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Introduction

Interdisciplinary Contexts of Special Pedagogy, Volume 22, is a new collection of scientific texts dealing with contemporary problems of special pedagogy.

The volume opens with texts on the activity of the elderly and experiencing this period of life with dignity.

Bernadeta Szczupał takes up the subject of dignity, everyday life and support for elderly people with disabilities. The author points to problems related to the lack of clear rules of protection of the rights of the elderly, and the consequent difficulties in undertaking systematic solutions related to care, support and assistance in various spheres of life.

Jolanta Izabela Wiśniewska undertakes reflections on changes taking place in the theoretical approach to adult education. She emphasises the role of educational activity aimed at the elderly. The author presents education as a lifelong process, which is also part of old age, and the changes that have taken place in modern society give the elderly an opportunity to participate in various spheres of life.

This issue is also raised by Maria Trzcińska-Król, in her article "Seniors in the media world". The text also refers to education in this period of life in such forms as e-learning and distance learning, but the author also stresses that mastering IT and media skills and

competences enables and facilitates the handling of everyday matters, such as making payments, booking tickets, etc. The text also contains reflections related to the issue of access of the elderly to new technologies. The author asks the question of what problems and opportunities arise before seniors in connection with the use of new technologies. She seeks the answers in the literature on the subject and in the presented research results.

The next three texts concern issues of people with autism spectrum disorders. Barbara Winczura raises the issue of early diagnosis. She points to symptoms observed in the first years of life (with a strong focus on symptoms in the first and second year of life) in terms of building social relations, the development of speech and communication, as well as emerging stereotypical and repetitive patterns of behaviour. The author also presents diagnostic tools used in early diagnosis for disorders from the autism spectrum.

Magdalena Charbicka provides readers with a characterisation of one of the areas where abnormalities in children with autism are observed – the development of play. She focuses on presenting the differences between stages of play presented by a child with normal development compared to a child with ASD, and presents the results of her research in this area. The conclusion she presents may be important for early diagnosis in this area on the one hand, and for therapeutic intervention on the other.

Lucia Bednářová discusses the subject of parents of children with autism spectrum disorders. She presents a review of research on the stress of parents of children with ASD, its influence on psychosocial functioning and the relationship with their disabled child.

Further texts deal with the issue of people with visual disabilities. In her first article, Joanna Gładyszewska-Cylulko discusses the course of the first phase of development in blind children included in E. Erikson's concept, stressing that its proper course is the basis for further development of a proper relationship between the immediate family and the child. He points out what consequences may occur in the development of blind children if there is a lack of

appropriate experience during the period in question. The author does not leave without an answer the question of how to prevent irregularities in the course of the first phase of development.

In her second text, the author takes up the issues of self-stigmatisation of people with visual disabilities. She explains the psychological mechanisms underlying stigmatisation, presents society's beliefs about blind people, and discusses the stages of development of self-stigmatisation and the conditions that strengthen it. As in her first text, the author attempts to indicate the possibilities of preventing this phenomenon in society.

Magdalena Szubielska, Katarzyna Pasternak, Marzena Wójtowicz and Anna Szymańska also took up the issue of social assessment of blind people. She presents the results of research concerning how children and adults evaluate art created by people with visual disabilities. The author attempted to answer the questions of whether the aesthetic assessment of art created by people with visual disabilities changes with the age of the audience and whether it depends on the category of products observed.

Paweł Cylulko also takes up the subject of visual disability. In his text, he discusses the possibilities of using music therapy to support the physical development of a blind child. He points to the role of the integration of music with various forms of movement in supporting psychomotor development and improving orientation and locomotion in space.

In her article, Agnieszka Jędrzejowska draws attention to the communication skills of children with Down syndrome. She presents the results of research on the ability of children with Down syndrome to communicate with their peers in a kindergarten group. The author indicates a selection of methods to improve communication in the studied children, as well as the features of the peer group supporting communication opportunities.

Renata Marciniak-Firadza presents the results of research on the development of word creation in children and adolescents with moderate and severe intellectual disabilities. The author draws attention to the way that word-forming structures exist in the linguis-

tic consciousness of the examined group and whether the newly created words are in accordance with the existing Polish language word-forming patterns.

The next text presents an interdisciplinary approach to the phenomenon of resistance. Beata Gumienny introduces “resistance” to special pedagogy, to the world of people with disabilities, as well as to the educational environment. The author points out that the discussed phenomenon is neglected in special pedagogy and requires detailed research exploration.

