniewicz, A. Krause, Wydawnictwo UWM, Olsztyn 2002, pp. 289–298.

- [21] Skałbiana B., *Nauczyciel jako aktor szkolnej codzienności – aspekty dramaturgii i władzy (Teacher as an Actor of Everyday School Life. Aspects of Drama and Power)*, [in:] *Nauczyciel we współczesnej edukacji. Diagnoza-Rozwój-Zmiana (Teacher in Modern Education. Diagnosis – Development – Change)*, eds. M. Kamińska, Z.P. Kruszewski, A. Gretkowski, B. Skałbiana, Szkoła Wyższa im. Pawła Włodkowica in Płock, Płock-Warsaw 2016, pp. 139–347.
- [22] Szynkowska Z., *Program nauczania a kompetencje nauczyciela (The Curriculum vs. Teacher Competence)*, [in:] *Kompetencje zawodowe nauczycieli a problemy reformy edukacyjnej (Professional Competences of Teachers and Problems with Educational Reform)*, ed. E. Sałata, Wydawnictwo Politechniki Radomskiej, Radom 2001.
- [23] Śmiechowska-Petrovskij E., *Kompetencje nauczycieli uczniów niewidomych i słabowidzących w zakresie wspomagających technologii informacyjno-komunikacyjnych (Competences of Teachers of Blind and Partially Sighted Students with Respect to Assistive Information and Communication Technologies)*, „Niepełnosprawność. Dyskursy pedagogiki specjalnej”. Niepełnosprawności złożone i sprzężone – konteksty normalizacji oraz psychospołecznej aktywizacji (Complex and Interlinked Disability – Contexts of Standardisation and Psychosocial Activation), 2016, no. 21, pp. 106–120.
- [24] Wolan-Nowakowska M., *Znaczenie kompetencji społecznych w pracy pedagoga specjalnego (The Importance of Social Competence in the Work of a Special Needs Teacher)*, „Lubelski rocznik pedagogiczny” 2016, vol. XXXV, issue 3, pp. 153–163.
- [25] *Kompetencje diagnostyczne i terapeutyczne nauczyciela (The Diagnostic and Therapeutic Competence of the Teacher)*, eds. D. Wosik-Kawala, T. Zubrzycka-Maciąg, Oficyna Wydawnicza „Impuls”, Kraków 2011.
- [26] Zaorska M., *Rola i miejsce pedagoga specjalnego w kreowaniu działalności edukacyjno-terapeutycznej (The Role and Place of Special Needs Counselor in Creating Educational and Therapeutic Activity)*. “Acta Universitatis Nicolai Copernici Pedagogika” 2012, vol. XXVIII (405), pp. 13–23.
- [27] Zaorska M., *Tyflopedagogika wobec wyzwań rozwoju współczesnej nauki i cywilizacji (Teaching Students with Visual Impairments in the Face of the Developmental Challenges of Modern Science and Civilization)*, [in:] *Tyflopedagogika wobec różnorodności współczesnych wyzwań edukacyjno-rehabilitacyjnych (Teaching Students with Visual Impairments in the Face of the Diverse Challenges of Modern Education and Rehabilitation)*, eds. K. Czerwińska, K. Miler-Zdanowska, Wydawnictwo Akademii Pedagogiki Specjalnej, Warsaw 2017, pp. 12–23.
- [28] Żółkowska T., *Normalizacja – niedokończona teoria praktyki (Standardisation – The Unfinished Theory of Practice)*, „Niepełnosprawność” 2011, no. 5, pp. 85–93, <<http://bazhum.muzhp.pl/media//files/Niepelnosprawnos/Niepelnosprawnos-r2011-t-n5/Niepelnosprawnos-r2011-t-n5-s85-93/Niepelnosprawnos-r2011-t-n5-s85-93.pdf>> [28.05.2019].



The perception of people with a physical disability towards those with a different kind of disability

ABSTRACT: Monika Skura, *The perception of people with a physical disability towards those with a different kind of disability*. Interdisciplinary Contexts of Special Pedagogy, no. 26, Poznań 2019. Pp. 343–368. Adam Mickiewicz University Press. ISSN 2300-391X. DOI: <https://doi.org/10.14746/ikps.2019.25.16>

Difficulties resulting from the social perception of people with disabilities, and the personal assessment of their own disability are important for her/his relationship with other people. Therefore, it is worth asking what the perceptions are, of those who experience psychosocial effects due to their physical disability, towards people with intellectual disabilities, hearing impairments, visual impairments, mental illnesses, as well as their own physically disabled group. To analyse the perception of people with a physical disability, the study explores three areas: the acceptance or rejection of society's stigmatization towards persons with disabilities; integrative versus separative social orientations of people with physical disability; social preferences of people with physical disability regarding other disabled people. The research sample consisted of 75 people with physical disabilities, who suffer from damage to the locomotor system. The data was collected using a questionnaire. The findings highlight that the response from those who were physically disabled agreed with the opinions of general society, not only with the issue of promoting integrated solutions and offering assistance, but also having the same preferences and opinions about specific types of disability. However, their perception regarding their own group was noticeably different from that of general society.

KEY WORDS: perception of disability, physical disability, society's opinions about disability, people with different kinds of disability

Introduction

Social conventions, values, mechanisms of marking and qualifying differences in which, the so-called, full valued, impose their own norms of normality on a different person, determine the whole of their social relations. This is done due to the accepted and reproduced image, the attitude created, and the socially propagated attitude. Human cognitive structure in which the basic scheme of construction, appearance and functioning of the human body, affect the perception of those considered non-standard. Shaped by cultural factors and social model – a prototype of a human – define ideas, perceptions and social relations. Regardless of age, religion or political beliefs, standards that are most desirable and valuable in the hierarchy of our society are: health, attractiveness, strength, physical fitness, high intelligence and success.¹

Assessing the clarity of certain external features, what is perceived as desirable and valuable, or what should be avoided, affects the quality of a relationship. In the meeting – human and I- physical characteristics, posture, gestures, clothing and other aspects are factors that cause attraction or repulsion of subjects. One's physical condition and appearance are particularly important in the modern world, in which the body extracted from private space, has become a cultivated product raised to the altars, omnipresent and perfect thanks to various kinds of efforts and treatments

Emotional tension caused by the dissimilarity of the other person may cause the perception of the individual as less valuable, imposing its own standards of assessment of the causes of disability,

¹ B.A. Wright, *Developing constructive views of life with a disability*. Rehabilitation Literature, 1980, 41(11-12), pp. 274-279; P. Schilder, *The Image and Appearance of the Human Body*, Kegan Paul, Trench, Trubner, London 1935; D. Umberson, M. Hughes, *The Impact of Physical Attractiveness on Achievement and Psychological Well-Being*, Social Psychology Quarterly, Social Psychology Quarterly 1987, Vol. 50, No. 3, pp. 227-236; M Hosod, G. Stone-Romero, G. Coats, *The effects of physical attractiveness on job-related outcomes: a meta-analysis of experimental studies*. Personnel Psychology 2006, Vol. 56, Issue 2, pp. 431-462.

ways of functioning and adaptation. Attitude focused only on the relationship with what is known and typical may mean avoiding, rejecting and even questioning the co-creation of society by people perceived as different.

The attitude towards people with disabilities is also determined by the political, economic and social factors dependent on specific cultural conditions in which the participants of the relationship exist. Reproducing the stigmatizing assessment of the presence of people with disabilities as a „burden“ threatening the community, may be manifested by indicating their non-productiveness, charging the costs of maintaining, caring for and protecting other people.

A particular difficulty in meeting a person with a disability is the presence of visible, severe disability or clearly disturbed behaviour. Stronger negative reactions are raised by the perception of a defect of significant external appearance, i.e. a meeting with a disfigured face, trunk deformities or whose appearance features indicate a mental disorder, intellectual disability or AIDS, someone who has lost sight or hearing, is ill with asthma, diabetes, cardiovascular and circulatory issues, or arthritis.² Therefore, body injuries which are perceived in the first contact with a person with a disability are important, i.e. limitations in movement, communication, degree of independence and self-care, and the occurrence of social stigmatization of a given disability.³

Stereotypical perception and mechanisms of specific treatment of people with disabilities, which impose values, norms and imaginations on them, force them to accept the limitations resulting from the

² L. Gething, *Generality vs. specificity of attitudes towards people with disabilities*, *British Journal of Medical Psychology*, 1991, 64, pp. 55–64.

³ L.M. Shears, C.J. Jensema, *Social acceptability of anomalous persons*, “*Exceptional Children*” 1969, vol. 36, 91–96; E. Goffman, *Stigma: Notes on Management of Spoiled Identity*. Englewood Cliffs, New Jersey 1963; B.A. Wright, *Developing constructive views of life with a disability*. *Rehabilitation Literature*, 1980, 41(11–12), pp. 274–279; R. Chubon, *An analysis of research dealing with the attitudes of professionals toward disability*. *Journal of Rehabilitation*, 1982, 48(1), pp. 25–30; M.E. MacLaughlin, M.P. Bell, D.Y. Stringer, *Stigma and Acceptance of Persons With Disabilities*. *Group & Organization Management*, 2004, Vol. 29 No. 3, pp. 302–33.

label given to them, stigmatizing names, categorization. All unusual, unconventional ways to perform various everyday activities are not met with understanding. A branding etiquette: disabled, handicapped or crippled, limits the perception of a person to a generalized image filled with social prejudices. A person with a disability is identified in the relationship as a “copy” of a given classification, and not as a unique individual. The attribution of the stigma deprives it of its positive qualities, gives it a label of the substance as a worthless, unnecessary member of society and involves such behaviour towards it as the restrictive name designates. Experience in quality direct interaction with people with disabilities and knowledge of their problems have been the subject of expertise carried out under the direction of Antonina Ostrowska⁴ with researchers from The Polish Academy of Sciences. The questions that were addressed to non-disabled respondents took into account the issues of proximity to people with disabilities, views on the integration of this group of people in their communities, their employment and the place they should occupy in society, the declaration of readiness to help them and to have social leniency towards people with various disabilities.

The juxtaposition and interpretations of the conducted research carried out on representative nationwide groups show that over the last thirty years, the percentage of people who express positive attitudes towards people with disabilities is constantly growing.⁵ Social activities are characterized by an increasing awareness of the life situation of this group of people, although there is still a lack of involvement in personal relationships (familiarity, friendship).

Previous Polish studies⁶ show that these people are perceived through the prism of physical fitness (weak, anxious, insecure, dis-

⁴ A. Ostrowska, *Niepełnosprawni w społeczeństwie 1993–2013* [Disabled people in society 1993–2013], Warszawa 2015, Wydawnictwo IFiS PAN.

⁵ A. Ostrowska, *Niepełnosprawni w społeczeństwie 1993–2013* [Disabled people in society 1993–2013], Warszawa 2015, Wydawnictwo IFiS PAN; M.T. Westbrook, V. Legge, M. Pennay, Attitudes towards disabilities in a multicultural society, *Social Science & Medicine*, 1993, 36(5): 615–623. DOI.10.1016/0277-9536(93)90058-C.

⁶ A. Ostrowska, *Badania nad niepełnosprawnością w Polsce* [Research on disability in Poland], Warszawa 1994, Instytut Filozofii i Socjologii PAN.

satisfied with life, nervous) and issues related to social activity (hidden, suspicious, insecure, dependent on loved ones, poor people). However, the results of the last poll⁷ show that the respondents still choose such features as: insecure, poor, and other features i.e. anxious, sad, nervous, complaining – ascribing them to the disabled as much as other people in society. In the context of the social mechanisms that have always existed, the stereotypical perception of a person who for some reason is different and a coherent context of different understandings of the problem of otherness, it would be interesting to attempt to look at the relationships that occur between people with disabilities.

The research carried out was aimed at showing how people with physical dysfunction perceive people with other disabilities (intellectual, visual, hearing, and mental illness) and what is the nature of interaction between them. It seems that the fact of experiencing difficulties, which are a consequence of the negative attitude of the social environment, may have significance in dealing with people whose „otherness” is also stigmatized. The analysis carried out will therefore be an attempt to answer the question whether in meetings with individuals with a different type of disability, people with physical disability share a stigmatizing perception and social definition that determines human values and affects the attitude of the interaction. Moreover, it seems interesting to follow the way of dealing with the disability of another person, or in a group of people with mobility problems, because this otherness is approved or negatively evaluated and removed.

Research Methodology

The respondents participating in my study are a group of 75 people with physical disabilities, who experience various kinds of damage to the locomotive organ, and who have a certificate of disa-

⁷ A. Ostrowska, *Niepełnosprawni w społeczeństwie 1993–2013* [*Disabled people in society 1993–2013*], Warszawa 2015, Wydawnictwo IFiS PAN.

bility. The respondents number 55.7% women and 44.3% men; their ages are as follows: under 30 years old – 31%, from 30 to 40 years – 29.9%, over 40 years – 39.1%; the majority (56.9%) are unmarried; nearly half have secondary and post-secondary education (46.6%) and slightly more than half study or are employed (51.2%); most reside in small towns (40.2%); almost 60% of the respondents were disabled from birth or lost their efficiency before the age of 18. The selection of the group was made on the basis of the availability of respondents. The respondents are people with physical disabilities living in the Mazowieckie voivodship and Warsaw.

The study used the diagnostic survey method and focus group interviews. The obtained results helped to construct the questionnaire, which was used to conduct the quantitative research. The questionnaire contained 45 questions, including 36 closed questions, 9 semi-open questions and 15 survey questions. The research was carried out through the personal access of the researcher to the respondents and the request to complete the questionnaire, which concerned the issue of proximity and social distance to people with a particular type of disability, social preferences, integration activities, responsibility for help and evaluation of people with other types of difficulties.

Research Findings

The purpose of the interpretations was to determine whether respondents, experiencing psychosocial difficulties resulting from their own disability, take over and share the common attitude and perception towards people with disabilities. Therefore, the first part presenting the results concerns the issue of the universal image of people with disabilities and its importance in the perception of people with other disabilities by people who have physical disabilities. The issues of perception and the social situation of people with disabilities were discussed here. The article also presents the results of the respondents' beliefs about people with a disability other than

having to do with motor skills. The second part of the analysis captures the respondents' convictions about the need for help and integration measures for people with disabilities. It also includes an attempt to identify trends present in the respondents' relations, which would help to determine whether people with physical disabilities seek to contact individuals with a different type of disability or try to avoid them.

Social Image of People with Disabilities in the Opinion of People with Physical Disability

In the created image of the social perception of people with disabilities, the elements of loneliness, weakness, social withdrawal and dependence on others are clearly highlighted⁸. Therefore, the respondents were asked – people with motor disabilities – what their opinion is about the features and general opinions defining people with various types of restrictions.

In the organized results, regarding which features are characteristic of a group of people with disabilities, the respondents disagreed with the majority of social opinions about people with disabilities. In particular, many respondents denied that people with various difficulties in functioning are weak, dissatisfied with life or fearful. On the other hand, the respondents agreed with the general assessment that the disabled are easier to hurt than non-disabled people and that these individuals are more often insecure.

The obtained analysis indicate that the respondents confirmed the presence of social schemes that stigmatize the dissimilarity of appearance and functioning with disability. They probably experience negative attitudes of their surroundings and are aware that other people with disabilities are also subject to social ostracism

⁸ A. Ostrowska, *Badania nad niepełnosprawnością w Polsce* [Research on disability in Poland], Warszawa 1994, Instytut Filozofii i Socjologii PAN.

as marked by the stigma of otherness-alienation. When assessing common opinions about people with disabilities, the respondents did not confirm social thinking patterns concerning the terms related to decision making, quality of life, and sustained the assessments that are related to difficulties in social interactions.

In order to get to know the point of view of people with physical disabilities regarding the specifics of social fear of otherness, which is disability, they were asked what kind of disability society most often avoids contact with. The majority of respondents – almost 75% – indicated that in their opinion the public is most worried about people who have mental problems. In the second place, they avoid people with intellectual disabilities, and in the third – people with mobility disabilities. Such an assessment coincides with the opinion that, according to research on this subject, the whole of society has, which also avoids, above all, those with mental illness and intellectual disabilities.

The results obtained show that the respondents did not negatively mark the sensory disability group. It seems that people who are blind and deaf, in the opinion of people with physical disabilities, do not arouse the reluctance of society by their presence. The respondents probably recognized that these people more often than other people with disabilities are able to hide their physical ailments, and thus can be treated as non-disabled individuals.

Different types of problems related to the experience of disability, still existing architectural barriers result in people with mobility disabilities to be dependent on the help, support and presence of other people in the immediate vicinity, who are generally able-bodied. However, the social environment in which people with mobility problems live is also created by other disabled people with similar illnesses and people with disabilities different from their own. The surveyed people with physical disabilities, were therefore asked what, in their opinion, the ratio of people with problems with mobility is, to people with different kinds of disabilities.

The surveyed people with physical disabilities were asked what, in their opinion, are the attitudes of people with physical disabilities

towards people with another type of disability (Chart no. 1). The majority of respondents – 60% – said that they are very good or good, but 30% have no opinion on the subject.

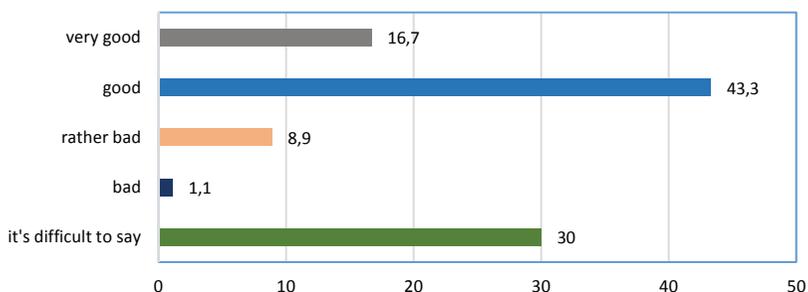


Chart no. 1. Opinion about attitudes of people with physical disabilities towards people with another type of disabilities (in %)

The aim of the conducted analysis is to determine whether the respondents – people with physical disabilities – themselves experiencing difficulties resulting from limitations and negative perception by the environment, establish unmediated, individual relationships with people with disabilities, or whether they duplicate the social perceptions concerning the image of people with limited mental development, reduced sensory efficiency and other impairments of mental function and mobility. Therefore, the respondents were asked to choose which of the adjectives, given in two groups – negative and positive – and which were the most suited to each group of people. Table no. 1 shows the negative adjectives data.

In order to find out whether the image of individuals with disabilities also includes positive opinions of respondents (people with mobility problems) they were asked to rate people with mobility disabilities, intellectual disabilities, visual disabilities, hearing disabilities and mental illness. The obtained data show that the respondents, marking the terms with a pejorative colour, duplicate social patterns and least favourably evaluate individuals with a mental

Table no. 1. Negative adjectives

In which groups people are:	Physical disabilities	Intellectually disabilities	Visual disabilities	Hearing disabilities	Mental illnesses
Apprehensive	5,6%	29,2%	6,7%	4,5%	53,9%
Weak	24,7%	25,8%	4,5%	2,2%	42,7%
Lonely	13,5%	23,6%	9%	7,9%	46,1%
Suspicious	10,1%	13,5%	12,4%	14,6%	49,4%
Unfriendly	14%	17,4%	5,8%	8,1%	54,7%
Quickly withdrawing	18,2%	26,1%	8%	3,4%	44,3%
Helpless	22,2%	28,9%	6,7%	2,2%	40%
Nervous	17%	5,7%	4,5%	9,1%	63,6%
Boring	11,4%	22,7%	3,4%	29,5%	33%
Complainer	62,5%	8%	3,4%	4,5%	21,6%
Self-conscious	27%	14,6%	22,5%	6,7%	29,2%
Dependent	27,3%	27,3%	14,8%	2,3%	28,4%
Bitter	34,1%	12,5%	4,5%	6,8%	42%
Secretive	16,7%	23,3%	8,9%	15,6%	35,6%
Poor	22,5%	29,2%	12,4%	5,6%	30,3%
Malicious	32,2%	9,2%	3,4%	3,4%	51,7%
Uneducated	9,1%	47,7%	2,3%	3,4%	37,5%
Argumentative	19,8%	16,3%	9,3%	5,8%	48,8%
Impatient	25,8%	23,6%	5,6%	5,6%	39,3%
Neglected	12,8%	30,2%	9,3%	0%	47,7%

illness. People with intellectual disabilities were usually second in the negative assessment of people with disabilities. People with sensory disabilities, especially those with hearing disabilities, were rarely chosen.

The respondents also assessed which of the positive definitions best describes each group of individuals with disabilities. The results obtained show that the respondents, by marking adjectives with a positive colour, most often referred to their own group. In the second place, the respondents most often positively assessed

individuals with visual disabilities. Then the respondents proceeded to indicate people with intellectual disability and people with hearing disabilities. Favourable assessments of people with sensory disabilities duplicate social opinions about this group of people. The most rarely chosen are positive adjectives in relation to individuals with mental illness. The perceptions of those who are physically disabled are consistent with those of general society with regards to people with intellectual disabilities, individuals with sensory disabilities and people with mental health issues. Table no. 2 shows the detailed results about positive adjectives data.

Table no. 2. Positive adjectives

In which groups people are:	Physical disabilities	Intellectually disabilities	Visual disabilities	Hearing disabilities	Mental illnesses
Brave	61,8%	11,2%	12,4%	6,7%	7,9%
Strong	58,4%	10,1%	16,9%	11,2%	3,4%
Sociable	75,6%	7,8%	8,9%	4,4%	3,3%
Unsuspicious	31,8%	40,9%	14,8%	5,7%	6,8%
Friendly	50%	28,9%	13,3%	4,4%	3,3%
Persistent	61,8%	1,1%	27%	4,5%	5,6%
Resourceful	62,2%	4,4%	23,3%	8,9%	1,1%
Calm	46,7%	3,3%	34,4%	15,6%	0%
Interesting	56,7%	8,9%	21,1%	10%	3,3%
Content	43,3%	23,3%	14,4%	7,8%	11,1%
Confident	66,7%	13,3%	8,9%	6,7%	4,4%
Independent	50%	6,7%	10%	27,8%	5,6%
Happy	40,4%	25,8%	14,6%	11,2%	7,9%
Outgoing	52,8%	25,8%	10,1%	9%	2,2%
Patient	35,2%	9,1%	45,5%	10,2%	0%
Wealthy	49,4%	13,8%	14,9%	14,9%	6,9%
Good-hearted	42%	26,1%	17%	6,8%	8%
Well groomed	59,3%	1,2%	16,3%	20,9%	2,3%
Educated	63,3%	5,6%	15,6%	11,1%	4,4%
Consistent	40,4%	18%	32,6%	9%	0%

In the opinion of the respondents, people with physical disabilities often complain (62.5%), they are bitter (34.1%) and malicious (32.2%). At the same time, in their opinion, it is this group of individuals with disabilities who are social people (75.6%), confident (66.7%) and educated (63.3%). The obtained data show that, most of the respondents with physical disabilities think that intellectually disabled people are: uneducated (47.7%), neglected (30.2%), apprehensive (29.2%), and poor (29.2%). Respondents also believe that these people are unsuspecting (40.9%), friendly (28.9%) and good-hearted (26.1%).

In contrast, they think that people with visual disabilities are insecure (22.5%), dependent (14.8%) and suspicious and poor (by 12.4%). In addition, respondents perceive these people as patient (45.5%), calm (34.4%) and consistent (32.6%). In the perception of many respondents, people with hearing disabilities are boring (29.5%), secretive (15.6%) and suspicious (14.6%). In the perception of the majority of respondents people with visual disabilities are boring (29.5%), secretive (15.5%) and suspicious (14.6%). Among the positive features, the most frequently indicated is that they are independent (27.8%), well groomed (20.9%) and calm (15.6%). Respondents estimated that mentally ill people are nervous (63.6%), unfriendly (54.7%) and fearful (53.9%). A few questioned indicated a positive determination in relation to this group of people: 11.1% indicated that they are content, 8% good-hearted, and 7.9% that they are courageous.

The opinions of the respondents concurred with that of general society regarding the perception of people with intellectual disabilities, individuals with sensory disabilities and people with mental health problems. In the opinion of the general public, people with visual or hearing disabilities create a kind of closed world that is incomprehensible to the "uninitiated". "The observers from the outside" often state that these people are suspicious, insecure, helpless (that respondents assessed people with visual disabilities in the same way) and boring and secretive (which was the same opinion as the respondents regarding people with hearing disabilities).

People with sensory disabilities are also perceived more positively than people with other difficulties. These disabilities are less visible and often, according to popular opinion, are associated with having some exceptional, disability-compensating talents. In the schematic thinking of society, people with visual disabilities are distinguished by humility and serenity, therefore they are, as the respondents indicated, patient, self-controlled and unanimous. The perception of people with auditory disabilities, whose deficiencies are completely invisible, is the most positive. This group of people is often considered to be able-bodied, therefore they are perceived, as the respondents indicated, as independent and well-groomed individuals. Whereas, people with mental illness and individuals with intellectual disabilities are particularly negatively perceived. Society is afraid of people who, due to various types of mental disorders, do not behave in a predictable and rational manner. They are usually perceived by society, whose views are similar to those of the respondents, as nervous and unfriendly people. Moreover, the obtained data shows that few respondents marked positive adjectives for this group of people.

In a society where the highest values include effective use of reason, accuracy and speed of decision making, calculations of profits and start-up as well as resourcefulness, a reduction of mental ability is treated as a particularly undesirable limitation. People with intellectual disabilities are therefore perceived, as the respondents indicated, as uneducated, neglected, fearful and poor. Regardless of this, individuals with intellectual disabilities are often called "big children" and in the common opinion they also function as trustworthy, friendly and kind-hearted people.

Analysis of the data show that the respondents, when assessing people with a disability other than their own, take over and reinforce social schematic assessments, and partly reject the prevailing opinions about people with mobility disabilities. In the group's own assessment, the respondents, on the one hand, admitted that people with mobility disabilities often complain, are bitter and mean, and

on the other hand, they have ennobledly indicated that they are sociable, confident and educated. In addition, the majority of respondents had positive adjectives for this group. Opinions of the general public⁹ are more generalized, focused on differences in appearance and limited possibilities.

Integrative versus Separate Social Orientations of People with Physical Disability towards People with the Other Kinds of Disability

The aim of the conducted research was to obtain information on what relations between people with mobility disabilities and people with a different type of disability looks like. Conducted analysis will be aimed determining whether the personal experience of negative treatment of disabled people induces respondents to a deeper, more authentic dimension of an encounter with another human being, regardless of its otherness or whether it causes taking over and duplicating social automatism of classification and imposing identity. People experiencing various types of physical and mental disabilities need care, help and support in everyday matters. Respondents were asked, therefore, who they think should take care of it and what their position is in relation to the currently functioning integration processes.

For more information about who is responsible for the help people with disabilities should receive, respondents were asked to rank their opinion: 1 - most need help, 2 - as the second in the sequence should help etc. until 6 or 7. The data represent the mean of elected answers and show to what extent the respondents indicated for responsibility for helping in a particular group. For the six groups (a,b,c,d,e,f) The lower that the number is, correlates to a higher level of perceived responsibility.

⁹ A. Ostrowska, *Badania nad niepełnosprawnością w Polsce* [Research on disability in Poland], Warszawa 1994, Instytut Filozofii i Socjologii PAN.

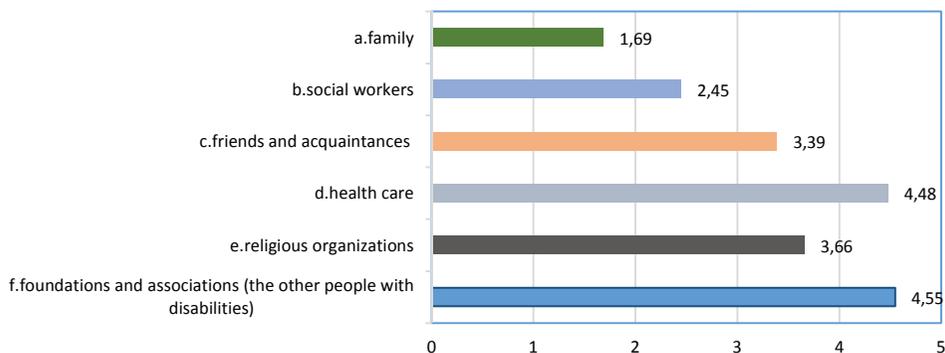


Chart no. 2. Responsibility for helping people with disabilities

Calculations show that most of those questioned ranked family in the first place (the mean of the response - 1.69). They considered, therefore, that help for people with disabilities should be provided primarily by relatives. Second, it is estimated that social workers should help (the mean of the response - 2.45). Similarly, it was indicated that health care should provide help to individuals with all sorts of problems in functioning, and friends and acquaintances (mean of the answers - 4.48 and 3.39). Least often they stated that assistance should be provided by religious organizations and by other people with disabilities who work in foundations and associations (mean respectively - 3.66 and 4.55). This data is shown in Chart no 2.

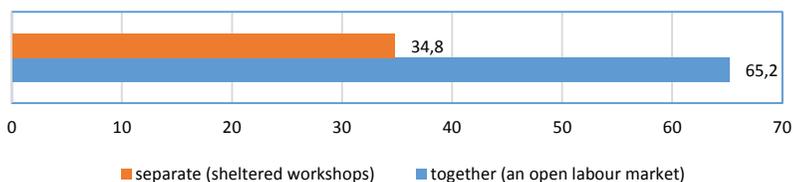


Chart no. 3. Separate or integrative forms of employment for people with disabilities (in %)

In order to determine the opinions of respondents on social inclusion, I asked if able-bodied people and physically disabled people and those with another type of disability should be together or separate in places such as the workplace, residential areas, schools or trips.

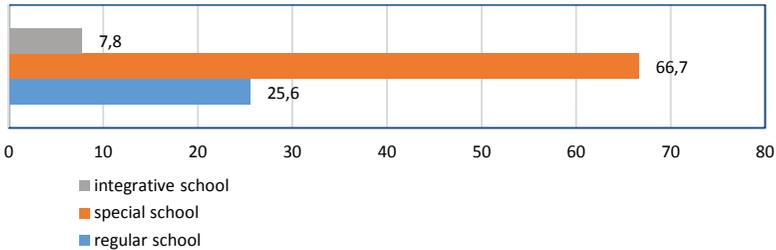


Chart no 4. Separate or integrative forms of schooling (in %)

The data obtained about the workplace show (Chart no. 3) that the majority of respondents are in favour of an integrative form of employment for people with disabilities – 65.2% of those interviewed. Answers expressing their opinions on how people should be educated, again show (Chart no. 4) that the majority of respondents, 66.7%, are in favour of integration. But some of those interviewed also believe otherwise: 25.6% – and said that the best schools are regular, and 7.8% – believe that individuals with a disability should attend special schools.

The aim of the study was also to determine the opinion of respondents on the matter of integration solutions in the construction of residential buildings. The results shows Chart no. 5.

The majority of respondents – 57.3% – considers that it is necessary to build settlements where people can live with all different types of disabilities with non-disabled people. While some of them would prefer housing estates that were built only for people with

physical disabilities and able-bodied individuals – thus marked 29.2% of the group. Among the respondents, there are also those who think that it would be best to build separate settlements for people with disabilities and their families and to adapt them to different types of disability (13.5%).

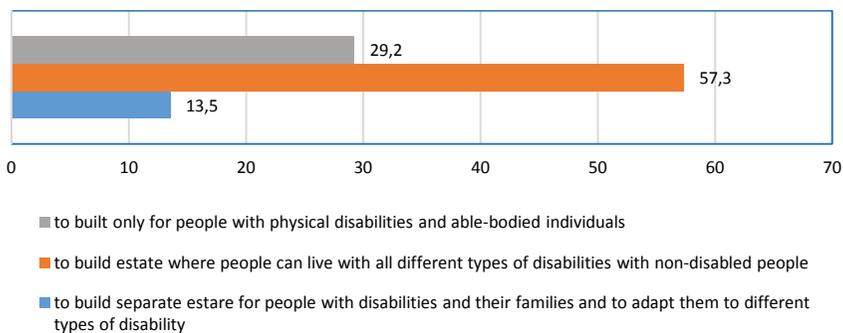


Chart no. 5. Integration solutions in the construction residential buildings (in %)

The respondents were also asked how to organize the meetings of different groups of people – able-bodied and disabled – on trips and recreational meetings in all sorts of clubs, community centres, etc.. The results show (Chart no. 6) that in the opinion of many respondents it is best when people with physical disabilities, people with another type of disability, and able-bodied jointly participate in all kinds of trips, events, meetings. 72.4% of the group marked in this way. Nearly 20% of respondents said that it is best when persons with different types of disabilities belong to the same clubs, community centres, and together they participate in common trips. Only 8% believe that it is better to organize separate trips, clubs, etc. for people with different kinds of disability.

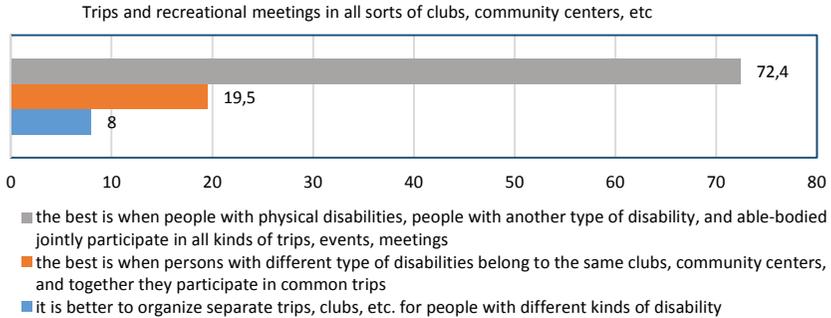


Chart no. 6. Organisation of meetings of different groups of people (in %)

The respondents were also asked about their willingness to help people with another type of disability. The results of the survey show (Chart no. 7) that the majority of respondents – 64.4% – said that if a person with a different disability lived in their neighbourhood, they would willingly help him/her in everyday life matters. Some of the interviewed – 16.7% – said they “would rather” help. Almost no one would refuse to assist (only 1.1%), and 5.6% said they „probably” would not help. Among the respondents 12.2% of those interviewed had no opinion on this matter.

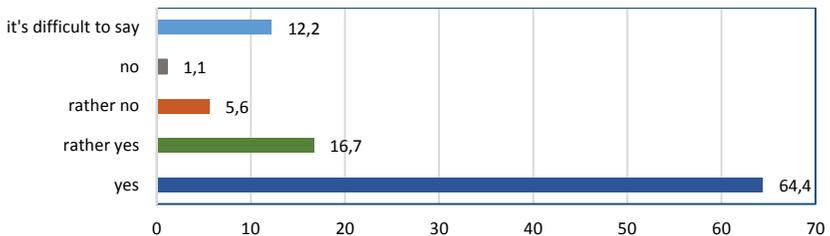


Chart no. 7. Personally helping disabled people (in %)

Seeking to discover if those opinions are the result of interpersonal experiences, or just conjecture, I asked about the frequency of

contact with respondents in those particular groups. The results show the surveyed person's proximity/intimacy and social distance towards people with intellectual disabilities, individuals with visual disabilities, people with hearing disabilities, persons with mental illness and people with physical disabilities. The obtained results are shown in Chart no. 8.

My results show that most questioned have relationships with people who have a similar type of disability. It turns out that more than half have or had such a person among their acquaintances, and 34.8% in the family and among close friends. The respondents meet or met also with individuals with sensory disabilities. Almost 40% count a person with visual disabilities as a friend, and almost 30% know one not so well or only by sight.

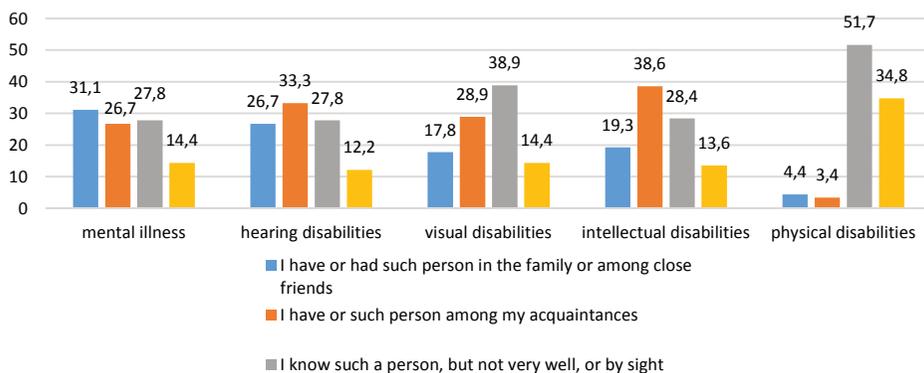


Chart no. 8. Contact of respondents with people with particular group of people with disability (in %)

Less often respondents meet or met with people with intellectual disabilities. Almost 40% are not very familiar with such persons or know them only by sight. Slightly fewer questioned – 28.4% – think about individuals with intellectual disabilities as a friend. However, 19.3% of respondents have a complete lack of contact

with this group. As my results showed, respondents have the most limited contact with individuals with mental illness. Over 30% do not know such people. Most of the other respondents, with similar frequency, emphasized that they have such people among their friends (27.8%) and that they know such a person, but not very well, or by sight (26.7%).

In addition, to determine what are the general social preferences of the respondents, they were asked, which of these groups they spend the most time with (including able bodied). The majority of respondents – 64.4% – have friends who are non-disabled. Some of those interviewed – 27.8% – stated that some of their friends have physical disabilities, and 7.8% said they are friends with individuals with disabilities other than physical. The obtained results are shown in Chart no. 9.

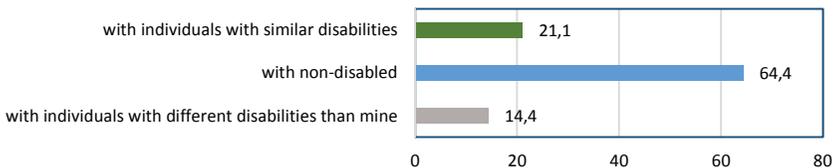


Chart No. 9. Spending time with people from all groups (including able-bodied) (in %)

Social Preferences of People with Physical Disability Regarding Other Disabled People

In order to gain knowledge about the choice of social relations of people with physical disabilities, respondents were asked which groups of disabled people they would be unwilling to have various types of social interaction with. The results are shown in Chart no. 10.

It turns out that in response to all the questions asked, respondents most often admitted that they would not enter into relationships with people with mental illness. The largest number of respondents indicated in this way with regard to possible neigh-

bourhood (75.6%), friendship (70%) and choice of partner / life partner (68.9%). It can therefore be concluded that the respondents particularly do not want to deal with this group of people in their immediate environment and in their personal relationships.

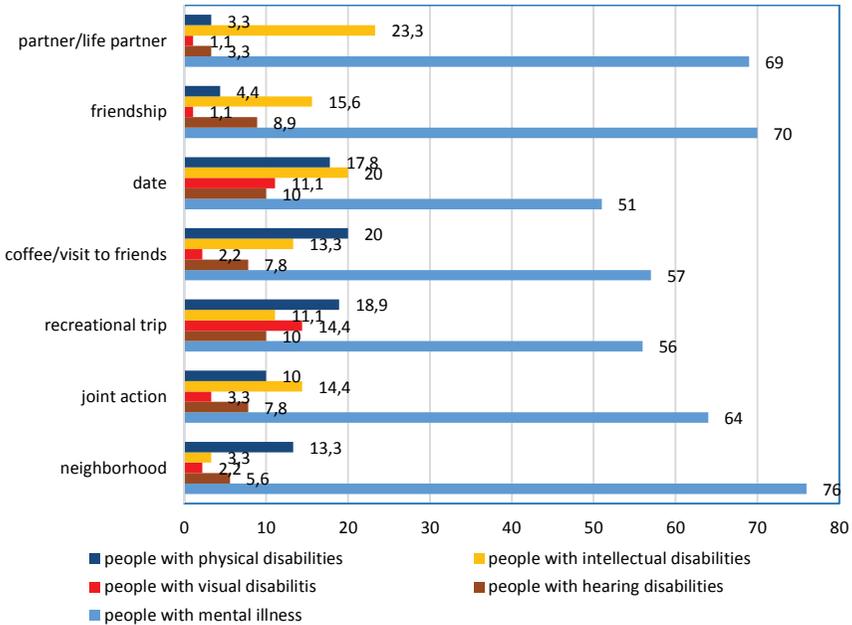


Chart no. 10. Frequency of choosing groups of people with disabilities, with whom the respondents would be unwilling to have social interactions (in %)

Similarly, people with intellectual disabilities are also not accepted in the closest contact (partner/life partner - 23.3%, date - 20%, friendship - 15.6%), but are, by the vast majority of the respondents, welcome as neighbours. Some of the respondents do not want to keep in touch with their own group in social relations: coffee/visit to friends - 20%, recreational trip - 18.9%, date - 17.8%. Many respondents do not mind friendship, creating a relationship or neighbourhood relation with people with similar difficulties in functioning

(negative answers were indicated by only 4% of those who were asked). Few respondents are opposed to making different types of interactions with people with hearing disabilities. The subjects to which such relationships interfere, indicated answers related to social life: a date and a recreational trip – 10%, friendship – 8.9%. Only 3.3% would not like to be with a partner in this group of people with disabilities. The respondents are least at odds with relationships with individuals with visual disabilities. This group of people was the least often indicated in relation to the closest contacts – the answer “no” was indicated by only about 1% of the respondents.

The obtained results indicate a definite choice of people with a physical disability by the respondents in all closer and further relations. Most of the respondents want to be with people with a similar type of difficulty in functioning in friendship and in joint action (85.2% and 79.8% respectively). Other groups of people with disabilities were less frequently marked (Chart no. 11).

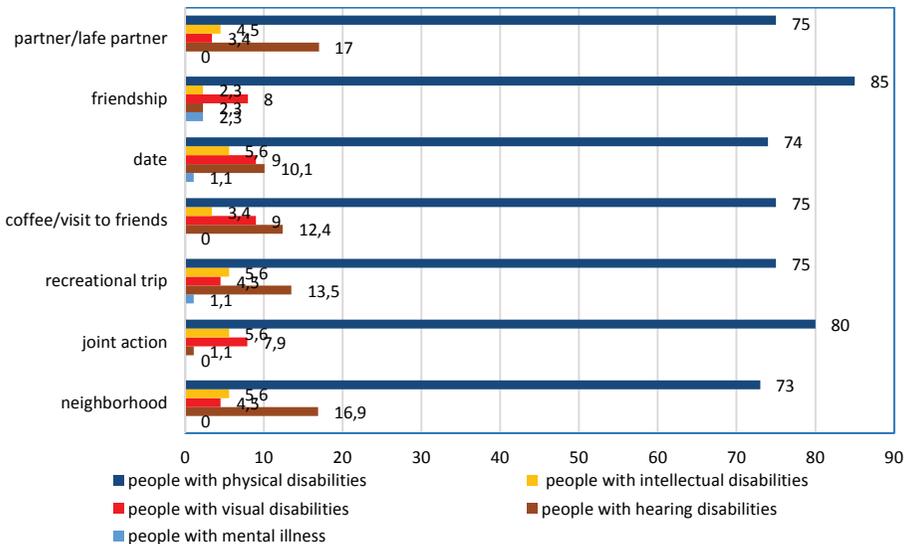


Chart no. 11. Frequency of choosing groups of people with disabilities, with whom they would willing enter into relationships (in %)

People with hearing disabilities are the second group in the order with which, according to the obtained research results, the respondents most often want to enter into relationships. A relatively large number of respondents indicated that they would be willing to be in a relationship with such a person or have them as a neighbour. There was less willingness to have interactions such as friendship or joint action. Those with visual disability were most often chosen in interactions regarding social life and cooperation (coffee or a visit to friends), and less often when it was about establishing an intimate relationship. The least often indicated by the respondents, and therefore least accepted in the relations, are people with mental illness.

Conclusion and discussion

The obtained data allows us to state that it is primarily able-bodied people who are the reference group for the surveyed people. With the able-bodied people, most of the respondents want to stay, live, cooperate, contain the deepest relationships, although, as the results indicate, these meetings are not always satisfactory for the respondents. It can therefore be concluded that those with disabilities who are most often surrounded by the respondents are probably also a source of their frustration and difficulties in interpersonal relations. In addition, it also turns out that the respondents know, apart from the able-bodied, above all people with mobility problems. With this group of people, they want to enter into all kinds of relationships and it is the only group among people with disabilities in which they look for friends and partners. The most popular positive terms in relation to people with physical disabilities can confirm that the contacts of the respondents are limited to this group only.

In the literature, we can find confirmation of the results we obtained, where the authors point to the incitement mechanisms be-

tween the groups. Meeres and Grant¹⁰ note that through the process of differentiation, whereby 'an individual portrays his or her own group (the in-group) as superior to a relevant other group (the out-group)', a more positive social identity will be created. The 'ownership' of a disability identity seems to be stimulated by two main motivators; first, the pride in identifying as a member of a minority group in a manner similar to other oppressed groups and, secondly, to restrict the number of competing groups for limited financial resources. On the other hand, the results of the study conducted by Watson¹¹ indicate many disabled persons do not see themselves as disabled and do not identify as disabled people. This means that they can see the lack of efficiency and difficulties resulting from it affecting people with different types of disability.

Less positive opinions about people with a different type of disability may result from the objective impossibility of establishing contact or a lack of willingness to meet another person who is also burdened. Negative assessments of the group of people with intellectual disabilities and, above all, individuals with mental illness, duplicate negative attitudes and social stereotypes, and confirm that the lack of direct contact makes it difficult to verify the negative valuation and reduce the distance in the relationships. More positive opinions about people with sensory disabilities, on the one hand, may also be due to a beneficial, social image of these groups, and on the other hand - a desire to interact with people whose disability is less visible. Deal¹² in his work confirms discriminatory practices and strategies that include focusing attention on those who have impairments and face discrimination in society (i.e. those

¹⁰ S.L. Meeres, P.R. Grant, *Enhancing collective and personal self-esteem through differentiation: further exploration of Hinkle & Brown's taxonomy*, *British Journal of Social Psychology*, 1999, 38, pp. 21-34.

¹¹ K. Watson, *Well, I Know this is Going to Sound Very Strange to You, but I Don't See Myself as a Disabled Person: Identity and disability*, 2002, *Disability & Society*, Volume 17(5), pp. 509-527.

¹² M. Deal, *Disabled people's attitudes toward other impairment groups: a hierarchy of impairments*, *Disability & Society*, 2003, 18: 7, pp. 897-910.

ranked lowest in the hierarchy of impairments) and disabled people, however, it is important that these discriminatory practices and strategies are addressed to further the common cause in seeking equality within society.

The obtained data leads to a similar conclusion that the most important factor in the perception and treatment of people with disabilities by the respondents has a social impact factor. The preferences and assessments of the respondents coincide with the common opinions on particular groups. The circumstance of a non-reflective deprivation of the social environment is more significant for relations with other people with disabilities than the frequency of contacts and similar difficulties related to the disability experienced.

Bibliography

- [1] Chubon R., *An analysis of research dealing with the attitudes of professionals toward disability*. Journal of Rehabilitation, 1982, 48(1), pp. 25–30.
- [2] Deal M., *Disabled people's attitudes toward other impairment groups: a hierarchy of impairments*, 2010, Disability & Society, Vol. 18, No. 7, December 2003, pp. 897–910.
- [3] Gething L., *Generality vs. specificity of attitudes towards people with disabilities*, British Journal of Medical Psychology, 1991, 64, pp. 55–64
- [4] Goffman E., *Stigma: Notes on Management of Spoiled Identity*. Englewood Cliffs, New Jersey 1963.
- [5] Hosod M., Stone-Romero E., Coats G., *The effects of physical attractiveness on job-related outcomes: a meta-analysis of experimental studies*. Personnel Psychology, 2006, Vol. 56, Issue 2, 431–462.
- [6] MacLaughlin M.E., Bell M.P., Stringer D.Y., *Stigma and Acceptance of Persons With Disabilities*. Group & Organization Management, 2004, Vol. 29 No. 3, pp. 302–333
- [7] Meeres S.L., Grant P.R., *Enhancing collective and personal self-esteem through differentiation: further exploration of Hinkle & Brown's taxonomy*, British Journal of Social Psychology, 1999, 38, pp. 21–34.
- [8] Ostrowska A., *Badania nad niepełnosprawnością w Polsce* [Research on disability in Poland], Instytut Filozofii i Socjologii PAN, Warszawa 1994.
- [9] Ostrowska A., *Niepełnosprawni w społeczeństwie 1993–2013* [Disabled people in society 1993–2013], Wydawnictwo IFiS PAN, Warszawa 2015.

- [10] Schilder P., *The Image and Appearance of the Human Body*. Kegan Paul, Trench, Trubner, London 1935.
- [11] Shears L.M., Jensema C.J., *Social acceptability of anomalous persons*, "Exceptional Children" 1969, vol. 36, pp. 91-96.
- [12] Umberson D., Hughes M., *The Impact of Physical Attractiveness on Achievement and Psychological Well-Being*, *Social Psychology Quarterly*, 1987, Vol. 50, No. 3, pp. 227-236.
- [13] Watson K., *Well, I Know this is Going to Sound Very Strange to You, but I Don't See Myself as a Disabled Person: Identity and disability*, 2002, *Disability & Society*, Volume 17(5), pp. 509-527.
- [14] Westbrook M.T., Legge V., Pennay M., *Attitudes towards disabilities in a multicultural society*, *Social Science & Medicine*, 1993, 36(5), pp. 615-623.
- [15] Wright B.A., *Developing constructive views of life with a disability*. *Rehabilitation Literature*, 1980, 41(11-12), pp. 274-279.



The Significance of Qualitative Research – Arts-based Research in Special Needs Education and Music Therapy

ABSTRACT: Sara Knapik-Szweda, *The Significance of Qualitative Research – Arts-based Research in Special Needs Education and Music Therapy*. Interdisciplinary Contexts of Special Pedagogy, no. 26, Poznań 2019. Pp. 369–388. Adam Mickiewicz University Press. ISSN 2300-391X. DOI: <https://doi.org/10.14746/ikps.2019.25.17>

One of the functions of art is understanding an individual and his or her potential. Art provides an individual with proper conditions and gives new opportunities to function regardless of one's age and disability. The purpose of this article is to get the reader acquainted with the significance of qualitative research especially in the context of arts-based research in special needs education and music therapy. In theoretical part, the authoress will attempt to answer the question of what benefits this research method brings and why it is useful.

What is to be described at the beginning quite extensively is the situation of research in special education and music therapy as a scientific discipline. This presentation will smoothly lead the reader to the essence of article, i.e. the arts-based research method. The definitions of arts-based research will be presented together with differences resulting from defining the notions connected with art. Examples will also be provided of research based on art resulting from the combination of two disciplines such as special needs education and music therapy. Moreover, the authoress will demonstrate her own research based on art with the application of music which emphasizes the significance of changes that occur within the music therapy process. Finally, the arguments which emphasize the significance of arts-based research will be mentioned.

KEY WORDS: arts-based research; music therapy; special needs education

Introduction

The term 'research' describes a studious inquiry or acquisition of new knowledge in a thorough and detailed manner.¹ Research is a planned investigation, aimed at discovering or obtaining a new perspective of a given issue. In turn, it contributes to expanding or changing existing assumptions of theoretical or practical knowledge.² Barbara Wheeler points out that conducting research leads to discovering something new, confirming existing knowledge or changing the way we perceive what we already know.³ In this article I would like to focus on the importance of qualitative research, specifically arts-based research (primarily music-based one) in the context of special needs education and music therapy. I would like to define what this type of research really is and to present examples of other researchers' studies as well as my own ones, within two disciplines, i.e. music therapy and special needs education. Despite the differences and ways of interaction, these two disciplines are very closely related due to the subject of interest, which is a human being, his/her capabilities, resources, but also difficulties or weaknesses. It is this common area that I would like to focus on.