Agnieszka Woynarowska asks about “The meanings of intellectual disability in the Internet users’ discourse” in her article, presenting the results of research, where she analyses the statements of Internet users referring to articles published online about norms, otherness, disability and Down syndrome.

The next text takes the reader to the Czech Republic. Tomasz Kasprzak presents the approach to education of people with multiple disabilities in the Czech Republic. He also analyses the term “multiple disabilities” by reviewing Polish and foreign language literature, with particular emphasis on the Czech approach.

The next four texts cover the issue of education of students with intellectual disabilities, starting with the choice of institution, through the trends in case law and diagnostic possibilities.

Jolanta Lipińska-Lokś presents a report from research on the opinions and experiences of parents in the area of their choice of education for children with disabilities. The presented material has the character of qualitative research. The author tries to indicate the conditions of parents’ earlier choices concerning the educational path of their children with disabilities and to determine the level of appropriateness of the choice of a given form of education.

Jacek Sikorski analyses the individual case of a student with moderate intellectual disabilities in the context of acquiring basic school skills, such as reading, writing and numeracy, and indicates the change in these areas over a period of 10 months as a result of the application of educational and therapeutic influences.

Mariusz Wielebski presents the readers with the way from the decision on special education to the individual educational and therapeutic programme. He analyses and interprets the regulations that controlled the creation of this document, its construction and the possibilities of proper use of this document in pedagogical work.

Izabella Gałuszka on the other hand, introduces in her text the problem of individual teaching for students whose health makes it impossible or significantly hinders their attendance at school. The author presents the results of research on the tendency to rule on individual teaching in the Małopolskie Voivodeship. Analyses have been undertaken, among others, of such aspects as the frequency of granting this type of education, the number of documents issued at different stages of education and the reasons for issuing this type of judgement.

The last scientific text of this volume is the publication by Aneta Jarzębińska, in which the author tries to indicate the sources of support for parents of children with a lethal congenital defect. She shows the specificity of parents' functioning after the diagnosis of a lethal defect in a child, describes the support that parents receive from medical staff, other parents or the hospice.

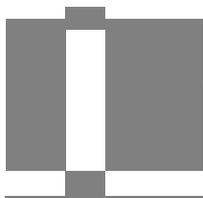
Volume 22 closes with a review of the monograph "The Emotions of Children and Young People with Difficulties in Development and Behaviour" prepared by Stanisław Kowalik and a report from the conference prepared by Jolanta Lipińska-Lokś.

Dear Readers, you hold in your hands Volume 22 of *Interdisciplinary Contexts of Special Education*, which gathers in one place scientific discussions on the subject of disability in its broadest sense. I would like to thank the authors for their efforts in working on their texts and their willingness to share their research results and reflections with the readers.

I encourage your further cooperation.

Aneta Wojciechowska

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ARTICLES



BERNADETA SZCZUPAŁ

The Maria Grzegorzewska University

Dignity, everyday life, support for seniors with disabilities

ABSTRACT: Bernadeta Szczupał, *Dignity, everyday life, support for seniors with disabilities*, Interdisciplinary Contexts of Special Pedagogy, No. 22, Poznań 2018. Pp. 15–26. Adam Mickiewicz University Press. ISSN 2300-391X. DOI: <https://doi.org/10.14746/ikps.2018.22.02>

The process of ageing is an inevitable life phenomenon in both the individual and social aspects. With the growing life expectancy of humans, the way of living in the old age becomes a challenge in the context of respect for the dignity of the elderly. In this article, I present selected theoretical issues concerning the sense of dignity, everyday life and helplessness of elderly people with disabilities, which is unfortunately often associated with it. I also show the complexity of contemporary problems and expectations and the challenges faced by older people with disabilities.

KEY WORDS: Dignity, everyday life, helplessness, support, help, elderly people with disabilities, social welfare homes

Introduction

The phenomenon of rapid population ageing, which occurs in most highly developed countries, is the cause of profound political, economic and socio-cultural changes. The steadily growing elderly population is a heterogeneous community in many respects, ranging from their age, state of health and extent of physical and mental

fitness, social and economic situation, place of residence, to the extent of support required in everyday life. The experience of old age these days is first and foremost an experience of change and a reaction to change, as well as an attempt to cope with it.¹ The categories of dignity and everyday life of elderly people mentioned in the title of the article have a specific impact on their quality of life, their helplessness and the need for support. Particularly elderly people with disabilities can experience many situations that undermine their sense of value, dignity and being a part of society. Old age and disability are phenomena that are often accompanied by stereotyping and discrimination. In today's social reality, despite the widespread recognition of the importance of human dignity, respect for the dignity of elderly people is a legitimate concern. The dignity of elderly people, expressed in their desire to have respect of the community in which they live, may be threatened by their deepening marginalisation. The dignified treatment of a human being means that in every life situation they are a subject, that they have freedom of choice, cannot be used, and their rights must be respected.²