Both disciplines are based on the same principles that are worth mentioning: 1. **personalisation** - special needs education and music therapy seek to protect personal dignity and identity; together they create a humanist culture focused on the individual and the relationship; 2. **early diagnosis and normalisation of life** - they create optimal conditions for development, sensitising people from the immediate environment to create attitudes of functioning of people with disabilities; 3. **responsibility** - they emphasise the shared responsibility of society for the private and public sphere of people

¹ Merriam Webster's Collegiate Dictionary, G.C. Merriam, Springfield 2002, p. 992.

² K. Bruscia, *The boundaries of music therapy research*, [in:] *Music Therapy Research: Quantitative and qualitative perspectives*, ed. B. Wheeler, Barcelona Publishers, Gilsum 1995, p. 21.

³ B. Wheeler, *Badania w dziedzinie muzykoterapii (Research in the Field of Music Therapy)*, [in:] *Podstawy muzykoterapii (Introduction to Music Therapy)*, ed. K. Stachyra, Wydawnictwo Uniwersytetu Marii Skłodowskiej-Curie, Lublin 2012, p. 243.

with disabilities; they do not marginalise the individual, but, according to the interactive model, show that disability lies in the relationship between people, not in the individual; 4. **subsidiarity** - the principle of individual learning and maturation of the individual; providing holistic support; 5. **broadening autonomy** - gaining independence, recognition of subjectivity and autonomy of individuals with disabilities; 6. **individualisation** - adaptation of therapeutic attitudes and activities to the category of a given disorder and the nature of people; relying on the individual's potential, possibilities and ways of developing them in various situations; 7. **multi-specialist approach towards the individual and cooperation with the family**.⁴

The differences and similarities between special needs education and music therapy are illustrated in the figure below, which primarily indicates the aforementioned area of interest of two disciplines and their principles.

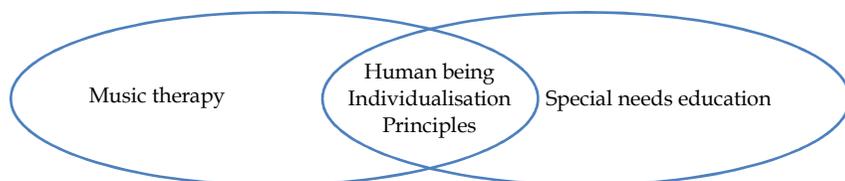


Figure 1. Common areas of special needs education and music therapy. Own study

***Arts-based research* in music therapy and special needs education**

Katarzyna Krasoń and Ludwika Konieczna-Nowak emphasise that art and pedagogy strive for empathy accumulated on the path

⁴ W. Dykcik, *Zakres i przedmiot zainteresowań pedagogiki specjalnej (Special Pedagogy – The Scope and Subject of Interest)*, [in:] *Pedagogika specjalna (Special Pedagogy)*, ed. W. Dykcik Wydawnictwo Uniwersytetu im. Adama Mickiewicza w Poznaniu, Poznań 2012, pp. 75–79.

of experience, bringing subjectified material,⁵ emphasising the importance of qualitative and individualising research, which in its nature is based on the uniqueness of the studied element. According to Krzysztof Konarzewski, each research object is unique and exceptional in qualitative research.⁶ Qualitative research in special education and music therapy focuses on understanding the psychological features of the individual and puts great emphasis on the details appearing in the therapeutic/research process. It is holistic, empirical, descriptive and empathic, based on the experience of the individual.⁷ Krasoń and Konieczna-Nowak also define it as interdisciplinary/transdisciplinary, intersubjective, and eclectic (especially research in music therapy).⁸ This interdisciplinary research in music therapy is moving away from one-sided methodological thought in favour of research fusion, data mixing, and diversity of approaches that allow for a broader research perspective.⁹ Intersubjectivity, in turn, is based on obtaining subjective material, or experiences acquired during the process both from a therapy participant and researcher.¹⁰

Research conducted in special needs education is used for theoretical, practical, exploratory, verification and diagnostic pur-

⁵ K. Krasoń, L. Konieczna-Nowak, *Sztuka, terapia, poznanie. W stronę podejścia indywidualizującego w badaniach muzykoterapeutycznych (Art, Therapy, Cognition. Towards an Individual Approach in the Research on Music Therapy)*, PWN, Warszawa 2016, p. 113.

⁶ K. Konarzewski, *Jak uprawiać badania oświatowe. Metodologia praktyczna (How to Do Research in Education. Practical Methodology)*, Wydawnictwa Szkolne i Pedagogiczne, Warszawa 2000, p. 77.

⁷ E. Ruud, *Music Therapy, Improvisation, Communication and Culture*, Barcelona Publishers, Gilsun 1998, pp. 57–62 (the Polish based on the authoress's translation from English).

⁸ *Ibidem*.

⁹ J.W. Creswell, *Projektowanie badań naukowych. Metody jakościowe, ilościowe i mieszane (Designing Scientific Research. Qualitative, Quantitative and Mixed Methods)*, Wydawnictwo Uniwersytetu Jagiellońskiego, Kraków 2013, p. 221.

¹⁰ K. Krasoń, L. Konieczna-Nowak, *Sztuka, terapia, poznanie. W stronę podejścia indywidualizującego w badaniach muzykoterapeutycznych (Art, Therapy, Cognition. Towards an Individual Approach in the Research on Music Therapy)*, op. cit., pp. 113–114.

poses.¹¹ Adam Stankowski and Natalia Stankowska also emphasise other functions of science that have a utilitarian dimension in special needs education - diagnostic, prognostic, instrumental-technical and humanistic functions.¹² It is worth stressing that special education as an academic discipline in Poland has a much richer range of trends, concepts and paradigms¹³ than music therapy. The latter is a young field that is dynamically developing in clinical and research terms. Brynjulf Stige distinguishes five areas related to music therapy: (1) **folk music therapy** - these are all activities related to music and support through musical activities; (2) **music therapy as a discipline** - an area of knowledge that covers the history, tradition of music therapy and its discourses; includes the research area; (3) **music therapy as a profession** - these are activities aimed at implementing appropriate standards qualifying music therapy as a profession; (4) **music therapy as a practice** - it is a process of creating music aimed at restoring the health and well-being of an individual; (5) **unprofessional use of music** that involves the use of music to improve health, but not by qualified music therapists. According to Stige, these five areas relate to music therapy as a whole. The researcher also suggests extending this term to many other directions to emphasise the diversity of this discipline.¹⁴ Both music therapy and special needs education are internally diverse disciplines, which is reflected in research conducted in these fields.¹⁵

¹¹ S. Juszczuk, *Badania jakościowe w naukach społecznych. Szkice Metodologiczne (Qualitative Research in Social Sciences. Methodological Outline)*, Wydawnictwo Uniwersytetu Śląskiego, Katowice 2013, p. 40.

¹² A. Stankowski, N. Stankowska, *Pedagogika społeczna i pedagogika specjalna wobec edukacji osób niepełnosprawnych (Social Pedagogy and Special Pedagogy in Relation to Education of People with Disabilities)*, "Chowanna" 2012, no. 2, pp. 325-333.

¹³ A. Krause, *Teoretyczne i empiryczne problemy pedagogiki specjalnej. Zarys obszarów badawczych ("Theoretical and empirical problems of special pedagogy. Outline of research areas")*, *Niepełnosprawność. Półrocznik naukowy*, 2009, no. 1, pp. 9-24.

¹⁴ K. Aigen, *The Study of Music Therapy*, Routledge Taylor & Francis Group, New York-London 2014, p. 11.

¹⁵ B. Wheeler, *Badania w dziedzinie muzykoterapii (Research in the Field of Music Therapy)*, [in:] *Podstawy muzykoterapii*, ed. K. Stachyra, op. cit., p. 241.

When discussing these studies, it is necessary to mention Evidence Based Practice in the context of music therapy. Evidence Based Practice (EBP) is the integration of the best available research and clinical experience (...), containing the overall characteristics of patients, taking into account their social, cultural context, values and preferences and needs. EBP is based on the assumption that all services should be effective, have solid scientific foundations and should be provided in the most effective manner (...) and the aim is to show that the procedures adopted are safe, effective and profitable. EBP (initially used in the field of medicine and psychiatry), has also been adapted to psychology, psychotherapy or music therapy today. However, there are some doubts related to EBP, which are mentioned by Andera Gilroy (not just about favouring an experiment as the research method, e.g. Randomized Control Trial), concerning the belief that confirmation of evidence by medical activities (i.e. only through quantitative research methods), may lead to inhibition of research in the field of music therapy or art therapy.¹⁶ In addition, due to the qualitative nature of the activities and the multiplicity of elements included in the music therapy process, such research (based only on quantitative data) would be impossible. Hence the author emphasises that individual practices and services related to art should develop their own interpretation of the evidence so that they can use the uniqueness of the field.¹⁷

Therefore, four levels of scientific evidence in art therapy and music therapy were suggested, arranged in a hierarchical manner:

- Level 1 "a" - results from at least one RCT (randomized controlled trial) or another controlled experimental study (or a quasi-experiment);
- Level 1 "b" - results of other studies, including qualitative and case studies;
- Level 2 - research results and an academic research paper;

¹⁶ A. Gilroy, *Arteterapia – badania i praktyka (Art Therapy, Research and Evidence Based Practice)*, AHE, Łódź 2009, pp. 21–22.

¹⁷ Ibidem.

- Level 3 - opinions of experts in the field;
- Level 4 - practitioners' opinions.¹⁸

The above interpretation of the evidence indicates the importance of qualitative research, hence I would like to choose four research methods that I will characterize briefly: **qualitative case studies, mixed-methods case studies, action research and artistic case study.**

Qualitative case studies, i.e. interpretative case studies are descriptive studies that do not require the introduction of a specific impact. They contain interpretations of observed events, data comes from various sources. In music therapy and special needs education, the therapist as a researcher is especially important as somebody who is involved in both the research and therapeutic/educational process.¹⁹ Another method is a mixed-methods case study. It is the fusion of qualitative and quantitative research methods. Mixed-methods projects using and implementing many strategies for mixing data, e.g. through triangulation (following here Uwo Flick²⁰ or John Creswell²¹).

The eclecticism of many methods and techniques means that we receive an overall assessment of the solution to the research problem, which can be further refined by another study. The third method is action research, which through its in-depth analysis and participation tends to improve the functioning of the practice. It directly refers to the existing problems of the individual/institution. The fourth method is **arts-based research**, to which I will devote more attention in the next subsection.

¹⁸ K. Krasoń, L. Konieczna-Nowak, *Sztuka, terapia, poznanie. W stronę podejścia indywidualizującego w badaniach muzykoterapeutycznych (Art, Therapy, Cognition. Towards an Individual Approach in the Research on Music Therapy)*, op. cit., p. 63.

¹⁹ A. Gilroy, *Arteterapia – badania i praktyka (Art Therapy, Research and Evidence Based Practice)*, op. cit., p. 158.

²⁰ U. Flick, *Projektowanie badania jakościowego (Designing Qualitative Research)*, Wydawnictwo Naukowe PWN, Warszawa 2013, p. 84.

²¹ J. Creswell, *Projektowanie badań naukowych. Metody... (Designing of scientific research. Qualitative, quantitative and mixed methods)*, op. cit., p. 221.

Arts-based research

*Arts-based research*²² is a kind of research which applies tools, procedures, and materials originating in arts. This research belongs to the field of qualitative research. The studies can refer to persons, groups, institution and describe musical, fine arts or dance activities.²³ *Arts-based research* is rooted in arts, but the researcher does not have to be an artist or author of the work. The expression by means of arts is a fundamental method of understanding and testing experience of persons involved in the study.²⁴ The *arts-based research* can be given a variety of names: *artistic inquiry*²⁵, *aesthetically based research*²⁶, *critical arts-based research*²⁷ or *arts based inquiry*.²⁸ There are also differences in defining certain terms, such as

- a) *artistic research*: the work of arts and the text refer to the concept and theories related to it; here the artist is a researcher. This kind of research requires the use of artistic methods while accumulating, analysing, and interpreting the data; the creative process is involved; the artistic values of the researcher are revealed here²⁹;

²² S. McNiff, *Art as reserach: Opportunities and challenges*. IL: intellect, Chicago 2013.

²³ A. Gilroy, *Arteterapia – badania i praktyka (Art Therapy, Research and Evidence Based Practice)*, op. cit., p. 134.

²⁴ K. Krasoń, L. Konieczna-Nowak, *Sztuka, terapia, poznanie. W stronę podejścia indywidualizującego w badaniach muzykoterapeutycznych (Art, Therapy, Cognition. Towards an Individual Approach in the Research on Music Therapy)*, op. cit., pp. 41.

²⁵ G. Knowles, A. Cole (eds.), *Handbook of the arts in qualitative research: Perspectives, methodologies, examples and issues*, CA: Sage, Thousand Oaks, 2008.

²⁶ L. Bresler, *Toward connectedness: Aesthetically based research*, "Studies in Art Education: A Journal of Issues and Research in Art Education", 2006, no. 48(1), pp. 52–69.

²⁷ S. Finley, *An Introduction to critical arts-based research: Demonstrating methodologies and practice of a radical ethical aesthetic*, "Cultural Studies-Critical Methodologies" 2014, no. 14(6), pp. 531–532.

²⁸ D. Ausitn, M. Forinash, *Arts-based Reserach*, [in:] *Music therapy research*, ed. B.L. Wheeler, 2nd Edition, Barcelona Publishers, Gilsum 2005.

²⁹ *Ibidem*, p. 459.

- b) *practice-led research* – here the artist is a researcher; the work and documentation of the process is a result of the research work.³⁰

The same author indicates three aspects of art having an impact on its relation with the research process.

- Art is self-reflective; hence, the creative act is a research act.
- **Art is a form of communication, and artistic activity becomes a research tool.**
- It is a kind of commodity where the work is the only object of research.³¹

The art plays an important role in both music therapy and special needs education. It functions as a form of communication, which, as if a non-verbal channel, allows achieving therapeutic goals, related to supporting the social, emotional, cognitive, motor or communicative sphere. The art has in itself a therapeutic use and its proper application / handling (by a qualified person, such as a certified art therapist or music therapist) can lead to reaching the goals postulated by special education or music therapy.³² The art, or more specifically its creation, usage and application, affects the patient / participant by means of changes in the functioning of the individual occurring during the creative / therapeutic process. The art with a therapeutic dimension was referred to by Edith Kramer, who emphasised that “the art in its nature is therapeutic” and can lead to positive changes in human being.³³ The appearing valorisa-

³⁰ A. Teikmanis, *Typologies of Research*, [in:] *Handbook for Artistic Research Education*, eds. M. Wilson, S. van Ruiter, Share Network, Amsterdam, Dublin, Gothenburg 2013, p. 164.

³¹ *Ibidem*.

³² B. Wheeler, *Music Therapy as a Profession*, [in:] *Music Therapy Handbook*, ed. B.L. Wheeler, The Guildford Press, New York, London 2017, pp. 9–10.

³³ K. Krasoń, L. Konieczna-Nowak, *Sztuka, terapia, poznanie. W stronę podejścia indywidualizującego w badaniach muzykoterapeutycznych (Art, Therapy, Cognition. Towards an Individual Approach in the Research on Music Therapy)*, op. cit., p. 18, after: W. Szulc (ed.), *Arteterapia jako dyscyplina akademicka w krajach europejskich (Art Therapy as an Academic Discipline in European Countries)*, Uniwersytet Wrocławski w ECARTE, Oficyna Wydawnicza ATUT, Wrocław 2010, p. 21.

tion of the work of arts, or hermeneutic analysis, is an interpretation of the work of art as a form of communication of the participant with the world. The process of creation and the therapeutic process are described and analysed in terms of relation taking place between the participant and the therapist (phenomenological analysis).³⁴ The researcher – within the *arts-based research* – wants to rediscover the meaning of artistic work by people marginalised socially, culturally and politically, as well as persons within the therapeutic process.³⁵ The researcher wants to understand the creative process rooted in art / music therapy.³⁶ The researcher wants to understand life experience of persons participating in the creative process, within their social and cultural context.³⁷ Moreover, the researcher wants to understand himself/herself within the social, cultural or historical context.³⁸

According to Diane Austin and Michele Forinash, the arts-based research is based on the necessity to implement aesthetic activities. According to the authors, the very implementation of music in the research, e.g. in the form of improvisation, does not imply its aesthetic and artistic values.³⁹ Alison Ledger and Jane Edwards, in

³⁴ K. Krasoń, L. Konieczna-Nowak, *Sztuka, terapia, poznanie. W stronę podejścia indywidualizującego w badaniach muzykoterapeutycznych* (Art, Therapy, Cognition. Towards an Individual Approach in the Research on Music Therapy), op. cit., p. 116.

³⁵ S. Gilbertson, *Improvisation and meaning*, "International Journal of Qualitative Studies on Health and Well-Being" 2013, no. 8(1), pp. 1-10; M.Viega, *Performing "Rising from the Ashes": Arts-based research results from the Study "Loving me and my butterfly wings": An analysis of hop-hop songs written by adolescents in music therapy, "Music Therapy Perspectives"* 2016, No. 34(1), pp. 46-47.

³⁶ A.R. Schenstead, *The timelessness of arts-based research: Looking back upon a heuristic self-study and the arts-based reflexivity data analysis method*, "Voices: A World Forum for Music Therapy" 2012, no. 12(1)/ <<https://voices.no/index.php/voices/article/view/2035/1779>>.

³⁷ D. Austin, *Revisiting Grace Street: a retrospective account on the creation of an arts-based research study of Alcoholics Anonymous*, "Music Therapy Perspectives" 2016, no. 34(1)/ miv046, DOI: 10.1093/mtp/miv046.

³⁸ A.R. Schenstead, *The timelessness of arts-based research: Looking back upon a heuristic self-study and the arts-based reflexivity data analysis method*, op. cit.

³⁹ D. Austin, M. Forinash, *Arts-Based Research*, op. cit., pp. 458-463.

turn, underline that the defining of the arts-based research cannot be subjected to unequivocal rules, since it is extremely heterogeneous. Defining such research and categorising it strictly in the art is impossible, and even unnecessary.⁴⁰

The examples of studies applying the *arts-based research* method or its elements, are research explorations and simultaneously therapeutic processes exhibited by the following researchers.

Paul Nordoff and Clive Robbins (1971, 1977), the creators of the Nordoff-Robbins, are first of them.⁴¹ The authors in their research and clinical work indicated that music therapy based on improvised songs, creating short musical “music theatres”, can bring about the development of communicative and social possibilities of children and youth with special needs.⁴² The techniques of music therapy they worked out with handicapped children in mind (and later for the young and adults) helped to develop their creative potential and “enhance their mental functions through positive experience and beneficial social experience”.⁴³ The authors described the kinds of musical creations of handicapped children in interaction with the therapist – starting with the game with full rhythmic freedom reaching a chaotic and creative game. Based on many observations and thorough microanalysis of therapeutic sessions (all musical behaviours), they prepared their own form of assessment of the level of participation of the child in its developing musical relation with the therapist.⁴⁴

⁴⁰ A. Ledger, J. Edwards, *Arts-based research practices in music therapy research*, “The Arts in Psychotherapy” 2011, no. 38, pp. 312–317.

⁴¹ P. Nordoff, C. Robbins, *Creative Music Therapy. A Guide to Fostering Clinical Musicianship*, Barcelona Publishers, Gilsum 2008.

⁴² P. Nordoff, C. Robbins C. *Music Therapy in Special Education*, The John Day Company, New York 1971.

⁴³ P. Nordoff, C. Robbins, *Terapia muzyką w pracy z dziećmi niepełnosprawnymi. Historia, metoda i praktyka (Music Therapy in Working with Disabled Children. History, Method and Practice)*, Oficyna Wydawnicza „Impuls”, Kraków 2008, p. 118.

⁴⁴ L. Konieczna-Nowak, *Wprowadzenie do muzykoterapii (Introduction to Music Therapy)*, Oficyna Wydawnicza „Impuls”, Kraków 2013, p. 53.

Carol Robbins and Clive Robbins (1991) with a group of persons with slight and moderate intellectual disability, created, prepared and actively participated in the musical performance which was presented to a great audience. Artistic activities included in the creation of the musical improved the self-esteem of persons participating in the musical project and decreased their hyperacusis.⁴⁵

Leon Miller and Gael Orsmond (1994, 1995), similarly to Nordoff and Robbins, applied improvisation in their research work, which brought about re-education of negative behaviours, such as: irritation, crying, stereotypical thinking, hyperactivity of people with slight and moderate disability. The authors used a variety of musical elements – complex sound productions based on the presence of many rhythmic, harmonic or melodic patterns.⁴⁶

In her research project, Satomi Kondo (2003) described the process of music therapy performed with a person dying in an intensive care unit. The researcher used the music created live and images which helped the patient to express emotions and experiences and allowed them to share their experience, and most of all supported them in their difficult passage.⁴⁷

Jacqueline Robarts (2003, 2006), a long-term researcher and music therapist working in a psychodynamic field, described the process of music therapy with a sexually abused girl. The process was based primarily on creating improvised songs and recording them. These techniques helped to express the hidden, subconscious sense

⁴⁵ C.M. Robbins, C. Robbins, *Self-communication in Creative music therapy*, [in:] *Case studies in music therapy*, ed. K. Brusica, Barcelona Publishers, Gilsum 1991, pp. 55–72.

⁴⁶ L.K. Miller, G. Orsmond, *Assessing structure in the musical explorations of children with disabilities*, “*Journal of Music Therapy*” 1994, no. 31(4), pp. 248–265; L.K. Miller, G. Orsmond, *Correlates of musical improvisation in children with disabilities*. “*Journal of Music Therapy*” 1995, no. 32(1), pp. 152–168.

⁴⁷ S. Kondo, *Special moments: Attending to a dying person during the music therapy session in the intensive care unit*, Niepublikowana praca magisterska, Simon Fraser University, Ottawa, Kanada, 2003, after: M. Viega, M. Forinash, *Arts-based research*, [in:] *Music Therapy Research*, ed. B. Wheeler, K. Murphy, Third Edition, Barcelona Publishers, Dallas 2016, pp. 495.

of sadness and solitude of the girl and allowed her to develop more self-esteem as a person and future woman.⁴⁸

Michael Viega (2013, 2016), in turn, described the process of creating hip-hop songs by teenagers with bad childhood memories (related to violence and abuse). The creative process based on writing lyrics and composing music led to increased consciousness of emotions experienced by participants.⁴⁹

Michael Viega (2013, 2016) applied music and poetry in the music therapy process of the AA group. The music they created – songs with therapeutic texts – became the basis for a musical (*Grace Street*), in which the therapy participants were actors.⁵⁰

Analysis of own research

With reference to the significance of *arts-based research* in music therapy and special needs education, I would like to present my own research, which places music within the human centre of interest and emphasises the significance of changes taking place during the music therapy processes. The two discussed studies are different in terms of methodology – the first study is based on the qualitative research and uses artistic case study, whereas the other study refers to mixed methodology.

The first study (2016–2019 – typical for *arts-based research*) concerned the creation of own songs by three young people with the so-called high-functioning autism and presenting them at a concert to an audience.⁵¹ The process of creating own songs (lyrics, melody, the kind of accompaniment) and experiences related to the concert,

⁴⁸ J. Robarts, *Music Therapy with Sexually Abused Children*, “Clinical Child Psychology and Psychiatry” 2006, no. 11(2), pp. 249–269

⁴⁹ M. Viega, *Performing “Rising from the Ashes”: Arts-based research results from the Study “Loving me and my butterfly wings”: An analysis of hop-hop songs written by adolescents in music therapy*, “Music Therapy Perspectives” 2016, no. 34(1), pp. 46–47.

⁵⁰ D. Austin, *Revisiting Grace Street: a retrospective account on the creation of an arts-based research study of Alcoholics Anonymous*, op. cit.

⁵¹ At present, the study is in the course of publication, 2019.

such as stress, the sense of responsibility and unity, became for them a path of social and emotional development. These experiences became an area for the development of many emotions, an attempt at identifying them and the way to share them with others – in a group of acquaintances or with strangers during the concert. The experience of creation presented them with a totally new way of expression – creative, in a safe therapeutic area, where jointly, as a group, they strived to understand one another. As Bill Nason points out (2016), most of the development occurs in relations with others (...); for neurotypical children it is part of a natural process; persons with an autism spectrum disorder cannot deal with it”.⁵² Therefore music therapy, non-directing impact, could show them strategies of development of social or emotional skills. It provided space for sharing and showing their creativity to people from outside the autism spectrum.

The other study was performed in the years 2013–2017⁵³ – “The significance of music therapy techniques in the support of an autistic child’s development” is a study which applied elements of *arts-based research*, based primarily on the phenomenological and hermeneutic paradigm. The aim of this study was to check the functioning of eight children with an autism spectrum during a music therapy process. Music therapy techniques were subjected to a detailed analysis (improvisation/creation, recreation and listening) on selected development areas of autistic children. The above procedure was based on mixed methodology, the main strategy of which was the parallel immersion.⁵⁴ In terms of the dominating – qualita-

⁵² B. Nason, *Porozmawiajmy o autyzmie (Let’s Talk about Autism)*, Wydawnictwo Uniwersytetu Jagiellońskiego, Kraków 2016, pp. 281–282.

⁵³ Praca doktorska „Znaczenie technik muzykoterapeutycznych we wsparciu rozwoju dziecka z autyzmem”, obroniona w 2018 roku na Uniwersytecie Śląskim, Wydział Pedagogiki i Psychologii w Katowicach.

⁵⁴ This strategy is characterised by one phase of qualitative and quantitative data accumulation. It includes the main method, on which the project is based, and secondary, which has an auxiliary function; the secondary method (here – quantitative) is immersed (embedded) in the dominating method, in this case the qualitative

tive – method, I applied a detailed description of the music therapy process, video recordings, in-depth qualitative analysis (qualitative analysis of musical and non-musical behaviours), the analysis of texts and documents. In terms of the immersion (quantitative) method, I used measurements (before commencing the therapy and after it) based on categorised observation by means of a tool using objective referees and quantitative data analysis.

Phenomenological aspects of this research project were visible in drawing up detailed session reports, subjected to categorisation. The identified categories were desired musical, undesired musical, relational desired musical, and relational undesired musical. These categories referred to the key occurrences and musical behaviours taking place during music therapy sessions. Each musical behaviour was attributed with a non-musical behaviour, which constituted communication as well as social and emotional subcategory (categories of relational desired and undesired musical behaviours) and cognitive and motor (categories of desired and undesired musical behaviours). All these activities had a specific code; hence, the given musical behaviour matched a defined non-musical behaviour. The above attempt to categorise musical behaviours and create a music therapy tool as desired and undesired behaviours is the only form of this kind of categorisation in the field of music therapy and autism in Poland. As a result, apart from the description of the child's behaviour, I described phenomenological characteristic of the relation taking place between the therapist and the participant, which is the result of systematic qualitative observation.⁵⁵

Results of my research are based on observed changes resulting from music therapy activities. Their objective research is impossible, since in the music therapy process the music experiences permeate

one – J. Creswell, *Projektowanie badań naukowych. Metody...* (Designing of scientific research...), op. cit., pp. 226–231.

⁵⁵ The doctoral thesis titled *The Significance of Music Therapy Techniques in Supporting the Development of Children with Autism*, defended in 2018 at the University of Silesia, Faculty of Pedagogy and Psychology in Katowice, pp. 136–137.

and their effects modify one another. However, qualitative results prove that improvised activities can affect and improve social and emotional sphere of the autistic child, whereas the activities based on re-creative activities shape the cognitive and motor sphere.⁵⁶

The meaning of arts-based research in special needs education and music therapy

Taking into consideration the above examples of studies related to the art of music – their variety in terms of research participants their age, social and cultural context, it is worthwhile to answer the thesis of this article – what is the meaning of *arts-based research* in special needs education and music therapy? The benefits of this method and why they should be used.

The art/music is an alternative form of communication with the world – they can be another method of gaining information about human beings, phenomena, and experience. Thanks to music, we can reach the individual – the personality, perception of oneself and of the world. Moreover, we can reach the problem of functioning people participating in the study and find out about the changes – social, emotional, communicative – which appeared during the creative/therapeutic process. The very possibility of experiencing the creative, meaningful process, can provide the sense of self-fulfilment, self-development and a broadly understood expression. The music can also constitute the tool to improve specific development spheres of persons with problems and limitations. It can break barriers and create communicative opportunities. It can be a space connecting people despite differences – social, cultural, and economic factors of the level of functioning or the scope of abilities. As Shaun McNiff pointed out, “experience gained from artistic activity of the patient can be a starting point for the patient’s cognition and im-

⁵⁶ Ibidem, pp. 303–304.

provement".⁵⁷ Using art in the studies can be a form of cognition (diagnosis) of the given person and the method of verification of therapeutic activities based on the art and their efficiency.

However, the most important aspect of art in the research and therapeutic process are the supporting activities, providing opportunities of change and development of the individual involved in the process. The art/music strives to understand and thoroughly recognise the individual, as well as perceive their potential which may be developed by means of specific activities. Individuals are supported and their mental functions are enhanced by means of positive observations and beneficial social experiences.⁵⁸ The art provides the individual with adequate conditions and opportunities of functioning regardless of age and kind of disability, disorder or difficulty. It does not only improve and correct, but most of all it stimulates and activates so that the individual could feel subjective satisfaction, happiness and fulfilment.

Bibliography

- [1] Krause A., *Teoretyczne i empiryczne problemy pedagogiki specjalnej. Zarys obszarów badawczych* ("Theoretical and empirical problems of special pedagogy. Outline of research areas"), "Niepełnosprawność. Półrocznik naukowy" 2009, no. 1, pp. 9-24.
- [2] Ledger A., Edwards J., *Arts-based research practices in music therapy research*, "The Arts in Psychoterapy" 2011, no. 38, pp. 312-317.
- [3] Schenstead A.R., *The timelessness of arts-based research: Looking back upon a heuristic self-study and the arts-based reflexivity data analysis method*, "Voices: A World Forum for Music Therapy" 2012, no. 12(1), <<https://voices.no/index.php/voices/article/view/2035/1779>>. Accessed on: 30.05.2019.

⁵⁷ S. McNiff, *Preference*, [in:] *Art-Based Research*, Fifth impression, Jessica Kingsley Publishers, London-Philadelphia, 2006, p. 13, after: K. Krasoń, L. Konieczna-Nowak, *Sztuka, terapia, poznanie. W stronę podejścia indywidualizującego w badaniach muzykoterapeutycznych* (*Art, Therapy, Cognition. Towards an Individual Approach in the Research on Music Therapy*), op. cit., p. 80.

⁵⁸ P. Nordoff, C. Robbins, *Terapia muzyką w pracy z dziećmi niepełnosprawnymi...* (*Music Therapy in Working with Disabled Children...*), op. cit., p. 118.

- [4] Stankowski A., Stankowska N., *Pedagogika społeczna i pedagogika specjalna wobec edukacji osób niepełnosprawnych (Social Pedagogy and Special Pedagogy in Relation to Education of People with Disabilities)*, "Chowanna" 2012, no. 2, pp. 325–333.
- [5] Aigen K., *The Study of Music Therapy*, Routledge Taylor & Francis Group, New York–London 2014.
- [6] Ausitn D., Forinash M., *Arts-based Reserach*, [in:] *Music therapy research*, red. B.L. Wheeler, 2nd Edition, Barcelona Publishers, Gilsum 2005.
- [7] Bruscia B., *The boundaries of music therapy research*, [in:] *Music Therapy Research: Quantitative and qualitative perspectives*, ed. B. Wheeler, Barcelona Publishers, Gilsum 1995.
- [8] Creswell J.W., *Projektowanie badań naukowych. Metody jakościowe, ilościowe i mieszane (Designing Scientific Research. Qualitative, Quantitative and Mixed Methods)*, Wydawnictwo Uniwersytetu Jagiellońskiego, Kraków 2013.
- [9] Austin D., *Revisiting Grace Street: a retrospective account on the creation of an arts-based research study of Alcoholics Anonymous*, "Music Therapy Perspectives" 2016, no. 34(1), 2016.
- [10] Dykcik W., *Zakres i przedmiot zainteresowań pedagogiki specjalnej (Special Pedagogy – The Scope and Subject of Interest)*, [in:] *Pedagogika specjalna (Special Pedagogy)*, ed. W. Dykcik, Wydawnictwo Uniwersytetu im. Adama Mickiewicza w Poznaniu, Poznań 2012.
- [11] Flick U., *Projektowanie badania jakościowego (Designing Qualitative Research)*, Wydawnictwo Naukowe PWN, Warszawa 2013.
- [12] Gilroy A., *Arteterapia – badania I praktyka (Art Therapy, Research and Evidence Based Practice)*, AHE, Łódź 2009.
- [13] Juszczak S., *Badania jakościowe w naukach społecznych. Szkice Metodologiczne (Qualitative Research in Social Sciences. Methodological Outline)*. Wydawnictwo Uniwersytetu Śląskiego, Katowice 2013.
- [14] Knapik-Szweda S., *Znaczenie technik muzykoterapeutycznych we wsparciu rozwoju dziecka z autyzmem (The Significance of Music Therapy Techniques in Supporting the Development of Children with Autism)*, a doctoral thesis defended in 2018 at the University of Silesia, Faculty of Pedagogy and Psychology in Katowice.
- [15] Knowles G., Cole A. (red.), *Handbook of the arts in qualitative research: Perspectives, methodologies, examples and issues*, CA: Sage, Thousand Oaks 2008.
- [16] Konarzewski K., *Jak uprawiać badania oświatowe. Metodologia praktyczna (How to Do Research in Education. Practical Methodology)*, Wydawnictwa Szkolne i Pedagogiczne, Warszawa 2000.
- [17] Kondo S., *Special moments: Attending to a dying person during the music therapy session in the intensive care unit*, unpublished master's thesis, Simon Fraser University, Ottawa, Canada 2003.
- [18] Konieczna-Nowak L., *Wprowadzenie do muzykoterapii (Introduction to Music Therapy)*, Oficyna Wydawnicza „Impuls”, Kraków 2013.

- [19] Krasoń K., Konieczna-Nowak L., *Sztuka, terapia, poznanie. W stronę podejścia indywidualizującego w badaniach muzykoterapeutycznych (Art, Therapy, Cognition. Towards an Individual Approach in the Research on Music Therapy)*, PWN, Warszawa 2016.
- [20] Bresler L., *Toward connectedness: Aesthetically based research*, "Studies in Art Education: A Journal of Issues and Research in Art Education" 2006, no. 48(1), pp. 52-69.
- [21] Miller L.K., Orsmond G., *Correltes of musical improvisation in children with disabilities*, "Journal of Music Therapy" 1995, no. 32(1), pp. 152-168.
- [22] Miller L.K., Orsmond G., *Assessing structure in the musical explorations of children with disabilities*, "Journal of Music Therapy" 1994, no. 31(4), pp. 248-265.
- [23] Viega M., *Performing "Rising from the Ashes": Arts-based research results from the Study "Loving me and my butterfly wings": An analysis of hop-hop songs written by adolescents in music therapy*, "Music Therapy Perspectives" 2016, no. 34(1), pp. 46-47.
- [24] McNiff S., *Art as reserach: Opportunities and challenges*, IL: intellect, Chicago 2013.
- [25] McNiff S., *Preference*, [in:] *Art-Based Research*, Fifth impression, Jessica Kingsley Publishers, London-Philadelphia 2006.
- [26] Merriam Webster's Collegiate Dictionary, G.i C. Merriam, Springfield 2002.
- [27] Nason B., *Porozmawiajmy o autyzmie (Let's Talk about Autism)*, Wydawnictwo Uniwersytetu Jagiellońskiego, Kraków 2016.
- [28] Nordoff P., Robbins C., *Creative Music Therapy. A Guide to Fostering Clinical Musicianship*, Barcelona Publishers, Gilsum 2008.
- [29] Nordoff P., Robbins C., *Music Therapy in Special Education*, The John Day Company, New York 1971.
- [30] Nordoff P., Robbins C., *Terapia muzyką w pracy z dziećmi niepełnosprawnymi. Historia, metoda i praktyka (Music Therapy in Working with Disabled Children. History, Method and Practice)*, Oficyna Wydawnicza „Impuls”, Kraków 2008.
- [31] Robarts J., *Music Therapy with Sexually Abused Children*, "Clinical Child Psychology and Psychiatry" 2006, no. 11(2), pp. 249-269.
- [32] Robbins C.M., Robbins C., *Self-communication in Creative music therapy*, [in:] *Case studies in music therapy*, ed. K. Brusica, Bracelona Publishers, Gilsum 1991.
- [33] Ruud E., *Music Therapy, Improvisation, Communication and Culture*, Barcelona Publishers, Gilsum 1998.
- [34] Gilbertson S., *Improvisation and meaning*, "International Journal of Qualitative Studies on Health and Well-Being 2013, no. 8(1), pp. 1-10.
- [35] Finley S., *An Introduction to critical arts-based research: Demonstrating methodologies and practice of a radical ethical aesthetic*, "Cultural Studies -Critical Methodologies" 2014, no. 14(6), pp. 531-532.
- [36] Szulc W. (red.), *Arteterapia jako dyscyplina akademicka w krajach europejskich (Art Therapy as an Academic Discipline in European Countries)*, Uniwersytet Wrocławski w ECARTE, Oficyna Wydawnicza ATUT, Wrocław 2010.

- [37] Teikmanis A., *Typologies of Research*, [in:] *Handbook for Artistic Research Education*, ed. M. Wilson, S. van Ruiter, Share Network, Amsterdam, Dublin, Gothenburg 2013.
- [38] Viega M., Forinash M., *Arts-based research*, [in:] *Music Therapy Research*, ed. B. Wheeler, K. Murphy, Third Edition, Barcelona Publishers, Dallas 2016.
- [39] Wheeler B., *Badania w dziedzinie muzykoterapii (Research in the field of music therapy)*, [in:] *Podstawy muzykoterapii (Introduction to Music Therapy)*, ed. K. Stachyra, Wydawnictwo Uniwersytetu Marii Skłodowskiej-Curie, Lublin 2012.
- [40] Wheeler B., *Music Therapy as a Profession*, [in:] *Music Therapy Handbook*, ed. B.L. Wheeler, The Guildford Press, New York, London, 2017.



Interdisciplinary Contexts of Special Pedagogy
No. 26/2019

MARZENNA ZAORSKA
University of Warmia and Mazury in Olsztyn
ADAM ZAORSKI
Nicolaus Copernicus University in Toruń

Issues related to the statutory ban on eugenic abortion in Poland (in the opinion of representatives of the community of people with disabilities)

ABSTRACT: Marzenna Zaorska, Adam Zaorski, *Issues related to the statutory ban on eu-genic abortion in Poland (in the opinion of representatives of the community of people with disabilities)*. Interdisciplinary Contexts of Special Pedagogy, no. 26, Poznań 2019. Pp. 389-403. Adam Mickiewicz University Press. ISSN 2300-391X. DOI: <https://doi.org/10.14746/ikps.2019.25.18>

The issues of eugenics, although they clearly emerged as late as in the second half of the nineteenth century, was not unknown to humanity in the distant ancient times. From the moment when F. Galton consolidated the theses currently recognized as eugenics, simultaneously introducing the concepts of “eugenics” and “eugenic”, eugenics very quickly found its supporters around the world. Its exceptional exemplification and development was noted in the first half of the twentieth century, which absolutely does not mean that it does not exist nowadays in a different form, using other methods of control and elimination of imperfections of the *Homo Sapiens* species, as well as undesirable social phenomena. This includes activities not only aimed at prevention, diagnosis or therapy of individual and civilization problems, but are also more radical ones, such as abortion carried out for eugenic purposes. Thus, the content of the article not only discusses eugenic issues in the theoretical context, but also presents opinions of selected groups of people with disabilities, participating in the implementation of the project entitled: “Implementation of the Convention on the Rights of Persons with Disabilities, a Common Matter”, conduct-

ed in Poland in 2016–2018, concerning the proposal to introduce a total ban on eugenic abortion into Polish legislation.

KEY WORDS: eugenics, eugenic abortion, disability, disabled person, opinion of disabled people on the ban on eugenic abortion

Introduction

Probably, since the beginning of humanity, representatives of the human species have been thinking about the ways to make people remain healthy, strong, fit, as well as psychophysically and intellectually active as long as possible. People living nowadays are also wondering about this issue, the more so because considering the successes of modern science (and in particular medical and technical sciences), they have increasingly greater potential to implement these postulates. The problem is, however, that if we look at the profile of *Homo sapiens*, we will find a lot of people who do not meet the set criteria of human perfection.¹ Hence, from time to time, representatives of the world of science and politics promote various concepts of introducing specific methods of improving the human species.

Reaching back to distant times, it is worth recalling the example of ancient Greece, where an educational path was created to shape an almost ideal man: morally pure, or simply good and combining high physical fitness with intellectual qualities and impeccable character traits. The ancient Spartans carried out a project to create a soldier man which, in addition to training his physical fitness, assumed the selection of good biological material. Children who were weak, sickly or disabled were abandoned in the mountains, on the outskirts of cities, or dropped from the rocks.² Only the strongest ones had to and should survive.

¹ P. Kossobudzki, Eugenika, czyli jak wychować nadczłowieka, „Gazeta Wyborcza”, 28 November 2013; <http://wyborcza.pl/piatekextra/1,129155,15041710,Eugenika_czyli_jak_wyhodowac_nadczlowieka.html>; access date: 4 February 2019.

² M. Musielak, *Sterylicacja ludzi ze względów eugenicznych w Stanach Zjednoczonych, Niemczech i w Polsce (1899–1945): wybrane problemy*, Wydawnictwo Poznańskie, Poznań 2008, pp. 21–22.

Selective ideas for human reproduction were also suggested by Plato, who argued that human reproduction should be controlled by the authorities. He proposed that the selection should be made by the government, through a controlled lottery, so that human feelings would not be hurt by the awareness of selection principles. In the work entitled "The Republic", he wrote: "(...) *in the Republic, the discipline and jurisprudence requiring only citizens who are healthy in body and mind to be dealt with, should be applied. However, those who are not healthy should be allowed to die (...)*".³

Almost two thousand years later, in 1983, in one of his speeches the contemporary President of the United States Ronald Reagan, referring to the future of humanity indicated that there would be a moment when every employer, doctor and every citizen would have to admit that the real problem is whether to affirm and protect the sanctity of all life or accept social ethics for which one human life has value while the other not. Reagan suggested that Americans would with time face a dilemma of choosing between the ethics of sanctity of life and the ethics of quality of human life.⁴

Scientific research conducted in 1983 among paediatricians and obstetricians by H. Kushe and P. Singer in the state of Victoria (USA) proved that 90% of obstetricians and 83% of paediatricians at least once in their professional work were of the opinion that the maximum effort should be made to save the lives of every disabled child. Almost everyone indicated that they would contact the parents before they decided to stop their efforts to save the child's life at all costs. Further experimental works addressing the discussed issues were carried out by the same researchers in 1987-1992, in Australia, Canada, Great Britain and Poland. They showed that while Australian, Canadian and British physicians have similar views and behaviour towards children who have no prognosis to

³ As cited in: M. Musielak, *Steryliczacja ludzi ze względów eugenicznych w Stanach Zjednoczonych, Niemczech i w Polsce (1899-1945): wybrane problemy*, Wydawnictwo Poznańskie, Poznań 2008, pp. 21-22.

⁴ R. Reagan, *Abortion and the Conscience of the Nation*, "Human Life Review", vol. IX, no. 2, 1983.

survive, Polish paediatricians are much more “conservative”. Nearly 98% of respondents in English-speaking countries rejected the view that every effort should be made to save the lives of children under all circumstances, while the opinions of Polish paediatricians were divided at a ratio of 50% : 50%.

Furthermore, if a decision to discontinue treatment were necessary, approximately 90% of Australian, Canadian and British physicians would consult with parents and nursing staff, while only 8% of Polish doctors would consult with parents, and 4% with nursing staff. Different opinions of Polish doctors can be explained by the influence of the Catholic Church proclaiming the thesis of the fundamental value of human life, regardless of its quality.⁵

Eugenics, as a concept of improving people in the historical dimension and today (selected aspects)

As civilization developed, people’s views on the ways to deliberately and consciously improve humanity were changing and crystallising depending on the prevailing philosophical views, the knowledge of societies about the nature of human, the achievements of science and the quality of life. However, as early turn of the nineteenth century, they were consolidated into a new field, which was called eugenics.

Eugenics is a term derived from the Ancient Greek language (Greek: εὐγενής, eugenes, “well-born”), introduced in 1869; concerned the selective reproduction of animals and humans in order to improve species from generation to generation, especially in terms of inherited traits.⁶

⁵ P. Singer, *O życiu i śmierci. Upadek etyki tradycyjnej*, PIW, Warszawa 1994, pp. 135-136.

⁶ F. Galton, *Inquiries into Human Faculty and its Development*, F.R.S. (First issue of this Edition 1883), J.M. Dent & CO, London 1907; *Eugenika*, Encyklopedia PWN (online version): <<https://encyklopedia.pwn.pl>>; date of access: 3 February 2019; M. Zaremba Bielawski, *Higieniści. Z dziejów eugeniki*, Wydawnictwo Czarne, Warsaw 2011. E. Black, *Wojna przeciw słabym*, Wydawnictwo Muza, Warsaw 2004.

The creator of eugenics is believed to be Francis Galton, a British scientist, cousin of Charles Darwin, who, studying obituaries, family histories and building family trees, came to the conclusion that high intelligence and other noble qualities are largely hereditary. In his work from 1883, he suggested that the best members of society should be encouraged to have more children, so that the virtues of their parents would spread with them in the population. It was Galton who first used the term „eugenics” (he introduced this concept in 1869).⁷ Thus, his idea at a rapid pace began to conquer the world and human minds, taking in many postulates and conducted activities extremely pathological forms. Over the following years, Galton perfected his definition of eugenics by including a category of the so-called positive eugenics, encouraging more frequent reproduction of the best individuals, and negative eugenics, discouraging the reproduction of less valuable individuals.

At the beginning of the 20th century, eugenic concepts, as in many other countries of the world, found numerous supporters and promoters also in Poland. They included social activists, scholars (in particular representatives of natural and medical sciences) and writers. In 1922, Polish Eugenics Society, was founded, which in the 1930s had approximately 10,000 members. The founder of the society was Leon Wernic, a doctor and social activist, the initiator of the establishment of the Ministry of Public Health; while its co-creator and president at the same time was, Leon Drożyński. In 1934–1938, Polish eugenics made attempts to introduce into Polish legislation provisions on forced sterilization, e.g. of alcoholics or people suffering from epilepsy. Some of them (e.g. Karol Stojanowski) placed the essence of Polish eugenics in solving the Jewish question (emigration, limiting natural increase, extermination).⁸

⁷ M. Zaremba Bielawski, *Higieniści. Z dziejów eugeniki*, Wydawnictwo Czarne, Warsaw 2011.

⁸ I. Sugalska, *Eugenika. W poszukiwaniu istoty niemieckiego totalitaryzmu*, Bogucki Wydawnictwo Naukowe, Poznań 2015, pp. 38–41, p. 52, pp. 165–172; H. Szczodrowski, *Co robi Polskie Towarzystwo Eugeniczne, „Zagadnienia Rasy”*, Yearbook 9, vol. 3, 1927, pp. 11–12; L. Wernic, *Eugenika jako nauka i jej granice, „Zagadnienia Rasy”*, Yearbook 15, vol. 7, no. 3, 1933, pp. 199–211.

Despite establishing the date of the creation of Polish eugenics, points on the selection of people in Poland were known and spread by representatives of Polish science, as well as political and social activists even before their official formalization. As examples, the personages of Aleksander Świętochowski, historian, positivist writer, social activist and Benedykt Dybowski, naturalist, doctor, zoologist, traveller and explorer can be mentioned. Aleksander Świętochowski was a proponent of evolution and the development of selection theses, while Benedykt Dybowski a supporter of anthropology, anthropotechnics, as well as their historical message, the regeneration of breeds and their refinement, which as a consequence leads to the the ideal in the form of good, beauty and physical strength associated with intellect, obtained in a human being.⁹ Ludwik Popławski, the journalist, politician, one of the creators of the national democratic ideology and Ludwik Krzywicki, sociologist, social activist, positivist, evolutionist, propagator of the ideas of K. Marx, also agreed with eugenics. They promoted Darwinism, F. Galton's theses, and advocated the implementation of eugenics in the area of Poland.¹⁰

After World War II, all scientific societies, including the Polish Eugenics Society, were covered by the tutelage of the Polish Academy of Sciences established in 1951. However, Polish eugenics continued to work on introducing eugenic laws (e.g. regarding the mandatory treatment of alcoholism, sterilization of "intellectually disabled and mentally ill").¹¹ At the same time, there were numerous and seri-

⁹ B. Dybowski, *Kilka uwag dotyczących stanowiska antropologii i jej przyszłej działalności*, „Światowit: Rocznik Muzeum Archeologicznego im. Er. Majewskiego Towarzystwa Naukowego Warszawskiego”, vol. XII, no. 3, 1924/1928, p. 14.

¹⁰ I. Sugalska, *Eugenika. W poszukiwaniu istoty niemieckiego totalitaryzmu*, Bogucki Wydawnictwo Naukowe, Poznań 2015, pp. 50-52.

¹¹ W. DeJong Lambert, *Przyczynek do myśli eugenicznej i tyssenizmu w polskiej biologii okresu międzywojennego i w latach powojennych*, [in:] *Eugenika – biopolityka – państwo. Z historii europejskich ruchów eugenicznych w pierwszej połowie XX w.*, eds M. Gawin, K. Uzarczyk, Wydawnictwo Neriton, Institute of History of the Polish Academy of Sciences, Warsaw 2010, p. 187; R. Zabłotniak, *Dzieje Polskiego Towarzystwa Eugenicznego*, „Kwartalnik Historii Nauki i Techniki”, no. 4, 1971, pp. 769-787.

ous voices of opposition to eugenics, which, because of the top-down condemnation of this concept (also by state authorities) led to a departure from eugenic ideas. The Polish Eugenics Society was dissolved in 1952, but it actually ceased its activity as early as in 1949.¹²

Nowadays, eugenics is understood as a system of views assuming the possibility of improving the hereditary traits of a species, which aims to create conditions that allow the development of positive hereditary traits and reduction of negative traits (in particular, this applies to hereditary diseases), by creating favourable conditions for the development of individuals with positive genetic traits.¹³ The scope of eugenics includes, among others, activities such as combating and preventing various types of internal diseases, genetic counselling, preventive measures regarding compliance with occupational hygiene, prevention and therapy of alcoholism, promotion of healthy behaviours and mental hygiene, as well as conscious parenthood. It also refers to the selective reproduction of a human being, whose purpose is to give life to children with the desired characteristics, especially those that best meet the criteria of racial purity (positive eugenics), as well as the elimination of individuals bearing undesirable traits (negative eugenics).¹⁴

Opinion of the community of people with disabilities on the statutory ban on eugenic abortion in Poland

Based on the so far conducted analyses, it appears that people with disabilities can constitute (and constitute) a special human

¹² M. Musielak, *Sterylicacja ludzi ze względów eugenicznych w Stanach Zjednoczonych, Niemczech i w Polsce (1899–1945)*, Wydawnictwo Poznańskie, Poznań 2008, pp. 211–268.

¹³ *Eugenika*, Encyklopedia PWN (online version): <<https://encyklopedia.pwn.pl>>; date of access: 3 February 2019.

¹⁴ *Eugenika*, Encyklopedia PWN (online version): <<https://encyklopedia.pwn.pl>>; date of access: 03.02.2019; E. Black, *Wojna przeciw słabym*, Wydawnictwo Muza, Warsaw 2004; M. Zaremba Bielawski, *Higienišci. Z dziejów eugeniki*, Wydawnictwo Czarne, Warsaw 2011.

category not only because of the presence of disability and experiencing its psychophysical and social consequences, but also because of the possible approach to eugenic issues. This is because they include individuals characterised by various types, degree, time of acquisition of disability as well as causes of disability. Often, these causes are not only of an inborn nature, but also genetically determined. Hence, learning the opinions of disabled people about a possible legal ban on eugenic abortion seems interesting from a scientific, legislative, but above all humanistic, universal point of view.

The project “Convention on the Rights of Persons with Disabilities¹⁵, a Common Matter” implemented in Poland in the period 2016–2018 has become an excellent opportunity to fulfil the demand to learn about the opinions of various communities of people with disabilities in Poland about the statutory ban on eugenic abortion. The project leader was the Polish Disability Forum (PFON), while the executors included: Warmia and Mazury Council of Disabled People (WMSON), Lublin Forum of Organizations of People with Disabilities, Regional Council (LFOON), the Maria Grzegorzewska University in Warsaw (APS) and the Domański Zakrzewski Palinka Law Firm (DZP). Content-related supervision over the implementation of the project was exercised by the Ministry of Family, Labor and Social Policy. The co-author of the present article participated in the implementation of the above-mentioned project in the status of a content-related consultant.

In the implementation of the first step (2016–2017), 1641 people with various disabilities and people associated with them participated. The goal was to identify areas where people with disabilities experience discrimination. During second stage (2017–2018), proposals of legal and non-legal actions aimed to eliminate spheres

¹⁵ *The Convention on the Rights of People with Disabilities* (CRPD), adopted by the United Nations on 13 December, 2006, signed by the Polish government on 20 March, 2007 and ratified on 6 September, 2012, constitutes currently, apart from the Universal Declaration of Human Rights (UN, adopted on 10 December, 1948), the most important legal act regulating the rights of people with disabilities.

discriminating against people with disabilities, were consulted. The measurable result of the project was a report that was published in 2017.

Analysis of the information contained in the report provides the basis for indicating the restrictions of people with disabilities in the area presented in the preamble and content of the Articles of the Convention. It also provides a real frame of reference for specific issues constituting a platform for discussing disability, its nature, possibilities of providing broad and purposeful support, at a high level in terms of quality and effectiveness, preventing the occurrence of disability in the perspective of the development of human civilization and the achievements of modern science from the point of view of the disabled themselves.

During the second stage of implementation of the above-mentioned project, participants of debates, during which selected discrimination issues were discussed, were asked to discuss and vote on the introduction into Polish legislation of a provision on a total ban on eugenic abortion. Voting took place using four possible options: recommendation necessary for implementation, recommendation desirable for implementation, support recommendation (in removing discrimination areas), unnecessary recommendation. Voting was conducted in secret, on specially prepared cards for voting on the discussed recommendation. The obtained voting results were presented in the "Report summarizing the community consultation debates carried out under the project: "Implementation of the Convention on the Rights of Persons with Disabilities, a Common Matter", the Polish Disability Forum, Warsaw 2017. 355 people (100%) participated in the series of debates on eugenic abortion, including 35 (10%) people with physical disability, 36 (11.5%) people with visual impairment, 43 (12%) people in both groups including intellectual disability and hearing loss, 23 (6%) people with mental disorders, 79 (22.5%) people with overall developmental disorders, 24 people (6.5%) of each group including neurological disorders, chronic diseases, multiple disability, simultaneous hearing and visual impairment (the deafblind).

Tables 1, 2 and 3 contain information on the participants' attitude to the analysed issue.

Table 1. General voting results of people with disabilities participating in the implementation of the project: "Implementation of the Convention on the Rights of Persons with Disabilities, a Common Matter" (2016–2018) on the introduction of a total ban on eugenic abortion into Polish legislation

Type of recommendation	N	%
Necessary for implementation	63	18.0
Desirable for implementation	15	4.0
Auxiliary	43	12.0
Unnecessary	234	66.0
Total	355	100.0

Source: Report summarizing the community consultation debates..., 2017, pp. 86–87.

Table 2. Opinion people with disabilities participating in the implementation of the project: "Implementation of the Convention on the Rights of Persons with Disabilities, a Common Matter" (2016–2018) on the introduction of a total ban on eugenic abortion into Polish legislation, general voting results, including the criterion of the type of disability

Type of disability	Necessary for implementation		Desirable for implementation		Auxiliary		Unnecessary	
	N	%	N	%	N	%	N	%
Physical disability	8	13.0	1	7.0	5	12.0	21	9.0
Visual impairment	8	13.0	2	13.0	9	20.0	17	7.5
Hearing loss	21	33.0	1	7.0	5	12.0	16	7.0
Hearing and visual impairment (the deafblind)	7	11.0	3	20.0	1	2.0	13	5.5
Intellectual disability	1	2.0	0	0.0	0	0.0	42	18.0
Mental disability	11	17.0	0	0.0	0	0.0	12	5.0
Disability, global disorders	6	9.0	8	53.0	15	35.0	50	21.0
Neurological disability	1	2.0	0	0.0	8	19.0	15	6.0
Disability, chronic diseases	0	0.0	0	0.0	0	0.0	24	10.5
Multiple disability	0	0.0	0	0.0	0	0.0	24	10.5
Total	63	100.0	15	100.0	43	100.0	234	100.0

Source: Report summarizing the community consultation debates..., 2017, pp. 86–87.

Considering the general voting results of the participants in the debates on the proposal of a complete legal ban on eugenic abortion in Poland, the conclusion has been crystallised that generally people with disabilities are against such a provision. As much as 66% declared that it is unnecessary, and 12% that it can have a possible auxiliary character in solving discrimination problems. Only 18% of people voted for the introduction of a provision of a complete ban on eugenic abortion in the Polish legislation, and 12% voted for its desired presence. Identical conclusions are presented by the results in Table 2, except that they were grouped based on the type of disability criterion.

Based on the data presented in Table 3, it is clear that the proposal to introduce a provision on the total ban of eugenic abortion

Table 3. Opinion people with disabilities participating in the implementation of the project: "Implementation of the Convention on the Rights of Persons with Disabilities, a Common Matter" (2016–2018) on the introduction of a total ban on eugenic abortion into Polish legislation, general data according to the type of disability

Type of disability	Necessary for implementation		Desirable for implementation		Auxiliary		Unnecessary		Total	
	N	%	N	%	N	%	N	%	N	%
Physical disability	8	23.0	1	3.0	5	14.0	21	60.0	35	100.0
Visual impairment	8	22.0	2	6.0	9	25.0	17	47.0	36	100.0
Hearing loss	21	49.0	1	2.0	5	12.0	16	37.0	43	100.0
Hearing and visual impairment (the deafblind)	7	29.0	3	13.0	1	4.0	13	54.0	24	100.0
Intellectual disability	1	2.0	0	0.0	0	0.0	42	98.0	43	100.0
Mental disability	11	48.0	0	0.0	0	0.0	12	52.0	23	100.0
Disability, global disorders	6	8.0	8	10.0	15	19.0	50	63.0	79	100.0
Neurological disability	1	4.0	0	0.0	8	33.5	15	62.5	24	100.0
Disability, chronic diseases	0	0.0	0	0.0	0	0.0	24	100.0	24	100.0
Multiple disability	0	0.0	0	0.0	0	0.0	24	100.0	24	100.0

Source: Report summarizing the community consultation debates..., 2017, pp. 86–87.

into Polish legislation was considered unnecessary by 100% of representatives of the community of people with chronic diseases and multiple disability, 98% of representatives of the community of people with intellectual disability, 63% with overall developmental disorders, 62.5% with neurological disability, 60% with physical disability, 54% with simultaneous hearing and visual impairment (the deafblind) and 52% with mental disorders. The discussed ban gained less than half of the supporters only among representatives of the community of people with visual impairment, 47% and hearing loss, 37%. Interestingly, people representing communities of very serious, complex disabilities, which in many cases may have (and generally have) an innate nature, including genetically determined one, such as e.g. multiple, intellectual disability, overall developmental disorders were against the discussed provision in 100% or almost 100%. The option of introducing into Polish legislation a provision completely prohibiting eugenic abortion, necessary to introduce, was supported by 49% representatives of the community of people with hearing loss, 48% of representatives of people with mental disorders, 29% of deafblind people and less than a quarter of representatives of people with physical disability (23%) and people with visual impairment (22%). The discussed provision found a few supporters among people with overall developmental disorders (8%), with neurological disorders (4%) and with intellectual disability (2%), and their lack was present in the community of people with chronic diseases and multiple disability. Noteworthy are the contrasting results of the attitude to the present provision in the case of people with hearing loss: 49% for the proposed provision and 37% against and the community of people with mental disorders: 48% for the present provision and 52% against. The obtained state of affairs can be explained by the non-identical size of individual groups representing individual disabilities. It can also be assumed that a certain picture of the approach of people with specific disabilities to the issue of a statutory total ban on eugenic abortion in Poland emerges.

As the topic of abortion is extremely sensitive, highly subjectified and extremely divergent in the social dimension, the opinions

presented by the participants of the debates were different, divergent and at times extremely contrary. Participants of the debates did not specify the consequences (including financial ones) of the lack of this recommendation, although they pointed out the inappropriateness of valuation of life and the need to leave the decision on the birth of a conceived child to their parents. During the discussion, a need to extend the provisions on still unborn children in Polish legislation by regulations regarding prenatal diagnostics and to place special emphasis on such a provision in recommendations related to deciding on pregnancy subject to eugenic discourse, was raised. It was also possible to hear the opinion that the issue of moral choice about the birth of a child belongs to parents, women, and this should not be arbitrarily determined by law.

Attention was drawn to the fact that the introduction of bans, especially on sensitive and controversial issues such as eugenic abortion, opens the door to illegal practices in a given area. At the same time, arguments emphasizing the innate and inalienable human right to life were raised. Every person, as a human being, acquires the right to life at conception. The necessity of multi-aspect support for future parents (especially mothers) of a child at risk of illness and/or disability, among others, by developing a network of facilities providing signalled help and care, was emphasized. The concern was expressed that the recommendation on eugenic abortion may focus public attention, and thus other recommendations related to the implementation of the provisions of the Convention may be implemented seemingly, symbolically, partly or not at all.¹⁶

Summary

From a formal point of view, controversy over eugenics has last since the second half of the 19th century. However, if we consider

¹⁶ Report summarizing the community consultation debates carried out under the project: "Implementation of the Convention on the Rights of Persons with Disabilities, a Common Matter", the Polish Disability Forum, Warsaw 2017, pp. 86–87.

the points proposed by its representatives, as well as the presence of real actions for the selection of the human species, the tendency to eliminate conditions and phenomena recognized as pathological, undesirable, not fitting into accepted standards recognized as the norm and the promotion of individuals meeting the criteria of genetic impeccability, required health condition, physical and intellectual fitness, as well as suitability for society, they have existed in the history of humanity since very distant millennia. They are also present in modern times, although they do not have such a direct nature and form. They are more masked, blurred and diffuse in scientific achievements, legal provisions, programs of people governing or claiming power, in actions postulating humanism, the inalienable rights and welfare of every human being, prevention, medical care, high quality of life, early diagnosis and early intervention in the circumstances of various individual and/or social problems, and therapy, including highly specialized therapy.

People's approach to theses proclaimed by eugenics, both historically and today, has a subjective, individualized and even intimate character, regardless of the criterion of fulfilling the ideals of human and social functioning proclaimed by eugenics and its supporters. As demonstrated by the above-presented data, the community of people with disability, like the dominant part of the society, does not differ significantly in the perception of selected eugenic postulates, and in particular the postulate regarding the introduction of a provision on a total ban on eugenic abortion into Polish legislation. This opinion is not only ambiguous, generally opposed to such a prohibition, but also leaves the right to decide on such sensitive matters to the interested parties, their personal responsibility, and their conscience. This means that disability is not currently the dominant determinant of the approach of specific people, and even communities of people with a specific disability to such important eugenic problems as the legal sanction of a ban or lack of a ban for and in view of the so-called eugenic abortion.

Bibliography

- [1] Black E., *Wojna przeciw słabym*, Wydawnictwo Muza, Warsaw 2004.
- [2] DeJong Lambert W., *Przyczynek do myśli eugenicznej i hygienizmu w polskiej biologii okresu międzywojennego i w latach powojennych*, [in:] *Eugenika – biopolityka – państwo. Z historii europejskich ruchów eugenicznych w pierwszej połowie XX w.*, eds. M. Gawin, K. Uzarczyk, Wydawnictwo Neriton, Instytut Historii PAN, Warsaw 2010, pp. 187–204.
- [3] Dybowski B., *Kilka uwag dotyczących stanowiska antropologii i jej przyszłej działalności*, „Światowit: Rocznik Muzeum Archeologicznego im. Er. Majewskiego Towarzystwa Naukowego Warszawskiego”, vol. XII, no. 3, 1924/1928, pp. 11–16.
- [4] *Eugenika*, Encyklopedia PWN (online version): <https://encyklopedia.pwn.pl/>; date of access: 3 February 2019.
- [5] Galton F., *Inquiries into Human Faculty and its Development*, F.R.S. (First issue of this Edition 1883), J.M. Dent & CO, London 1907.
- [6] *UN Convention on the Rights of Persons with Disabilities*, UN, New York 2006.
- [7] *UN Convention on the Rights of Persons with Disabilities*, Journal of Laws of 25 October 2012, item 1169.
- [8] Kossobudzki P., *Eugenika, czyli jak wychować nadczłowieka*, „Gazeta Wyborcza”, 28 November 2013; http://wyborcza.pl/piatekextra/1,129155,15041710,Eugenika_czyli_jak_wyhodowac_nadczlowieka.html; date of access: 4 February 2019.
- [9] Musielak M., *Sterylizacja ludzi ze względów eugenicznych w Stanach Zjednoczonych, Niemczech i w Polsce (1899–1945): wybrane problemy*, Wydawnictwo Poznańskie, Poznań 2008.
- [10] *Report summarizing the community consultation debates carried out under the project: “Implementation of the Convention on the Rights of Persons with Disabilities, a Common Matter”*, the Polish Disability Forum, Warsaw 2017.
- [11] Reagan R., *Abortion and the Conscience of the Nation*, “Human Life Review”, vol. IX, no. 2, 1983, pp. 7–16.
- [12] Singer P., *O życiu i śmierci. Upadek etyki tradycyjnej*, PIW, Warsaw 1994.
- [13] Sugalska I., *Eugenika. W poszukiwaniu istoty niemieckiego totalitaryzmu*, Bogucki Wydawnictwo Naukowe, Poznań 2015.
- [14] Szczodrowski H., *Co robi Polskie Towarzystwo Eugeniczne*, „Zagadnienia Rasy”, Yearbook 9, vol. 3, 1927, pp. 11–12.
- [15] Wernic L., *Eugenika jako nauka i jej granice*, „Zagadnienia Rasy”, Yearbook 15, vol. 7, no. 3, 1933, pp. 199–211.
- [16] Zabłotniak R., *Dzieje Polskiego Towarzystwa Eugenicznego*, „Kwartalnik Historii Nauki i Techniki”, no. 4, 1971, pp. 769–787.
- [17] Zaremba Bielawski M., *Higieniści. Z dziejów eugeniki*, Wydawnictwo Czarne, Warsaw 2011.



On the phenomenon of scientific work of Zbyszko Melosik

ABSTRACT: Bogusław Śliwerski, *On the phenomenon of scientific work of Zbyszko Melosik*. Interdisciplinary Contexts of Special Pedagogy, no. 26, Poznań 2019. Pp. 405–439. Adam Mickiewicz University Press. ISSN 2300-391X. DOI: <https://doi.org/10.14746/ikps.2019.25.19>

The subject of analyses are issues of research undertaken in scientific publications by Zbyszko Melosik from the Adam Mickiewicz University in Poznań, the content of which is of key significance to reforms in paedagogical sciences after the year 1989 in Poland, as well as to the understanding of international and domestic value of the cooperation of this scientist with academic circles. It is also an example of the establishment and evolution of the Poznań research school in culture, comparative and general paedagogy. They indicate a clear union between the conditions of socio-cultural and education studies in light of the assumptions of post-modernism and critical paedagogy and the richness of sources by this author, connecting Polish paedagogical thought with the world discourse on socialisation and broadly understood education.

KEY WORDS: Paedagogy, pop culture, post-modernity, pathologies, university, higher education, scientific school, fundamentalism, multiculturalism

¹ Full professor of the Faculty of Paedagogical Sciences of the Maria Grzegorzewska University in Warsaw, Poland.

The university is (...) an ideal meeting-ground for teachers capable of imparting their knowledge, and well equipped to develop it by research and innovation and students entitled, able and willing to enrich their minds with that knowledge.

(Magna Charta Universitatum)²

Autobiographical introduction

As one's life passes, every scholar becomes aware of how fast time has passed from the moment they met another researcher in academic circles – and in my case, it is Zbyszko Melosik – the treatises of whom and the debate with whom significantly influenced my own approach towards science. I met the then-contemporary doctor Z. Melosik for the first time at the Faculty of Humanities of the Nicholas Copernicus University in Toruń, where we came – dangerous minds – from various universities (he – from the Adam Mickiewicz University of Poznań, me – from the University of Łódź) to the unique Polish Seminar „Absent discourses”, headed by professor Zbigniew Kwieciński. On the one hand, one felt an inter-generational distance with respect to the Elder Masters, authors of significant monographs, numerous articles or speeches at conferences who were known to us. On the one hand, we were accompanied by a feeling of a community of the younger generation, tied not only with the age of life, but also with the fascination of the necessity to liberate paedagogy from the arms of socialism and its remains.

We had luck to enter the new political system full of knowledge acquired earlier, the thousands of pages of scientific literature we read abroad, behind the “iron curtain”: Zbyszko Melosik – mainly in the United States, me primarily in the FRG. We thus represented – as a result of reception of scientific knowledge on education – dif-

² Magna Charta Universitatum (Great Charter of Universities), Observatory Magna Charta Universitatum, on-line at <<http://www.magna-charta.org/resources/files/the-magna-charta/english>> [access: 17.11.2019].

ferent cultures of humanities and social sciences, from countries with different political systems, different approaches to paedagogy, yet perfectly complementary. We could talk and talk about the latest currents of paedagogical thought that had different historic sources, developed differently in their continents, creating a unique opportunity to quickly pick up the slack as a result of its absence from Poland. It was a time of the censorship, Marxist-Leninist indoctrination and the manipulation by political leaders, as inheritance of the People's Republic, being done away with.

We did not have to compete with each other as to who read more or faster about something important in the world, or who was better at interpreting certain works, when we had to fill in the hole left over after communism, remove the "blind spots" in science to fit in with world thought, theories, paradigms which, in a time of rising democracy and socialist paedagogy protected by the ranks of employees, could constitute an exit to freedom. I had the feeling that within the reality of the new statehood we are struggling towards a different authority for emancipation paedagogy, for which postmodernism had become a grand impulse, pretext or even justification to construct research work. Each of us reconstructed contemporary paedagogical thought in a different way and inscribed in it their own engagement either in the academic field, within the development of their own environment of university paedagogy, or additionally in the space of public and private education. Behind all this remained the "invisible hand" of liberalism and the supporting watch of prof. Z. Kwiecińskiego, who protected our contestation or radically controversial views.

We were, however, not "under the care" of the Professor, because – as Aleksander Nalaskowski poetically described it two years ago during a conference, in his paper entitled "*Pedagogika w cztery strony*" [*Paedagogy in four directions*] – we were "four horsemen of the Apocalypse". The fourth one was Tomasz Szkudlarek. As A. Nalaskowski confirmed it from the perspective of time: (...) *each of the horsemen, being one of the four, was different, entirely different. That might just be the only bridge of comparison. Because each of*

these “young lions” constructed something, did not enter into corporations to destroy others, was not ruthless and, serving others, did not take the throne of justice.³



Fig. 1. From the left: T. Szkudlarek, A. Nalaskowski, Z. Melosik and B. Śliwerski, 2012 source: A. Nalaskowski)

As is clearly seen, a time of memories, generous comparisons, selfless references arose, as commenced by A. Nalaskowski as the youngest of us all. I will focus, however, on our Jubilarian. Now, my time has come to thank one of the riders of the “Wild West” for long years of cooperation and His enormous contribution to educa-

³ A. Nalaskowski, *Pedagogika w cztery strony* (typescript of an unpublished lecture, given during the Polish Conference „Prawica-Lewica-Wychowanie” [Right wing-Left wing-Education] at the Faculty of Paedagogical Sciences of the Nicholas Copernicus University in Toruń on December 5th, 2012), p. 1.

tion sciences in our country. I will try to uncover from such a broad body of work at least some of treatises, ideas, research approaches most significant for me, but primarily for paedagogical sciences, which become an unattained form, structure and style of the phenomenal message of discourse and theory in a manner that is difficult to replicate. In Z. Melosik I respect the high literary culture, including in the area of reviews, because, like very few, he is able to share his own thoughts and opinions very truthfully, deeply and in the author's aid. He is a master of reception and explication of the most difficult issues that permeate into paedagogy from philosophy, psychology, medicine, political sciences or sociology. He handles this best, putting, to a certain extent, the research passion of his doctoral students at risk. It must not wonder that quite every doctoral student is a future, independent scientist, or even titular professor.

Post-modernity as the common denominator of research and its application in science and in practice

At this point I will not commence a dispute on whether Poland is a post-modern, post-modernist country or not, in order to show the intensely relevant scientific identity of thought with Zbyszko Melosik under different temporary and spatial conditions we got to live and work in. Thanks to the first scientific monographs of this researcher of Poznań, all of them deeply significant already, I was able to search for an answer to the question as to the extent, in which Anglo-American educational discourse arriving in Poland in the first years of the political transformation can inspire or provoke theory and transformational practice in our country; is it possible to read thanks to them a Polish-themed change in the context of issues of necessary reforms of schools and the education of teachers?

The post-modern education discourse in contemporary education sciences, initiated by Zbigniew Kwieciński, Lech Witkowski, continued by Zbyszko Melosik, fit in perfectly with the material

reflection on the qualitative capacities of application of deep structural and methodical changes in education.⁴ Their treatises authorised the chances of paedagogy in a world of science, where one could be able to cross boundaries of traditional academic fields, releasing oneself at the same time from the ever-present predominance of modernist knowledge discourses. Disclosing the paedagogical potential of post-modern concepts of education along with their limitations, Melosik did not seek to crown any one of them as most significant, nor drive them away using modernist perspectives on education. Pluralism and multi-dimensionality of the socio-cultural reality do not allow this discourse to take away from any of the modernist discourses acknowledged by science any sort of basis to claim the right for their analyses and value systems to be acknowledged as universal. As Z. Melosik rightly wrote:

the post-modern discourse – forgoing totality in the description of the world – hides within itself an optimistic and positive thesis: **every** theory may to a certain extent describe the world. The social world is not ontologically monolithical. It is diverse, complicated, internally contradictory, it is dynamic, ever open, constantly becoming. Hence, instead of accepting the assumption of a search for any megatheory or post-theoretical opinion, it seems reasonable to approve the idea that **every** theory can allow us to reach some sort of field of social reality or look at a specific area from a different perspective.⁵

⁴ Conf.: *Ku pedagogii pogranicza*, ed. by Z. Kwieciński and L. Witkowski, UMK Toruń 1990; *Spory o edukację. Dylematy i kontrowersje we współczesnych pedagogiach*, Selection ed. by Z. Kwieciński and L. Witkowski, IBE, Warszawa 1993; T. Szkudlarek, B. Śliwerski, *Wyzwania pedagogiki krytycznej i antypedagogiki*, Oficyna Wydawnicza „Impuls”, Kraków 1992; T. Szkudlarek, *Wiedza i wolność w pedagogice amerykańskiego postmodernizmu*, Oficyna Wydawnicza „Impuls”, Kraków 1993; *Nieobecne dyskursy*, ed. by Z. Kwieciński, UMK Toruń, part I. – 1991, part II – 1992, part III – 1993, part IV – 1994; Z. Melosik, T. Szkudlarek, *Kultura, tożsamość i edukacja. Migotanie znaczeń*, Kraków: Oficyna Wydawnicza „Impuls” 1998; Z. Melosik, *Współczesne amerykańskie spory edukacyjne*, UAM, Poznań 1994; idem, *Postmodernistyczne kontrowersje wokół edukacji*, Wydawnictwo Edytor, Poznań-Toruń 1995.

⁵ Z. Melosik, *Postmodernistyczne kontrowersje...*, op. cit., pp. 20-21.

Despite the theoretical lag of paedagogical sciences as compared to post-modern states, Polish academic circles quickly made up the distance specifically thanks to monographs of Z. Melosik, who also through his speeches during domestic conferences and paedagogical assemblies was also able to speak about metatheoretical matters in a style that was uniquely communicative and attractive. We were provided with suggestions helping us to understand real, multi-dimensional relations between education and knowledge on the one hand, and authority on the other; between the subject of paedagogical activity and the social structure that envelops it; he even encouraged us to work towards the creation of a "better world". No single interpretation of education can be superior to another, just as there are no "better" or "worse" theories of education or upbringing. In a pluralist and globalised world, we need to accept the existence of personal, decentralised, heterological and specifically local forms of truth, among which every one of these may be the truth for "a different version of the world".

In the same extent, my approach to education and education science was identical to that of Zbyszko Melosik, the core of which was to cause, thanks to actual, relevant education discourse, Polish education science to be liberated from the complex of being the "inferior other" and for it to become a permanently experimenting scientific discipline that reinforces creative practice and allows diverse theoretical discourses and meta-reflections to permeate into it. The education scientist from Poznań aptly suggested to me that paedagogy as well must let go of the desire to aspire to completely encompass the education reality and to reform it from the top down. Thanks to his treatises, I could much better understand the possibilities of usage in education of such discourses as: post-structuralism as a theory of social life and its educational contexts; post-modernist controversies surrounding global education; global ecology as a post-modern challenge for eco-education; multi-cultural education along with its struggle for the shape of the politics of representation; education and the make-believe culture; the post-modern world of consumption; popular culture along with its

paedagogical potential and youth music as the post-modern cultural test. *Travelling different concepts, one can note that what was "key" for one, is already "marginalised" in another; what is "macro" in one, is "micro" in another. "Entering" languages offered to us by diverse discourses we see the richness of meanings the world in which we live is being described with. Such a journey teaches one humility towards the world – it is too complicated and internally contradictory, distributed and decentralised to be "totalised" into a single narration.*⁶

The post-modern discourse reconstructed by Z. Melosik finally exposed mutual relations between paedagogy/ education and emancipation. The latter is, in fact, one of the fundamental objectives and reference systems of the majority of didactic theories and practices in the post-modern world. If one, as a paedagogue, would like to guide local, non-totalising politics and education, then they could become aware of the problems and dilemmas that await them. If, in fact, post-modernity removes universal values, then projects of paedagogical activities should find their substantiation in the idea of "local" emancipation. Within this context, paedagogues could consciously take the risk of a struggle for the shape of narrations typical for our society, starting with values characteristic for our society and the country we live in. Educational projects thus need not be based on essential values and concepts, and teachers were not expected to aspire to "bring in" portions of a specific discourse into the people's consciousness. A paedagogue would also be aware of the fact that the world and its truths are socially constructed in one way or another, and that in this regard they could take on the role of a conscious participant in the struggle for the shape of the "current version of reality".⁷ The educator or teacher assuming a post-modern version of their own paedagogy would thus have to be aware of the fact that they will live within the context of permanent risk and uncertainty.

For the first time, educators of the post-socialist period had the opportunity of aesthetic yet post-modern contact with a scientific

⁶ Ibidem, p. 285.

⁷ Ibidem, p. 279.

publication devoted to the humanities at the conclusion of modernity, which Z. Melosik authored together with T. Szkudlarek. Their book was the first *post-modernly* written work in Polish paedagogy, to which the authors attached a disc with the entire work. Why? In order to encourage readers to enter into intertextual dialogue. Their invitation was clear: *Enter yourself into our text, add yourself, modify it, edit it, transform it, flip it, erase it, do what you want. We do not pretend to have the right to the "final word". We release this text into time and space.*⁸ This was no coyness or any sort of commercial "winking" at the recipient, because both authors (some of Poland's youngest professors in paedagogy) were known for their humility and, what's rare in the circles, openness to actual dialogue.

Already in the introduction to the book, they stated the enormous joy they experienced with the experiment of co-construction of the text, when they would send a fragment or a part to one another on a disk, consenting to the partnerly modification of it. As it turned out, what one wrote, for them a thread in a personal analysis, the other modified, amended, *redistributed accents, led the paths of narration in a slightly different direction*⁹. Is it not the perfect example of what did transpire over the next few years in the broader (public) scope, when the on-line availability of works (research results) of scientists became more available and intertextual for their addressees? *Hence, no individual fragment has a single author. The author is always dual (or – to voice the statement radically – this text has no author). The "nonmodernity" of this path of emergence of the text on the one hand is "post"-modern (rescinding authorship is a sign of the times of postmodern culture, as is writing text exclusively on the screen).*¹⁰

Reading and interpreting the text or its fragments and using the electronic capacity to immediately become part of the content, without any reservations and limitations, we could adapt them ourselves to our dreams, ideas, to our knowledge or imagination.

⁸ Z. Melosik, T. Szkudlarek, *Kultura, tożsamość i edukacja. Migotanie znaczeń*, Kraków: Oficyna Wydawnicza „Impuls” 1998, p. 12.

⁹ *Ibidem*, p. 9.

¹⁰ *Ibidem*.

Thanks to this, the book by Zbyszko Melosik and Tomasz Szkudlarek really did enter into a cycle of “intertextuality”, and perhaps even lost its original authors somewhere along the way. Indeed, the form of the book was aligned with its content, faithfully recalling the spirituality of its authors, who are, after all, united through the community of the anti-fundamentalist approach to science and paedagogy. Hence, who did not yet understand or experience what post-modernity is and what effects it may bring with itself (texts, contexts and interpretations), was not dismayed by the offer made by both authors, to try to jointly walk the ‘path’ of thinking about the surrounding reality. We could face THEIR “truth” and “fiction” or become aware of both the metaphysical as well as the natural, ever so clear, charm of everyday life.

I recall this treatise because it is a unique narration on experiencing the *ordinariness* and reality of social life, of the crisis of humanities, including paedagogy, and its practical applicability in the area of school education, along with the entire context of dramas and hopes. Retreating from the modernist struggle to tame human souls and to charm readers with theory, the authors encourage us to take a deeper „breath” of alternative *reality* and theories and to relativise our own biography or the modes of conceptualisation of reality. They treat paedagogy as one of many cultural practices, as one of the modes of articulation of the world, as one of the forms of the politics of representation.

It is also worth reaching out to this book in order to find out why:

- even the greatest philosophies and theories do not have a chance to shape people and reality?
- paedagogical theory, different from philosophical theory, is commonly believed to be quite an unquestionable form of theory?
- even those teachers truly fond of their pupils at school have the subtlest, and through this, a very dangerous, power over them?
- the museum, being a special kind of paedagogical text, disciplines the viewer’s eye, divides it and rules it?

- a journey across multiple theories may be a source of optimism and potential knowledge of man on their own reality?
- education is inevitably political in character?
- one can design educational interventions only on the basis of a critical analysis of the paedagogies that surround us?
- in the post-modern world, values do not play a key role in processes of rooting and identification of an individual?
- life in a world devoid of stable meanings, the specifics of which are described by fragmentary media messages and the ideology of consumption, is an indication of a "pretend, non-authentic identity"?
- decisions over the phone and law set out during conferences are the beginning of post-modernity in politics?
- the concept of freedom is the apogee of aspirations of modern humanism?
- introducing pupils into a world of "legal" culture, sanctioned by the curriculum, at the same time, in good will, we try to disinherit them from the culture with which they came to school?

Why, why, why...? Thousands of questions come to mind, attracting and yet raising austerity in alternate, in terms of excessively quick responses. The reader shall furthermore ponder such issues as sacrum and the everyday, culture and death, humbug, or chaos, satan and free will, popular culture and pop-style values. Intertextuality, the co-presence of the above dilemmas and professorial micro-stories can, within us, give rise to the will to interfere in them, or perhaps it could cause us to feel as if we ourselves were being created by some (someone's) fictions. It is hence now the readers, meaning, the paedagogues, who must decide whether they would want to include it in the biographies of the authors of the book, or perhaps enter it into their own.

Engaged at the end of the 1980s and beginning of the 1990s in favour of the grassroots class teachers' movement and proprietary curricula in education, I could - through explication and application of scientific discourses - restore the constructive rank and significance in education e.g. of the right of teachers, pupils and their par-

ents to bear full responsibility for the choice of mode of learning, allow the actual transpiration of the freedom to be oneself and to determine one's identity independently, solidify local forms of knowledge, strip "totalising authority" away from the discourse of consumption (advertising and fashion) or maximise and experience a range of available experiences and modes of searching for expression as part of the constructivist model of proprietary education. The publications by Z. Melosik encouraged one to spread the strategy of social participation in and takeover of education in our country, to make education democratic, with participation of all subjects of education interested in it, among others, thanks to the heads of the Polish ministry of education, by them consenting to the grassroots transformation movement as a work of social transformation. The process of inclusion of patterns of change in public education proceeded from individual innovators (transformation leaders), proprietary initiatives of social actors (parents, associations or religious congregations) or scientists. I could be engaged for the benefit of initiation, publication and implementation in Poland, in the first half of 1990, of grassroots innovations through their induction (grassroots encouragement) or diffusion of the new as alternative partial or complete solutions.¹¹

In view of Z. Melosik, the world is constructed antagonistically, being in constant struggle for power, domination of one discourse over another. Were one to look at diverse paedagogies from the perspective of post-structuralism, one could note that in every society, there is an ongoing discursive struggle of different scientific "versions" of education reality for legalisation. This takes place at the expense of alternative versions, and constitutes the operation of

¹¹ See B. Śliwerski, W. Śliwerska, *Edukacja w wolności*, Kraków: Oficyna Wydawnicza „Impuls” 1991; B. Śliwerski, *Wyspy oporu edukacyjnego*, Kraków: Oficyna Wydawnicza „Impuls” 1993; idem, *Edukacja autorska*, Kraków: Oficyna Wydawnicza „Impuls” 1996; idem, *Jak zmieniać szkołę*, Kraków: Oficyna Wydawnicza „Impuls” 1997; idem, *Edukacja pod prąd*, Kraków: Oficyna Wydawnicza „Impuls” 2001; idem, *Problemy współczesnej edukacji. Dekonstrukcja polityki oświatowej III RP*, Warszawa: WAiP 2009.

their “exclusion and inclusion”, meaning, it protects certain interpretations, marginalises others and forces one to go silent. The meta-narration of social life created in this manner represses its alternative versions. Alternative paedagogy, in confrontation with the top-down reforms implemented by one government after another, always belonged to the reality that was outlawed by the exclusion of the discursive practices that create it. *Proponents of alternative theories utilise usually very different epistemological, moral and ideological perspectives. (...) At that time, very frequently, theories are transformed into conceptual and strategic ideologies. As B. Mercer vividly writes, “the pages of academic journals and scientific papers (...), seminar halls (...), see passionate accusations being hurled from the fortifications of one paradigm towards the fortress of another paradigm: “your [paradigm] is conservative and promotes discrimination and inequality – and yours is radical and promotes conflict (...)”; “yours is blind to central changes – and yours is blind to the obviousness of order; “yours is idealistic, utopian, out of touch with reality – yours is the same (...)”. And so, the battle of paradigms goes on.*¹²

This very apt interpretation of the war of discourses in a pluralist world made me commence studies on contemporary paedagogical thought from this very perspective, in order to see in them what is praised by their creators and voided by their critics as unwanted under conditions of Polish democracy.¹³ The transformation threshold in Poland after 1989 challenged academia to open up to new, hitherto unknown basic paradigms in open society education. To see the project of innovative (alternative) education in the context of competitive mobility that has the task of giving rise to mutual exclusion of paedagogical methods struggling to obtain the place “at the core”, and not the “outskirts”, to have the first say in explaining and valuing education, to exclusive promotion of a specific

¹² Z. Melosik, *Współczesne amerykańskie...*, ibidem, p. 173.

¹³ B. Śliwerski, *Współczesne teorie i nurty wychowania*, Kraków: Oficyna Wydawnicza „Impuls” 1998 (9th edited and expanded edition, 2015); idem, *Pedagogika dziecka. Studium pądocentryzmu*, Gdańsk: GWP 2007; idem, *Współczesna myśl pedagogiczna. Znaczenia. Klasyfikacje. Badania*, Kraków, Oficyna Wydawnicza „Impuls” 2009.

“version” of reality – it allowed me to avoid working with innovators of the fundamentalist (totalising) role of individual solutions in education. The competitive perspective of alternatives in education or paedagogy must have led to mutual enmity (e.g. ideological, personal, institutional) and depreciation of opposing views as being devoid of (scientific, ethical, political, etc.) value.

Irrespective of the paradigmatic disputes giving rise to the necessity of changes in education, in the beginning of the political transformation in Poland there emerged the problem of their core, scope and quality. It is thanks to treatises by Z. Melosik one can recognise in studies of models of teaching, to what extent the change to be designed with their use takes a modernist or post-modernist shape, if with respect to the latter, the categories of difference, *otherness* and diversity take to the foreground. In politics of reformation of education we clearly see the conflict between the struggle of the ministry of education to clarity, unambiguity, the educational ordering of the world, in which “*one knows what to do*” (or – *which is essentially the same – they believe they know*), in which *one knows how to calculate the probability of an event, and one knows how to improve or reduce such probability; a world, in which the relation between specific situations and the effectiveness of certain actions is more or less fixed, hence, it allows one to rely on past successes as direction signs towards future successes*¹⁴, and the contemporarily not avoidable any more ambiguity of educational situations, including structural and programme solutions and related innovations.

In open, pluralist societies, no government attempting to control education according to a “top-down” strategy has any chance of self-implementation, as it will face the wall of opposition by those who do not accept, respect or to a certain extent even do not like this government. This applies to all governments – leftist, liberal or conservative. Over the course of more than 27 years of political transformation in Poland after 1989, politicians have still not

¹⁴ Z. Bauman, *Wieloznaczność nowoczesna. Nowoczesność wieloznaczna*, transl. by Janina Bauman, Wydawnictwo Naukowe PWN, Warszawa 1995, p. 12.

learned that as a result of elections they are to rule a country, but not the souls of its citizens and their children, much less over teachers professionally prepared to work with them. I rarely get the chance to meet professor Z. Melosik and to jointly discuss fundamental issues for paedagogy as an educational or extra-scholar science and practice, which were first devastated during Nazi totalitarianism, then during Soviet totalitarianism, with the ensuing inability to depart from the leftovers of the *homo sovieticus* until today, despite the ongoing political and sociocultural transformation. Thanks to the fact, however, that his treatises are written with scientific distance to the reality of our education and science, they are universal, timeless in character.

Pop culture contexts and implications for body and health

Zbyszko Melosik counts among the few Polish paedagogues who are interested in the body as a pop culture phenomenon. He published a treatise on just this subject, placing the category of the body and of health in the society of consumption, at the same time fusing his own research with those being conducted at the same time by other scientists. In his treatises, he describes selected cultural changes in the contemporary world and interestingly presents discussions concerning the implications brought about by them (potentially) for education theory and practice. Thanks to constant transgression of research fields that he partakes in which would seem reserved for (positivistically) autonomous sciences, we are able to more deeply enter this discourse to include new perspectives and modes of research. Who was unable to feed his cognitive sensitivity with the perfect analysis of societal modes of construction of identity by youths, in particular with respect to femininity and masculinity¹⁵, may fill this emerging “hole” between the world of paed-

¹⁵ Z. Melosik, *Tożsamość, ciało i władza. Teksty kulturowe jako (kon)teksty pedagogiczne*, Wydawnictwo Edytor, Poznań-Toruń 1996.

agogy of health and the world of everyday youth life with a further confrontation between modern and postmodern thinking.

Considering the issue of body and health, common for the entire volume and its authors, we can clearly see a specific arrangement of cultural locations and practices, which the modern man engages their psychological and social energy in. As the head of team studies and editor of the publication drawn up on their basis, he aptly interpreted human passions, capacities, forms, designs and objectives of human engagement centred on what only seemingly looks permanent on the "map of significant meanings". In his text entitled *Teoretyczne problemy promocji zdrowia i edukacji zdrowotnej* [*Theoretical problems of promotion of health and health education*], he performs a meta-theoretical study of health discourses in contemporary society. In this volume, he also notes the body and health as being included in popular culture texts, when he presents a series of epistemological openings of post-modern culture and politics in consumerist societies. At the same time, it is his encouragement to look at their sources, substantiations and implications. He vividly characterises this post-modern world of consumption to move on to the deconstruction of such modern discourses as: *McDonald's, identity and health; Coca-Cola: a soft drink as a "model" of life and identity; The tyranny of being thin and its consequences; Plastic surgery, the body and identity.*

The area of the most personal and intimate sphere of human life, sexuality, is uncovered by Z. Melosik in course of an analysis of cultural and social sources, contexts and consequences of introduction to the pharmaceutical market of the newest cure for impotence – Viagra. He writes about it together with M. Cylkowska-Nowak not stopping at making available this quite "hot" discourse on this medicine as a unique phenomenon of questioning the rule of man in public and private life, but at the same time making available the results of his own surveys among studying Poles. They confirmed a range of 'cultural anxieties' prevalent among the respondents. In a further joint text as well, entitled *Contemporary youths: the body,*

*health and popular culture*¹⁶, they present the results of research among academic youth that were aimed at grasping, how the young generation in our country perceives their body and what is their attitude towards its "ideal", television hosts (models), the world of fashion and plastic surgery. The life style analysis accompanying these diagnoses confirms just how dearly our education system needs a significant turn in the pro-health education and schooling of the young generation, which eats badly, does not exercise, is dependent on substances, sick and care-free or overworked, and at the same time – unaware of all the hazards that stem from this lifestyle.

Finally, brilliant texts by Z. Melosik concerning the health and identity profiles in advertising: the Marlboro Man and the Virginia Slim Woman represent advertising mechanisms and strategies that lead to a reorientation of society's lifestyle to fit the pattern, form and image of products promoted by the media, to the creation by these of a world of illusions, dreams or desires. He uncovers alongside the hidden dimension of advertisements, as texts, the creators of which, reacting to societal trends, inscribe with cultural "traps" of consumer dependencies. The results of survey studies that apply to the perception of advertisements of tobacco products by Polish youths become perhaps the ultimate alarm signal for education scientists in order for them to work on anti-advertising education that would make youths sensitive, or perhaps, that would desensitise against this veritable "virus" of consumer culture.

As my academic experience shows, teachers are not particularly interested in works by multiple authors, being used to monistic interpretations of paedagogical theories from the time of the People's Republic. At the same time, the time of socio-political transformation in our country was best utilised by these academic institutions, in which multi-dimensionality is sought and publicised for a specific educational problem that would seem to be homogeneous in terms of content. This definitely includes health and the body,

¹⁶ *Ciało i zdrowie w społeczeństwie konsumpcji*, ed. by Zbyszko Melosik, Wydawnictwo Edytor s.c., Toruń-Poznań 1999.

about which Z. Melosik rightly writes that it is not possible to formulate their single, "ultimate" and culturally universal definition. *After all, these are not states that are exclusively "objective", which are 'given', but – largely – social constructs*¹⁷. Hence, it is not permitted to ascribe the promotion of health only to those schools that were included in the Schools for Health in Europe Network, executing in the years 1992–1995 Poland's programme under the patronage of Poland's Institute of Mother and Child. This idea may be implemented in diverse educational communities, small and large public or private schools, the paedagogical staff of which rejected the biomedical concept of the body and of health.

In the search of education promoting health and properly perceived corporeality of children and youths as well as their teachers, no "slogans" are necessary that might lead to the "objectification" of clients or that might make them just a "special" or an addition to obtain from the state or commune budget more financial resources, but they should be solutions that guarantee everyone the right to make decisions on their own "corporeality". Every Polish school should be an environment of health and of the respected human body. One should become aware of the type of paradigm, health discourse and promotion the designed changes, innovations or experiments should be part of. If we would use this to contain a **functional-structural approach**, then the category of health becomes a claim against teachers to perform such investments in "human (pupil) capital" so that in the future they could provide "repayment" and "profit" as "dividends". In this respect, the promotion of health boils down to the promotion of rational health behaviour that corresponds to standards and recommendations developed by medical doctors, and pupils are supposed to adhere to them without remarks. In course of health education oriented in this way are subjected to permanent control, manipulated to fit in with educator expectations. On a sidenote, schools of this type employ teachers who deny with their behaviour or actions the standards imposed on

¹⁷ Ibidem, p. 7.

pupils (e.g. diet) or the practices of healthy everyday lives (e.g. because they smoke tobacco or drink alcohol, etc.).

A different cognitive paradigm characterised by Z. Melosik is the theory of **economic and cultural reproduction**, according to which health and the body are a commodity that can be bought and sold, hence, they are not available for everyone. A school promoting health thus legitimises the imposition of cultural arbitrariness of the group dominating a specific community, thus confirming the presence of social inequalities in this regard. Education becomes powerless against social, cultural and economic differences or divisions among children and youths or their socialisation environments, stubbornly trying to impose the required (healthy) life style on everyone, as if everyone did actually have equal access to it. In light of **critical theory**, in turn, the discourse of health and body may be an area of struggle for liberation from domination, injustice and alienation for the benefit of objectification of teachers, pupils and their parents in the care for a change to the own status quo, for a better condition of health and of the body. This support of free individual and collective will to shape competences in terms of constructive social criticism through education is awakening among all entities of the learning process of the awareness of own and social rights in this area of their lives (e.g. patient rights) and awakening criticality of thinking about institutions that strip individuals of their own activity or the ability to act.

A different discourse in health promotion education is **pragmatism**, in light of which the status of truth about health and its promotion is ascribed on the basis of functionality of a specific form of knowledge. The value of health and the body is socially constituted, being dependent on the time, place and on the circumstances. It is thus important only if it proves itself positively in action. However, from the point of view of a further discourse, which is – according to Z. Melosik – poststructuralism, the core of the struggle for the health of healthy life is the production of meanings and the imposition of these as valid, in line with the power relations present in society. *Within the context of assumptions of poststructuralism, it is nec-*

essary to answer the following questions: why such a place and time are dominated by these and not other modes of perception of the "body" and the issue of "health"?; what is the source of new discourses in this regard?; why do people (sometimes radically) change their views on the subject?¹⁸

In a period of preparation of new curricula, Melosik's book should become the source of greatly valuable inspirations to construct „intersubjective education paths” that are so dearly needed by the young generation. thanks to this, one could help pupils to improve the levels of their own awareness in making choices and in social practices related to their body and health, so that they could proceed in their personal and adult lives logically and rationally. As Z. Melosik rightly assumes in this work, (...) *the body and health should be perceived not only in biological and medical categories, but also in cultural and social ones*¹⁹, and if so, then who knows, perhaps in a sense they will dominate the core and objectives of general school education in the 21st century.

Interdisciplinary treatises by Polish scientists on still other phenomena of our daily lives that is content, events, processes and actors that become popular culture, that is: tradition and post-modernity, art and technology, *humanum* and *cogito*, education and socialisation, *sacrum* and *profanum*, etc., have become the subject of a different work edited by Z. Melosik.²⁰ It was these that provoked the creative utilisation of domestic researchers, inspired them to undertake own research, in order to, using a language that is partially isomorphic with respect to reconstructed popular culture, open us up to its „consumption”, „relishing in it”, „experiencing it” through the lens of own reflection and biographical experiences, in order to see in this a message for broadly understood education. The content included in this monograph migrates to various fields of research interests of specialists in social sciences. What is interest-

¹⁸ Ibidem, p. 20.

¹⁹ Ibidem.

²⁰ *Kultura popularna: teksty, rekonstrukcje i interpretacje*, ed. by Zbyszko Melosik and Agnieszka Gromkowska-Melosik, Poznań 2011.

ing is that what is only sketched out, marginal for one author, yet still perceived as a veritable sign of popular culture, another expands upon it and considers it key for the understanding of what they perceive in others as being less significant. It is thus clear how everyone complements everyone else despite the fact that this is certainly not a purposeful effect, even if it was provoked by a publication's editors by a thrilling debate.

Accordingly, a further collective work of the education scientist of Poznań charms with the style of its narration, frequently moving on to essay-like descriptions and explications of interesting phenomena, at the same time, being aware of processes that become invisible rites of our identities. The authors handled very well the recognition of socialisation and education aspects of what seemingly should remain outside of the scope of research interests of scientists. Travelling is important in our lives (as they tend to educate), significant are issues of our identity, the feeling of own value and respect in light of pressure of our corporeality that remained taboo for years, accordingly necessary is the spiritual sphere and the sphere of life successes, necessary are social ties in light of the mediocrity of pragmatic orientations of life, etc. Thanks to Melosik, the authors of this volume take on issues that hitherto slipped away from the hands of researchers as being less important. And now, thanks to methodologically correctly executed studies, we are able to understand how many events are there in our daily lives, the significance of which is existential for the processes of education, socialisation of identity, professional development or existential dilemmas of persons of various ages (from childhood all the way to the age of slipping into senility – as D. Demetrio wrote²¹). It is worthwhile to enter their educational reasoning.

The authors of articles know their research fields very well, utilise metaphor with great erudition, make use of analogies, comparative or historical and philosophical references. The superficial,

²¹ D. Demetrio, *Edukacja dorosłych*, [in:] *Pedagogika. Subdyscypliny wiedzy pedagogicznej*, ed. by Bogusław Śliwerski, Gdańsk: GWP 2006, p. 145.

fragmentary, soft and mediocre in the pop culture world is covered by them from the position of high culture, however, without the presence of mass culture or its positive influences on the civilisation process being questioned. Everything may be pop in our world, and that is why these kinds of analyses force us to look for limits, the outline of which allows one to see the presence and the animation of high culture, intelligence, mastery instead of banalisation, the destruction of timeless values, populism and the flicker of meanings. If this author's diagnosis is correct in that pop culture time is short, when it is the more worthwhile to capture the changes that occur within it and the events that make it up, so as to have the opportunity to bounce back from the bottom. After all, the limit is the space that separates what is known from what is not (yet) known. Thanks to such a treatise, the difference between what is culture and what is pop culture becomes ever clearer. We return in this volume, as if after a very long journey around the world, to the foundations of development of culture. If pop culture takes its place in the numerator of the fraction of our existence, then the world of the European civilisation, based on, among others, Christian values, is found in its denominator.

The newest book by Zbyszko Melosik, entitled „*Kultura popularna i tożsamość młodzieży: w niewoli władzy i wolności*” [*Popular culture and youth identity: Enslaved by power and freedom*]²² does not leave us passive with respect to issues of transgression of pop culture to our daily lives, including areas of life that were hitherto reserved for high culture only. Thanks to his analysis of the newest social theories we will understand, just how important a role this knowledge may play in the construction of education studies and the interpretation of their results. The participation of an entity in popular culture, the fact that our daily lives are permeated by it, becomes a challenge for high culture, meaning, for education as well, which must cope with this *aporia* of reproduction of high culture as consti-

²² Z. Melosik, *Kultura popularna i tożsamość młodzieży. W niewoli władzy i wolności*, Kraków, Oficyna Wydawnicza „Impuls” 2013.

tuting the ultimate form of civilisation heritage. The content of this book is so well-designed and has such a dynamic of materially differentiated narration that we are able to taste even the most refined (spiritual) content of cognitive theories or models that, it would seem, are only reserved for true connoisseurs.

According to the theory of socio-cultural homology, this treatise will be read by those who seek to confirm their high status, and are just “hungry” for own cultural arbitrariness. And this is exactly the objective, because it is not for academic lecturers or students that affirm practices typical for lower classes, despite them wanting of or holding higher education diplomas. The author, however, sows in us disquiet as to whether or not it is really so that the objective of the contemporary school is not to equip pupils with tools to allow them to relish in any works of culture, but to prepare them to pass tests that are only in place to measure their superficiality and the randomness of their knowledge and skills?

The richness and logical selection of content allows one to read cultural codes that hitherto were hidden and weakly promoted in education. Melosik writes his books in such a way that we read them with the passion of football fans watching their team play. Once again, we are able to participate in a “match” of high culture with pop culture for the value of education, refereed by the author, ensuring adherence to canonical rules of play of „the players on each team” and their interpretation. As usual, we receive a meal for the soul meant for the omnivorous that will satisfy the most demanding of desires. However, unlike the tasting of and relishing in beer, in order to receive the content fully one has to have their „taste buds” prepared. It is doubtless also a book for those who (...) *struggle to demonstrate and show the priority of their own life style over the life styles of other classes through the determination of cultural forms that they represent with the designation «canonical», «legitimized»*.²³

And finally, this treatise provides us with an answer to the question, to what extent popular culture, cultural texts, condition the

²³ Ibidem, pp. 31–32.

freedom of (re)creation of our identity. The author returns here to issues touched upon earlier, to expand upon them and update his work, for instance, speaking about fast-food corporate invasions of the world of our consumption, illusory methods and means guaranteeing alleged happiness, life success or a way out of depression, all to feed the thus-created level of narcissism. The ultimate part of the monograph is excellent – it concerns the regulation and control of identity in contemporary society, as it discloses to us the processes, mechanisms and socio-technical activity of authority in democratic states that in a hidden manner strip citizens of their subjectivity, of real influence on social, cultural or political processes.

What Z. Melosik writes about is the last call for Polish elites that they should stop consuming temporary goods that stem from their cooperation with authority if the effect would be an increased intensity of removal of national, cultural, religious, etc., identity from their own society. On the one hand, the question arises as to whether the identity of any one of us is really designed to live in the neo-liberal slavery of the politics of authorities that boast freedom and in reality seek to limit it surreptitiously? This education scientist from Poznań shows what is written in Western Europe by famed economists and political scientists, namely that a specific type of fascism is returning in the form of extreme *statism*, meaning, a [political] system, in which the state dominates the individual and all private organisations²⁴.

It is sufficient to take a closer look at the bureaucratisation and institutionalisation of the lives of citizens continuously expanding within Polish society, as citizens are stripped of their own identity as a result of domination of processes of standardisation of lives of children and youths from the time of preschool already, and through the application of legal norms in adult lives as the sole modes of adjustment of daily lives. The juridisation of cultural, education but also emergency rescue or health promotion or protection processes violates the fundamental liberties of man under the guise

²⁴ See J. Goldberg, *Lewicowy faszyzm*, Poznań, Zysk i S-ka Wydawnictwo 2013.

of caring for their development. Subordinating man and reality to indicators becomes a hidden mode of authoritarian governance that fakes our liberty in the space of its illusions. What is worse, the boundaries between science and expert opinion that becomes ever more strongly subordinated to commercialisation of knowledge, resulting in a flight away from responsibility for one's opinions or reviews of the actions of the authorities or its designs by experts loyal to those in power.

Melosik aptly forgoes the valuation of any sort of subdivision into high/ low culture. The removal of valuation of both types of cultures has a point, as long as it does not threaten the feeling of community of cultural identity in the family environment. I do not want to enter into a discussion here, but I believe that only encouragement to conclude that low culture is not lower, describes continuation of remaining in the illusion of being open to it; and one must remember that through low culture, values of high culture may be implemented. Thus, the category of delay of valuation to the extent allowed of parents, teachers in light of their levels of tolerance (Lat. *tolero* – cope with what is different) allows one to return to their own identity that they need not change, that they need not be in conflict with, but which they may allow to travel into a world of other values or other experiences, without needing for these to be acknowledged by us or by those under our care as being our own forever.

Any sort of delay allows the transposition of civilisation values in the part that is truly universal, timeless. Social constructivism need not necessary lead to a “point of paedagogical helplessness”, but at most to a “hesitation”, because, helpless is one who is not convinced as to their own values, so, they start to lose faith in them, or rather in the basis of their own identification with respect to them. Perhaps facing popular culture, those originating in high culture could only strengthen and not weaken our identities if we become aware of what we are able to do or what we are already losing, or what was not part of us because we did not understand, not accept it fully. The core of identity is also decided upon by primary socialisation and its secondary overlays, hence, paedagogy may provide not as much sources,

because these rest in the family, in the natural environment of origin and life, but rather arguments, experiences, stimuli that will reinforce, strengthen or exclude them to be replaced by inversion – with anti-identity. In public discourse one can read the question, how is it that a citizen of the US or the UK becomes an Islamic terrorist? The paedagogy of struggle with a specific shortcoming of the world is weakly developed, barely sketched out, and it may have two faces. Here we have an unemployed person, stripped of any chance of living a decent life, despite being educated, healthy, powerful, despite having aspirations, etc., who enters into a life of crime because they conclude that this world does not fit in with their needs.

It is an enormous advantage of this book that Z. Melosik closes it with a description of his own attitude or even a paedagogical settlement with reality, in which, after all, he also lives, and in which he created for many years works for further generations of education specialists and broadly understood researchers in social sciences. I do not hide the fact that I haven't read for a long time a treatise that would be supported by arguments so well, that would use the newest sources of international research on post-modern societies and the pop cultures developed in them with a greater or lesser loss for our civilisation.

Sensitisation to academic pathologies

Higher education, in particular its key function and responsibility for scientific research, remains at a stage of organisational and programmatic, administrative and legal as well as economic changes that are hidden as revolutionary, but which in actuality do have this magnitude, and as a result of which its functioning experiences grave disturbances. This is not the first revolution in the history of universities and higher education facilities (medical, technical, agricultural, economic ones, etc.), but it permeates ever strongly and quickly into deep axionormative, missionary structures of Polish facilities as well, thus delineating for them the structural framework

of “necessary” changes. These impact first the organisational and economic basis for higher education, forcing it to adapt the cultural core, related to the sense of scientific research and the education of academic ranks for their purposes, to alleged market expectations. An ever more stronger shift is seen away from a higher education and science model rooted in European culture, meaning, from the model of Humboldt, to the pragmatic, Anglo-American model, which subordinates science and academic education to demands of the market economy and the bureaucracy that feeds itself on it, and the related control of supply and demand.

We are thus seeing a reduction of scientific facilities that have been constructed for years, frequently continuing century-long traditions, to be replaced by temporarily existing research teams, the main binder for which is the economical, technological or sociotechnical factor, and not timeless values of willing to attain the truth. Scientists must thus answer the question, whether and to what extent they consider it proper to participate in education and research work, in which the historic model of relations between the master and the student fades away, to be replaced by deconstruction of sense and subjects? Do changes related to the process of education, its internationalisation in the spirit of the declaration of Bologna, the unification of diploma validity, the increase of flexibility in the designation of didactic programmes, international exchange and the execution of research projects really have to violate national schools and academic communities that are fundamental for scientific research?

Without a doubt, my interests in the hospital of academic paedagogy were a derivation of Z. Melosik’s scientific treatise that was entitled – *Uniwersytet i społeczeństwo. Dyskursy wolności, wiedzy i władzy* [The University and society. Discourses of freedom, knowledge and authority].²⁵ Written with incredible analytical and synthetic talent, the treatise on social changes in terms of functions

²⁵ Z. Melosik, *Uniwersytet i społeczeństwo. Dyskursy wolności, wiedzy i władzy*, Poznań, Wydawnictwo WOLUMIN 2002.

and roles of the university turned out to have been published in a moment that was very important for Polish academia and education policy, as on the one hand it became a part of the social debate on the project 'Strategy of development of higher education in Poland until 2010', initiated by the Polish Ministry of Education in the year 2010, and on the other hand it responded perfectly to a range of dilemmas in terms of the ongoing discussion about the quality of higher education. This treatise was published in the same year that the Polish University and National Accreditation Commission were called into existence. It cannot wonder as to why the core idea of Z. Melosik was the discourse category that remains at the core of the analytical concept of M. Foucault and is understood as a system of knowledge, concepts or thoughts, incorporated in social practices and occurring in the real world.

Social discourse on university education can thus be treated as a specific type of legitimisation of paedagogical knowledge and detailed educational practices (paedagogies) that correspond to it. It is hence that, which provides university education subjects with a diagram, a pattern of thinking about it. The subjectivity of persons is thus the product of discourses in which they exist, and which are pronounced from various places. Some are privileged through discourse, others discriminated. Discourse is an indivisible configuration of authority-knowledge (and not of authority and knowledge). Within knowledge there is authority, and within authority there is knowledge (who has authority - has knowledge, and *vice versa*). Every truth in the humanities is the result of authority, and through this it is not objective. The possibilities of expression by persons of the meanings of concepts or words and of their definition are limited by the social position taken up by them (in society and in institutions). Discourse may thus be both an instrument as well as the effect of authority, but also a hindrance, a trap, a centre of resistance or finally a vantage point for an opposing strategy.

In contemporary paedagogy, the analysis of significance of discourses of freedom, knowledge and authority as conducted by Zbyszko Melosik allows one to perceive the university as an educa-

tional institution that produces and legitimises them or that limits the 'right to speak'. Discourse expresses itself not only with respect to university, but it is also interested in the form or uniqueness of its education offer depending on the socio-political context as offered by this type of facility. It is universities that have fundamental meaning for the dissemination and selective publication of discourse and their societal internationalisation, controlling access to them. Hence, following the analysis of contexts of operation of universities as chosen by Z. Melosik, it is thus worth it to take a closer look at just how much liberty, authority and knowledge there is thanks to them. The author recreates in this treatise the state of mutually opposing ideologies, concepts and theories of higher education depending on changing socio-political conditions.

It is not significant that in case of the majority of his paths, he refers to US and UK reality, because – as he rightly notes in the introduction – they can also be used to refer to the Polish situation. The greater is the merit of this leader, not only for education science, from Poznań in that he demystifies for Polish readers the myths at play that they have been “fed” for years on the alleged *americanisation* of higher education. One could thus ask whether we are really not only societally but also institutionally compared in this area of the nation's life and development? Thanks to the treatise by Z. Melosik, the issues fundamental for university education were accentuated with unique clarity; these are:

- What is the role of the university in the society of knowledge subjected to processes of globalisation?
- What are the criteria of academic freedom? What end should it serve, what should it provide? What does it limit/ what must limit it?
- Who and using what criteria is to define the “progress of knowledge”? What are the standards of legitimisation and dissemination of “true knowledge”? What is, in essence, the academic canon?
- To what extent may entities financing university operation defend or reduce academic freedom?

- What is the impact of relations between scientific knowledge and personal knowledge of the academic teacher on the education of students (hidden or undisclosed)?
- What conditions must be fulfilled in order for the knowledge collected within a university to have the status of universally significant knowledge?
- What consequences for academic functions of universities are carried with the departure from their autonomic status towards market orientation or the bureaucratic model?
- What influence on the quality of university teaching does real care for standards and levels in the area of academic promotion have? What really hides behind academic advancement procedures?
- How will the role of the academic lecturer change? etc.

The acquisition of scientific identity always requires a “mirror” that is the academic community. The reconstruction of practices and criticism of the tenure system conducted by Z. Melosik, or the procedures of academic progress at United States-based universities forms a uniquely current part of the Polish debate on the domestic procedures of acquisition of scientific titles and degrees and the institutions that guarantee their correctness! Various approaches, paradigms and discourses are becoming significantly important for the contemporary social and legal debate surrounding the prepared, yet another update to the Polish act on higher education and scientific degrees and titles, which in this community form in essence a form of struggle for status and the ability to *do* science at universities, in particular in terms of humanities. Z. Melosik was not without reason a member of the Polish Central Committee for Degrees and Titles, and now belongs to its most valued and respected super-reviewers.

His book should primarily be read by university scientific staff, education system authorities but also politicians or students. The latter the more so that they may recognise mechanisms of commercialisation of higher studies and their implications in non-state and state education. This treatise should be a scientific aid in the politi-

cal, parliamentary debate on the necessity of changes in the process of financing of science and higher education in the Third Polish Republic. Zbyszko Melosik shows here very dangerous consequences for the development of universities and science, in the form of the economic factor in academic life aver gaining importance and significance within the knowledge or knowledge-based society (commercialisation of higher education). Writing about the social functions of universities, he was able to show in this book the influence of academic education and diplomas on the future biography of the individual and on processes of social stratification. This provides us with a grand argument in the ongoing debate on the role of higher education in the process of equalisation of the education opportunities of youths, in the maintenance of development of its ubiquity and availability.

The above book enriches Polish subject literature, particularly in the area of sociology of education and comparative paedagogy, offering entirely new contexts and theories as well as critical reflection on their applications in the West, liberating us from "local emotions" and elevating the "objectivism of the debate" in academic circles and in society. This a unique treatise that does not have a counterpart in our country, hence, it traces a path to freedom and to a structural diagnosis of contemporary changes of the university as an institution, the functions and forms of which are not so obvious any more. At the same time, it forms a kind of call to a reform of the traditional "education theatre", sensitising society to an increase of moral sensitivity with respect to this temple of wisdom.

Comparative studies in paedagogy

Doing research in the area of contemporary paradigms, streams or paths in paedagogy, it is worth starting with a search for an answer to the question, what every one of them is or is not, how are they defined and where to seek sources of their uniqueness. One cannot deal with comparative studies of thought without studying the

works of Z. Melosik. One of his recent monographs, entitled *Teoria i praktyka edukacji wielokulturowej* [*Theory and practice of multicultural education*]²⁶ consumes in a sense perfectly his numerous world trips. Knowledge is a text created by someone under some circumstances, transporting some unique individual cognitive perspective, dependent on the conditions of its construction. In it, he masterfully deconstructs, but also criticises or even redefines, certain conceptual categories so that we would be able to understand that a text has its randomness and fragmentariness, purpose and integrity. Zbyszko Melosik is able to disclose the workshop used to construct and deconstruct contemporary theories and practices of multicultural education, with the knowledge of the art of comparative studies, as few others can. The construction of narration in this treatise is complex, multi-level, very broadly expanded and supported by a logical substantiation of arguments. The monograph has clear cognitive values as it introduces us to a world of education theories and solutions in perspectives of multicultural education that are weakly recognised in Poland, from countries such as the United States, Australia or Spain. In this, he does not hide his sensitivity to phenomena and senses of actual functioning of specific solutions within them.

It is impossible to analyse today the wealth of comparative studies in paedagogy along with its subject of research without referring to this book as well, as it contains not only well-chosen examples of the the phenomenon of multiculturalism in education, but also because that it discloses disputes concerning the core and the scope of entanglement of the processes of education in ideologies and politics as well as in cultural changes that take place within the area of metatheory. Once again, the education scientist enriches Polish subject literature, in particular in the area of sociology of education and comparative paedagogy to include all new contexts and theories. He shows just how one should go about doing critical reflection on the applications of these paedagogies across three continents, to also

²⁶ Z. Melosik, *Teoria i praktyka edukacji wielokulturowej*, Kraków: Oficyna Wydawnicza „Impuls” 2007.

liberate us from “local emotions” and raise the “objectivism of the debate” in academic circles and in society. Particularly today, in light of the unique reinforcement of migration movements from Arab states that are burdened by war, it becomes clear that not all politicians study sufficiently thoroughly issues of intercultural drama and conflict.

Just as researchers in history have to conduct very tiresome comparative studies in archives, collecting relevant documents and traces of existence of specific phenomena, Z. Melosik also conducted very difficult, time-consuming and thorough studies on subject literature distributed across foreign libraries so as to capture in every locality, in every region and nation what is becoming global, what is becoming a part of the community of experiences and thoughts and what *makes* the difference. It is a grand study demystifying United States culture and the logic of *staging* reality produced by the media, the fragmentation of identity in the consumption society and the commercialisation of ethnic cultures. With a narration that is characteristic for its style that is very colourful and well-documented by scientific sources, he describes to us the permeation of multi-cultural relations and experiences not only into politics, but also to education and to everyday lives. It is thus clear that his treatises may be used not only by students of paedagogy, sociology or psychology, but also cultural, earth or political sciences.

Finally, one should note the very interesting reconstruction of the methodological basis in contemporary world humanities that apply to the structures of the scientific field of each discipline within social sciences. The author expands upon our knowledge on new paradigms emerging in the discursive debate, for instance, the “pastoral paradigm” or the antifundamentalist paradigm. The heterogeneity of contemporary scientific debate thus delineates a new field to proponents of science. After all, they have to handle not only new epistemological ideas but also analyse in detail the consequences of the theoretical position reconstructed by them. Without a doubt, the most interesting instance in his examples of regional and education identities are those that apply to contexts and con-

troversies of Australian multicultural education. All this makes Z. Melosik's treatise a work that one cannot put down, experiencing within it the author's cognitive fascination and – what is uniquely important – a uniquely balanced, distanced and responsible analysis of the studied phenomena. We find in this book a response to the question on just how could multicultural paedagogy react to the gradual “dissolution” or dispersion of ethnic and racial identities in the ever-present discourse of consumption.

Nobody among contemporary paedagogues is able to write about difficult things using a simple language and about seemingly simple, everyday issues – in a philosophical and deeply cultural manner, as Zbyszko Melosik is able to write. In his analysis of issues of inter- and multiculturalism as well, he awes us with the ability to read a foreign culture, and at the same time encourages one towards a reflective journey, to transgress to other cultures in a tactful manner, with authentic respect, and without any sort of violation of the own identities of its relevant representatives. This book is a further pearl in my library, as it binds within itself the subtle, very personal culture of the author meeting Another, a different world, with a unique capacity to find within it everything that may be close or common to us. Just like the “Little Prince” of Polish education science, Z. Melosik acquaints us with the culture and education of three continents, describes to us the conditions of formation of the identities of individuals and ethnic groups that, living in a situation of “difference” and “uniqueness” were to a certain extent thrown into the maelstrom of the processes of globalisation and of possible ideological takeover. We stand before an open door leading to a labyrinth of multiculturalism, and hence, within this work we receive the key to conduct comparative ethno-paedagogical studies.

As years pass, Poland is also becoming culturally diversified country. The treatise by Z. Melosik is for us not only an opportunity to prepare well ahead of change, but a veritable passport to our own consciences and culture, to the retention of our own identity that is to that or a different extent one of a “minority”. This is also a perfect comparative study of diverse cultures that could serve politicians and

paedagogues to help eliminate from the process of education of young generations the remains of fundamentalism or even ethnic or racial hate, to oppose the establishment of closed cultural and language enclaves. Fundamentalism in the humanities, and in pedagogy in particular, is difficult if, proclaiming its statements and laws as the only truth or the only reasonable, the best – even if they are frequently confrontational, opposing others – it believes that there is no need to let other scientific schools voice their thoughts, and if its theses are to be binding on all, irrespective of their acceptance. It thus takes from others away the right to own generalisation of knowledge or theory, does not allow new research perspectives, and at the same time limits the development of science. This type of power attitudes leads at the same time to the dogmatisation of the main assumptions of a given direction, pronouncing their uniqueness.

Conclusion

The scientific school is where its master is, and a master for Poznań is prof. Dr. hab Zbyszko Melosik, dean of the Faculty of Education Studies of the Adam Mickiewicz University, in his jubilee year. The internal freedom of the teacher/ master is, in the order of his being, provided to him along with his nature, but one has to agree at the same time with philosophers that in the order of perfection, meaning, in the order of participation in freedom, it was provided to him by his masters. As very few are able to – in academic circles that continue to be highly hierarchical – he could liberate himself, conquer and solidify his internal freedom, or the freedom to choose and complete the objectives he planned on, which in itself became the capacity to oppose external pressure, to provide and infect those under his care and his co-workers with internal freedom. It is thus clear that all publications by Melosik fascinate and endlessly envelop, because the care for the fulfilment of the greatest dream of 20th century humanists is very clear within them – to construct civilisations of *humanum*, or enclaves of love.

Bibliography

- [1] Bauman Z., *Wieloznaczność nowoczesna. Nowoczesność wieloznaczna*, transl. by Janina Bauman, Wydawnictwo Naukowe PWN, Warszawa 1995.
- [2] Demetrio D., *Edukacja dorosłych* [in:] *Pedagogika. Subdyscypliny wiedzy pedagogicznej*, ed. by Bogusław Śliwerski, Gdańsk, GWP 2006.
- [3] Kwieciński Z., Witkowski L. (red.), *Ku pedagogii pogranicza*, UMK Toruń 1990.
- [4] Kwieciński Z., Witkowski L. (red.), *Spory o edukację. Dylematy i kontrowersje we współczesnych pedagogiach*, IBE, Warszawa 1993.
- [5] Magna Charta Universitatum (Great Charter of Universities), Observatory Magna Charta Universitatum, on-line at <http://www.magna-charta.org/resources/files/the-magna-charta/english>, access on 17.11.2019.
- [6] Melosik Z., *Teoria i praktyka edukacji wielokulturowej*, Kraków, Oficyna Wydawnicza „Impuls” 2007.
- [7] Melosik Z., *Ciało i zdrowie w społeczeństwie konsumpcji*, Wydawnictwo Edytor s.c., Toruń – Poznań 1999.
- [8] Melosik Z., Gromkowska-Melosik A., *Kultura popularna: teksty, rekonstrukcje i interpretacje*, Poznań 2011.
- [9] Melosik Z., *Kultura popularna i tożsamość młodzieży. W niewoli władzy i wolności*, Kraków, Oficyna Wydawnicza „Impuls” 2013.
- [10] Melosik Z., *Postmodernistyczne kontrowersje wokół edukacji*, Wydawnictwo Edytor, Poznań – Toruń 1995.
- [11] Melosik Z., Szkudlarek T., *Kultura, tożsamość i edukacja. Migotanie znaczeń*, Kraków, Oficyna Wydawnicza „Impuls” 1998.
- [12] Melosik Z., *Tożsamość, ciało i władza. Teksty kulturowe jako (kon)teksty pedagogiczne*, Wydawnictwo Edytor, Poznań – Toruń 1996.
- [13] Melosik Z., *Uniwersytet i społeczeństwo. Dyskursy wolności, wiedzy i władzy*, Poznań, Wydawnictwo WOLUMIN 2002.
- [14] Melosik Z., *Współczesne amerykańskie spory edukacyjne*, UAM Poznań 1994.
- [15] Nalaskowski A., *Pedagogika w cztery strony* (typescript of an unpublished lecture, given during the Polish Conference „Prawica-Lewica-Wychowanie” [Right wing-Left wing-Education] at the Faculty of Paedagogical Sciences of the Nicholas Copernicus University in Toruń on December 5th, 2012).
- [16] See J. Goldberg, *Lewicowy faszyzm*, Poznań, Zysk i S-ka wydawnictwo 2013.
- [17] Szkudlarek T., Śliwerski B., *Wyzwania pedagogiki krytycznej i antypedagogiki*, Impuls, Kraków 1992.
- [18] Szkudlarek T., *Wiedza i wolność w pedagogice amerykańskiego postmodernizmu*, Kraków, Oficyna Wydawnicza „Impuls” 1993.
- [19] Śliwerski B., *Problemy współczesnej edukacji. Dekonstrukcja polityki oświatowej III RP*, Warszawa, WAIp 2009.

- [20] Śliwerski B., *Edukacja autorska*, Kraków, Oficyna Wydawnicza „Impuls” 1996.
- [21] Śliwerski B., *Edukacja pod prąd*, Kraków, Oficyna Wydawnicza „Impuls” 2001.
- [22] Śliwerski B., *Jak zmieniać szkołę*, Kraków, Oficyna Wydawnicza „Impuls” 1997.
- [23] Śliwerski B., Śliwerska W., *Edukacja w wolności*, Kraków: Oficyna Wydawnicza „Impuls” 1991.
- [24] Śliwerski B., *Współczesne teorie i nurty wychowania*, Kraków, Oficyna Wydawnicza „Impuls” 1998 (9th edited and expanded edition, 2015).
- [25] Śliwerski B., *Wyspy oporu edukacyjnego*, Kraków: Oficyna Wydawnicza „Impuls” 1993.



The role of sketching within the process of creative maturation of an architect in 21st century – sketching from nature in cognitive development

ABSTRACT: Olga Chrzanowska, *The role of sketching within the process of creative maturation of an architect in 21st century – sketching from nature in cognitive development*. Interdisciplinary Contexts of Special Pedagogy, no. 26, Poznań 2019. Pp. 443–458. Adam Mickiewicz University Press. ISSN 2300-391X. DOI: <https://doi.org/10.14746/ikps.2019.25.20>

In the XXIst century, there is a debate whether an architect should practise freehand drawing. This article covers statements about both advantages and drawbacks concerning this activity.

Firstly, sketching remains an universal and timeless medium in cognitive development for artists, due to its engagement with various types of deep concentration at once, such as: practical, theoretical, aesthetic or scientific attention focus. What is more, through the medium of freehand drawing from nature, an architect is introduced to experience natural and build environment, by both reason and physical presence in a setting. In addition to this, there is a strong resemblance of methods within cognitive and creative process of an architectural design.

On the other hand, the concepts of *artistic freedom* and *genius*, which appeared in XXth century, seem to strongly support the idea, that there is a little or no purpose of learning, development, and practise for an artist. Apart from that, recently there happen to be a common belief that manual methods lose their importance in an era of super fast and precise technology or hyper-realistic visualizations and simulations. Freehand drawing fails to reach the standards of the temporary definition of an *ideal*. If other qualities of manual techniques remain unrecognised, such methods

could be abandoned, lose popularity and recognition. These and other controversies concerning freehand drawing are presented and discussed.

In conclusion, to show XXth and XXIst century's approach towards this problem several architectural studios and their methods are introduced. Among many others there are modern architects: Peter Zumthor, Le Corbusier, Louis Kahn, Alvar Aalto and Frank Gehry, that provide numerous examples of drawings, paintings, studies and sketches from nature. Moreover they emphasize the crucial role of manual techniques within architectural design too. To summarise there is a quotation from Alvar Aalto with a remark about this topic: *It is not through simple sketches and superficial similarities that they [painting, sculpture, architecture] influence each other, but through "materia": an intellectual analysis of the chosen material.*

KEY WORDS: sketch, architectural design, XXIst century

1. Introduction: thesis, theoretical and terminological background

The text will take the following theses under consideration: the drawing from nature is a significant instrument of the cognitive technique of the architect; the cognitive technique impacts that design technique; the development of both these areas is the basis of the creative maturation of the architect.

1.1. What is "creative maturity" and how it develops?

Creative maturity is a term defining the individual development of an artist. Ernst Hans Gombrich used this term on numerous occasions¹ while describing art history on the basis of the characteristics of selected artists. To his understanding, the creative maturity would appear after the process of education in school of with a master, and remained as the responsibility of the artist. It is a certain simplification, used to indicate, that creative maturity is a process dependent on internal, rather than external factors, and it occurs on the artist's part.

¹ E.H. Gombrich, *O Sztuce*, Poznań 2016.

1.2. "Disegno" i.e. drawing and design, the common genesis of the concepts

Primarily the Latin term *disegno* was an abstract term, meaning to designate, to indicate, and to direct². During the Italian Renaissance, with the development of the humanities, it was linked to the term "draw", as drawing was no longer treated objectively, but also as a presentation of the creator's intentions. *Disegno* had meant both drawing and design already since the 14th century in the works by Cennini³, and in this dichotomous form, it functions in Italian to this day. As an allegory, *disegno* was presented as a figure holding a compass and a mirror⁴, indicating the duality of the theory: on the one side, the image, model, while on the other, the idea, the intention. This simultaneous move to the external (to the object) and to the internal (to the subject) is clearly highlighted in the definition of the concept, and it also is the essence of the practice.

1.3. The drawing from nature and the other types of drawing

According to the dictionary, the drawing from nature is the "first realisation of the artistic concept, that is subject to changes in the following development of the work of art".⁵ It is such a type of drawing, that aims to record the course of thought of the creator. In painting, sculpture and architecture, this effort, depending on the discipline and the level of precision, has various names: *squizzo*, *study*, *modello*, *bozzetto*, *maquette*. It is the basis of study and work, it is performed swiftly and freely, without too much attention to precision. It allows to make mistakes and to correct them on an ongoing basis. Moreover, the types of drawings are distinguished in re-

² W. Tatariewicz, *Estetyka Nowożytna*, Wrocław 1967, p. 233.

³ Ibidem, p. 42.

⁴ Ibidem, il. XXIII.

⁵ Szkie w: *Słownik Języka Polskiego PWN*, Warszawa 1995, p. 382.

gard to techniques, media, themes, etc. However, in the case of these solutions, the source of knowledge, the origin of the information about the drawn content. On this basis, one may distinguish three types of drawings: from nature, from memory, and from imagination. The drawing from nature is done *in situ*, and its themes may include both nature and architecture, while the technique is essentially freeform (however the artists selection of the technique is not without meaning). By allowing to evaluate the information regarding the drawn object on an ongoing basis, it develops the cognitive technique and constitutes the basis for the drawing from memory and from imagination.

2. Arguments

2.1. The drawing from nature is a significant instrument of the cognitive technique of the architect, as it may operate on varying kinds of concentration

Focus is defined as the concentration of the consciousness on the subject matter. Władysław Tatarkiewicz lists types of focus as the methods of organising knowledge. Primarily, in accordance with the distinction established by Aristotle, there are two basic types of concentration: *practical and theoretical*. The aim of the practical concentration is to, make, transform, preserve or removal, while the theoretical concentration is dedicated to seeing and cognition. Regarding the theoretical focus, there are two attitudes: *scholarly* aiming to the classification, comparison, systematisation, to questions regarding the cause and the aim of the subject matter, and *aesthetic*, in which the subject matter's nature is absorbed directly and substantively. In the latter division, within the framework of the aesthetic attitude, there is a distinction between direct, and indirect contemplation, or, in other words *forms and contents*.⁶

⁶ W. Tatarkiewicz, *O filozofii i sztuce*, Warszawa 1986, pp. 167-174.

Possessing the knowledge regarding various types of focus, and their characteristics, we may intentionally select a cognitive method. Adjusting it to our character, and the character of the subject matter, on which we focus, we assume control over the form and the contents of our thought. Each discipline adopts certain codes. The codes of disciplines are recognisable to all, on a certain level, however applying and transforming them in own work require adept knowledge of its elements and principles. Therefore, the multi-aspect cognition, as well as, cognition training, are important and necessary for the work of a professional, including an architect. However the question remains: how, particularly, can the drawing from nature operate on these types of focus? Below, we shall present the selected issues and examples.

First, the drawing from nature allows to operate with various types of concentration within the range of one action. Within the framework of the mental operations, required to create a projection, an image of the object, various types of focus intertwine and complement our information about the subject matter. Intention and purpose, related to creating the drawing, belong to the practical focus. Additionally, it is important, that during the process of drawing, the image that appears on the piece of paper, is a subject of continuous evaluation and judgement. The decision regarding another stroke, are made on an ongoing basis within the context of reacting to own actions. Therefore, it is visible, that cognition is not only related to the object of the drawing, but also of the subject of the drawing person, it is a reaction to both the character of the drawn object, and the temperament of the person who draws it. The dual sensitivity during drawing, regarding the self, and the surrounding world, allows for a conscious, intentional, auctorial choice of the cognitive and creative path.

Second, drawing from nature is an exercise dedicated to various types of focus, as, during the creation of the drawing, continuous analyses and syntheses of the subject matter are performed. These are the two basic logical tasks used in both the humanities and in the natural sciences. Additionally, the skilful use of the aforemen-

tioned, guides us through the process of drawing. Regardless of whether the drawing is performed by composition⁷ or construction⁸, the passing between the understanding of the general and the particular, and vice versa, expands the range of information about the drawn, learned subject matter. The drawing from nature is a particular visual note from cognition, it aids the architect in recognising form, content, and their mutual dependencies. Additionally, due to drawing, the information defined in such way, functions in our consciousness instantly, without concepts, plastically.

Ultimately, remaining as a physical object in a notebook or a sketchbook, the drawing supports the memory of the creator, allowing him to return to the subject matter. Documenting the considerations is essential from the viewpoint of the complexity of the issues in architecture as a matter located on the crossroads of various different disciplines: visual, social, construction-oriented. Conversations with the great creators of architecture, conducted by means of their works, may last for years. A good example is the collection of sketchbooks of the American architect, Louis Kahn, from his travels to Europe and Africa, filled with drawings of churches, pyramids, villages, as well as, natural landscapes, and mountains.⁹ Le Corbusier complements his book titled *Vers une Architecture* with numerous, freehand, models of houses from the ancient Athens, Rome and Pompei.¹⁰ The universal language of architectural solutions, exists in every style and age, therefore, engaging in this peculiar conversation with the past artists is so important. Drawing allows to create copies, to study, and consider the subject matter of both the man-made, and the natural world. Maintaining the continuity in the cognition of various issues, allows to reintroduce a given issue, and conduct further considerations, or, to retract and revise own views.

⁷ By constructing on the composition that was assumed initially.

⁸ By constructing the composition of object as they appear on the piece of paper.

⁹ R. McCarter, *Louis Kahn*, London 2005.

¹⁰ C.E. Jeanneret-Gris, *W stronę architektury*, Warszawa 2012, pp. 210–221.

2.2. The drawing from nature is a significant instrument of the cognitive technique of the architect, as it allows to create a record being an interpretation of a sensual experience

In the world of architecture, the sensual experience and the cognition by reason, exist simultaneously. Juhani Pallasmaa, a Finnish architect and theoretician of the 20th century, in his book titled *"The Eyes of the Skin"* writes that the "privileging of the sense of sight over the other senses is an inarguable theme in Western thought".¹¹ Favouring one sense over the others accompanies many other transformations in culture. However, the reduction of the experience of the world, to the sense of sight, may fragment the complexity of the perception process and isolate from the world.¹² The *somaesthetics* theory, that currently appears in philosophy, raises a similar issue, assuming that our corporeality and its belonging senses are the "indispensable medium for all perception".¹³ Richard Shusterman, a philosopher and one of the progenitors of somaesthetics presents the following, three-fold meaning of *soma*, i.e. the intelligent, thinking body, in architecture. In the first aspect, he describes the body as the point of reference for architecture, referring to Plato, Vitruvius, St. Paul, Freud, and finding numerous analogies between the idea of the body of a house or a temple. The second context, is the placement of the body in the very same material space and dimension, as architecture, which results in interpreting mass and the dimensions of the building, in relation to ourselves. Finally, Shusterman finds a relation between the body and the architecture, also within the range of causes and effects of architectonic activity. He describes architecture as a space, which serves the purposes of meeting the need for contemplation, both intellectual, and corporeal.

Drawing from nature encourages multi-sensual cognition, impacts the aesthetic and functional judgements on architecture. Pal-

¹¹ J. Pallasmaa, *Oczy skóry*, Kraków 2012, p. 49.

¹² Ibidem.

¹³ R. Shusterman, *Myślenie ciała. Eseje z zakresu somaestetyki*, Warszawa 2016, p. 19.

lasmaa writes as follows: "The live encounter with Frank Lloyd Wright's Fallingwater weaves the surrounding forest, the volumes, surfaces, textures and colours of the house, and even the smells of the forest and the sounds of the river, into a uniquely full experience".¹⁴ The buildings are not isolated works of art, they exist in the atmospheres, sounds, and they react with them. Contemplation during drawing, the focus and the calmness, sharpens senses and increases our cognition. The hands hold the pencil differently in cold weather, and differently in a busy, loud street. The subject matter does not change essentially, however, the body and the mind may be subject to various determinants, which, in an inapparent way, inscribe themselves onto the pages of the sketchbook. It is of essential significance for the cognitive technique of the architect. It reveals, that architecture is not solely an artistic creation, that is separated from reality. The coordination of the project also requires the awareness of the features of the building, perceived by its users or spectators.

2.3. The cognitive technique impacts the project technique, as there exists a synonymy of the issues and the instruments in designing and learning architecture

Drawing is used in design in a way related to the definition of the very term. Palasmaa writes: "design as a process of going onward, and the emergence of hundreds of ideas, during which, partial solutions and details are always tested for the gradual emergence of the solution from thousands of requirements and criteria, from the personal views of the architect, regarding the coordination and harmony, in a complete architectonic, or artistic whole".¹⁵ Testing, searching and change during work on the final solutions are decided upon on the basis of drawings and maquettes.

¹⁴ J. Pallasmaa, *Oczy skóry*, Kraków 2012, p. 54.

¹⁵ J. Pallasmaa, *Mysłąca dłoń*, Kraków 2015, p. 132.

In cognition and design, the same issues appear, that require analysis and synthesis, and the instrument of their solving is the drawing. Vitruvius writes about the sic basic factors of architecture: *ordinatio, dispositio, eurythmia, symmetria, decor, distribution*.¹⁶ He defines *dispositio* as the “putting of things in their proper places and the elegance of effect which is due to adjustments appropriate to the character of the work. Its forms of expression (Greek: *ideai*) are these: groundplan, elevation, and perspective”.¹⁷ In the design technique, the architect uses the *disegno* instrument (sketch, drawing, symbol) to determine the *dispositio* of the forms of the architecture. Exactly the same motif may be used in cognition. In result of such a procedure, the technique of the architect, will be more organised and cause-effect oriented. In result of such study and its application, it is possible to consciously develop own technique methods, both cognitive, and design, and to adjust them to the character and the aims of the architect. An alternative for this, is the chaotic technique, with methods picked at random. Then, it is difficult to maintain the course and the results of such a process.

3. Counterarguments

3.1. Discarding technique for the sake of artistic freedom as a trend in the 20th and the 21st centuries. Genius. The theory of discarding technique completely.

A premise exists, that appears in contemporary art, that both the technique and its lack within an artist, is a convention. The main roles of the artist since the 19th century, have been: imitation, discovery, or creativity.¹⁸ With the dogma, developed already in the Renaissance, and based on the love for man, his originality, and individuality, “creativity remains to be the artist’s primary function in modern

¹⁶ Witruwiusz, *O Architekturdze Ksiąg Dziesięć*, Warszawa 1956, p. 15.

¹⁷ *Ibidem*.

¹⁸ W. Tatarkiewicz, *Dzieje sześciu pojęć*, Warszawa 2012, p. 318.

times.¹⁹ Its immanent feature is the novelty based on the particular ability, talent, that are impossible to explain rationally. Hence, the *Genius*²⁰ well rooted in culture, based more on the mystical properties of the person, rather than on the work, technique, or the faithfulness to tradition. In such an attitude, the technique is “often ascribed to activities related to pure production, and its lack, to pure creativity”²¹. With all the aforementioned premises, truly, one may consider discarding technique in general. However, there is no certainty, whether it is possible, or it is purely a premise, a form of a manifesto. Technique, as the “general assortment of methods and needs used by someone in artistic, scientific work, etc.”²² is, by definition, impossible to discard, as we always apply some methods or means. Therefore, one may discard the technique of his predecessors, their way of working, one may also discard the theory of a permanent technique, approaching the new subject matter in new ways. The accompanying uncertainty may be stimulating for many.

However, freedom and creativity, based on such uncertainty, may also exist in a system based on technique. Then it is based on transgressing the technique, or discarding it temporarily, in order to find the right question, or answer to a particular issue. Within the context of architecture, a significant number of artists that constitute the contemporary canon, uses self-confirmed technique methods, and they highlight their importance. Peter Zumthor, a Swiss architect and the winner of the prestigious Pritzker award, shows photos from his studio, filled with miniature models, sketches and drawings. He publishes two books, both describing his original cognitive technique²³, and he acknowledges the essential nature of craft in creation.²⁴ Another example is Rem Koolhaas, who has an office with two aspects. Its two parts, OMA and AMO are respectively

¹⁹ Ibidem.

²⁰ C. Freeland, *Art Theory: A Very Short Introduction*, Oxford 2001, p. 88.

²¹ K. Czerni, *Jerzy Nowosielski Sztuka po końcu świata Rozmowy*, Kraków 2012, pp. 118-119.

²² *Warsztatał w: Słownik Języka Polskiego PWN*, Warszawa 1995, p. 614.

²³ P. Zumthor, *Myslenie Architektury*, Kraków 2010.

²⁴ P. Zumthor, *Atmospheres*, Basel 2006.

responsible for the design practice, and the research and development of architecture theories. Such combination indicates a deep belief in the common issues at the crossroads of cognition and practice, theory and technique.

3.2. Discarding the manual technique for the sake of the digital technique, with the swift development and the popularisation of digital technologies in the 20th and the 21st centuries. The theory of discarding the manual technique

Digitalisation, as well as, new technologies, gaining popularity in various disciplines, have also entered architecture. Their impact on the technique of the architect, occurs both on the cognitive and on the design level. Within the aspect of cognition, new sources of information are added, such as, e.g. the Internet. The easy access, and the numerous contents, are definitely an advantage. However, the algorithms that manage the processing of information in the Internet, are, firstly, oriented on the most popular search results, and, secondly, as they are a part of the market, they are subject to manipulation. Therefore, as the issues of knowledge, are subject to numerous influences, since the 1970s, more and more attention has been turned towards the sociology, the production, or consumption of knowledge, and the results of these processes.²⁵ The contents of virtual reality, presenting an increasingly regular source of knowledge, change the entire cognition patterns. However, referring to the new instruments of the author information recording, such as, e.g. digital cameras, their general accessibility is not without significance. The lens, and the software that controls the light uptake, and the camera focus, create a very specific image of the reality. To a person with artistic education, it is one of many ways of recording the image of the world, but not necessarily the best one. It would be difficult to find an objective aspect, in which the photo would be better than a drawing, to a learning architect, considering the various defini-

²⁵ P. Burke, *Spółeczna historia wiedzy*, Warszawa 2016, p. 580.

tions of realism, and various cognitive aims. Moreover, the issue also lies in our definition of perfection, which currently is influenced by the development of modern technologies and their paradigms. Within this context, new theories regarding architectural design appear. Parametrisation and optimisation, as concepts taken from the world of production management, and currently, data management, start to seek out their place in architecture.

In result of the tendencies related to the rapid development of digitalisation, and cultural changes, a reluctance may appear, against the traditional methods and the manual technique in cognition and designing architecture. Drawing, the freehand sketch, without having many advocates, and being considered as an imperfect instrument in the modern definitions of this word, may lose followers, and fade into a cultural obscurity, remaining but an exotic show of unpopular, unnecessary skills. Such statements are based on discarding the manual technique due to not seeing it as a source of potentials, essential in the contemporary world. A premise also appears, that the analogue and digital technique cannot co-exist. However, the reality shows, that these practices, as possessing various methods and aims, may complement each other, as is demonstrated by the American architect from the 20th and the 21st centuries', Frank Gehry. His miniature models created in his studio manually, are first scanned in 3D, then processed in software for construction design and planar optimisation, and afterwards, are corrected manually. Travelling between the real and the virtual world, they are subject to evaluation both by the artist's hand, and by the algorithms of the computer software. One of the icons from the end of the 20th century, located in the Guggenheim Museum in Bilbao was designed exactly this way in the artist's studio.

4. The future questions and Summary

Within the context of the subsequent considerations, a question regarding the future fate of the architect's drawings appear, as they are created and used by the author. On the one hand, we are deal-

ing with raising the drawings to the art status, and organising exhibitions in contemporary art museums. The ability to examine the studies by the preceding artists is not a new phenomenon, as Paul Cezanne's drawings were available for purchase by the centimetre. The adepts of painting would come to his studio, where they could buy a fragment of his drawings cut out from a piece of cardboard or canvas, for study purposes.²⁶ On the other hand, currently, one may notice the reduction of drawings to commercial objects: a product, a logo, or advertisement materials, as in the case of one of the Warsaw skyscrapers. In turn, another question is, whether drawing is related to an architectonic style, political or market tendencies and the position of the architect in society. Due to abundant monographs, and archive sources, we know that the modernist architects of the 20th century, would draw much, they eagerly organised exhibitions of their paintings, and, as can be seen by their works, they were surely aware of the trends in painting and graphics of their time. Is the situation similar, regarding the context of the post-modernist and new modernism architects, as well as, of styles from previous ages. It would be crucial to conduct further studies and considerations in these directions.

To summarise the subject matter of the article, the discussion takes place on two essential planes. First, whether the architect should draw freehand or not. Second, in result of the former: if we are to draw, then how should we do it, and if not – what would be the substitute? In the above review, the selected potentials and hazards resulting from assuming the first position, have been presented. The universal and timeless potential has been presented regarding the drawing from nature as the means of learning reality. The advantages of drawing from nature, within the range of the autonomy of an individual experience, have been described. An attempt has been made made to respond to the contemporary accusations posed against the manual techniques, within the context of them being replaced by digital methods. The significance of the

²⁶ A. Volland, *Stuchajac Cezanne'a, Degasa i Renoira*, Warszawa 1962, s. 42.

responsibility for the process of a creative maturity of the artist, has been highlighted. In order to demonstrate examples, references was made to the technique methods of selected architects of the 20th and the 21st centuries. The permanent study, permanent interest, are a result of trust for the world, the architecture, to the fact, that they contain contents important to us. The instrumental apparatus, used for conducting such studies is based on selected artistic and logical methods, adjusted by the artists to their needs.

It is advisable to raise one more issue. An issue, often raised, and related to drawing from nature, is the danger of the mimetic, simple similarity between the drawn objects, and those that would later be designed. Obviously, the record of shapes and colours from nature, does not translate directly from art, painting and drawing, to architecture. The issue is described in an exceptionally accurate way by the Finnish architect of the 20th century, Alvar Aalto, in his essay titled "*Painting, Sculpture, Architecture*"²⁷ revealing that the search for architectonic solutions, conducted via the medium of a sculpture or painting, reveal the specifics of the subject matter in a more profound way, allow the intellectual analysis of the subject matter, and to see it in numerous instances. According to Aalto, an architect should be a conductor in an orchestra containing three plastic arts, i.e. by means of graphic description, allow to the issues to occur between painting, sculpture and architecture, as symphonies are played in a dialogue between instruments.

4.1. The role of drawing in the creative maturity of an architect in the 21st century – drawing from nature and the cognitive technique

In the 21st century, there is a debate whether an architect should practise freehand drawing. This article covers statements about both advantages and drawbacks concerning this activity.

²⁷ A. Aalto, *Synopsis Painting, Sculpture, Architecture*, Basel 1980.

Firstly, drawing remains a universal and timeless medium in cognitive development for artists, due to its simultaneous engagement with various types of deep concentration, such as: practical, theoretical, aesthetic or scientific attention focus. Moreover, through the medium of freehand drawing from nature, an architect is introduced to experience natural and build environment, by both reason and physical presence in a setting. In addition to this, there is a strong resemblance of methods within cognitive and creative process of an architectural design.

On the other hand, the concepts of *artistic freedom* and *genius*, which appeared in 20th century, seem to strongly support the idea, that there is a little or no purpose for learning, development, and practise for an artist. Apart from that, recently there happen to be a common belief that manual methods lose their importance in an era of super fast and precise technology or hyper-realistic visualizations and simulations. Freehand drawing fails to reach the standards of the temporary definition of an *ideal*. If other qualities of manual techniques remain unrecognised, such methods could be abandoned, lose popularity and recognition. These and other controversies concerning freehand drawing are presented and discussed.

In conclusion, to show the 20th and the 21st centuries' approach towards this problem, several architectural studios and their methods are introduced. Among many others there are modern architects: Peter Zumthor, Le Corbusier, Louis Kahn, Alvar Aalto and Frank Gehry, that provide numerous examples of drawings, paintings, studies and sketches from nature. Moreover, they emphasize the crucial role of manual techniques within architectural design too. To summarise there is a quotation from Alvar Aalto with a remark about this topic: *It is not through simple sketches and superficial similarities that they [painting, sculpture, architecture] influence each other, but through "materia": an intellectual analysis of the chosen material.*

Bibliography

- [1] Aalto A., *Synopsis Painting, Sculpture, Architecture*, Birkhauser, Basel 1980.
- [2] Burke P., *Spoleczna historia wiedzy*, Warszawa 2016.
- [3] Czerni K., Jerzy Nowosielski, *Sztuka po końcu świata Rozmowy*, Znak, Kraków 2012.
- [4] Freeland C., *Art Theory: A Very Short Introduction*, Oxford Univ. Press, Oxford 2001.
- [5] Gombrich E., *O sztuce*, Arkady, Poznań 2016.
- [6] Jeanneret-Gris C.E., *W stronę architektury*, Fundacja Centrum Architektury, Warszawa 2012.
- [7] McCarter R., *Louis Kahn*, Phaidon, London 2005.
- [8] Pallasma J., *Myśląca dłoń*, Instytut Architektury, Kraków 2015.
- [9] Pallasmaa J., *Oczy skóry*, Instytut Architektury, Kraków 2012.
- [10] Shusterman R., *Myślenie ciała. Eseje z zakresu somaestetyki*, Książka i Prasa, Warszawa 2016.
- [11] Tatarkiewicz W., *Dzieje sześciu pojęć*, PWN, Warszawa 2012.
- [12] Tatarkiewicz W., *Estetyka Nowożytna*, Ossolineum, Wrocław 1967.
- [13] Tatarkiewicz W., *O filozofii i sztuce*, PWN, Warszawa 1986.
- [14] Witruwiusz, *O Architekturze Ksiąg Dziesięć*, PWN, Warszawa 1956.
- [15] Zumthor P., *Atmospheres*, Birkhauser, Basel 2006.
- [16] Zumthor P., *Myślenie Architektury, Karakter*, Kraków 2010.
- [17] Vollard A., *Stuchając Cezanne'a, Degasa i Renoira*, PIW, Warszawa 1962.

Published on the basis of an authorised copy

Cover design: Izabella Grzesiak

Technical editor: Dorota Borowiak

Computer DTP: Eugeniusz Strykowski

WYDAWNICTWO NAUKOWE UNIWERSYTETU IM. ADAMA MICKIEWICZA W POZNANIU

61-701 POZNAŃ, UL. FREDRY 10

www.press.amu.edu.pl

Sekretariat: tel. 61 829 46 46, faks 61 829 46 47, e-mail: wyd nauk@amu.edu.pl

Dział sprzedaży: tel. 61 829 46 40, e-mail: press@amu.edu.pl

Ark. wyd. 24,50. Ark. druk. 28,75.

DRUK I OPRAWA: VOLUMINA.PL DANIEL KRZANOWSKI, SZCZECIN, UL. KS. WITOLDA 7-9