The situation of rapid ageing of the population also leads to some specific consequences for social policy, threatening the collapse of the pension, health and care services systems. The increase in the burden of non-working age population on the working-age population lowers the value of support potential ratios, which determine the ability of the society to provide informal support to the oldest people. Needs of old people, their approach to everyday life, as well as their relations with their environment and immediate circles, exclusion, forms of activation, life, health and economic situation have recently become an extremely topical research problem

¹ Z. Strzelecki, J. Witkowski, *Przeszłość i perspektywy demograficzne Polski*, Warszawa, Rządowa Rada Ludnościowa, Biuletyn, 2009, no. 54, pp. 33–60.

² B. Szczupał, *Równość wobec prawa jako jeden z warunków realizacji praw człowieka z niepełnosprawnością*, *Niepełnosprawność – półrocznik naukowy*, 2009, no. 1, pp. 149–155.

for researchers in a number of scientific disciplines. However, many studies ignore the aspect of ageing of people with disabilities, who often face difficult situations in everyday lives.³ In daily life, elderly people with disabilities need help and support in particular. Ageing is a multi-faceted process that encompasses both physical and mental change, with physical impairments, hearing loss, visual impairments and loneliness being just some of the problems faced by elderly people.⁴

In addition to the problems faced by the majority of senior citizens, the elderly with disabilities have to face many other particular limitations. Elderly people with disabilities constitute a very diverse group. These are both persons with congenital disability or disability acquired in earlier stages of life, as well as those who become disabled in late adulthood as a result of the emergence of various conditions leading to disability or reducing their abilities. The first group consists of people who have entered the phase of old age, already adapted to the disability, which was present in their lives from birth. This group might face problems connected with the consequences of the ageing process overlapping with the difficulties resulting from previous disabilities. On the other hand, among people with disabilities acquired at a later age, health problems overlap with the effects of ageing, such as for example losing a spouse, loss of employment, loss of social position, and are therefore experienced more severely.⁵ The growing number of elderly people, including people with disabilities, represents a major challenge for the society. It is necessary to draw attention to the problems of this group, as well as to study the phenomenon of ageing people with disabilities and the process of becoming a person with disabilities in old age.

³ A. Matysiak, *Is Poland really 'immune' to the spread of cohabitation?*, Demographic Research, 2009, Vol. 21, pp. 215–234.

⁴ J. Heitzman, *Psychiatria w geriatriczynie*. Wydawnictwo Termedia, Poznań 2018, pp. 12–35.

⁵ A. Gutowska, *(Nie)pełnosprawna starość – przyczyny, uwarunkowania, wsparcie*, Interdyscyplinarne Konteksty Pedagogiki Specjalnej, 2015, no. 8, pp. 9–33.

Dignity and everyday life of elderly people with disabilities

In today's social reality, despite the widespread recognition of the importance of human dignity, reflecting on the respect for the dignity of older people is a legitimate concern. It is important that the person copes with their old age and the associated sense of self-dignity. They have to first deal with a number of matters on their own and come to terms with their state. According to the World Health Organisation, a certain cause and effect sequence of events may be occurring in many elderly people: illness – damage – incapacitation – disability.⁶ In the sphere of declarations, the dignity of older people is recognised as an important value and a crucial objective of actions aimed at preventing discrimination. Dignity always remains the main point of reference, it is incomparable with other determinants of the law and cannot be replaced with any other values. In the majority of legislation applicable to elderly people, they do not appear as a separate category of beneficiaries, and they do not possess any specific rights on the basis of their age. Poland lacks clear rules for the protection of the rights of the elderly (which have been present for many years in the documents of the United Nations, the Council of Europe and the European Union.)⁷

The internal determinants of human dignity should be looked for in their personality, particularly in their biopsychosocial predispositions, moral sensitivity, self-esteem, lifestyle and quality of life. With the life expectancy of humans growing longer, the way of living old age becomes a challenge in the context of respect for the dignity of the elderly.⁸ The basis for dignified treatment is experi-

⁶ A. Gutowska, „(Nie)pełnosprawna starość – przyczyny, uwarunkowania, wsparcie, Interdyscyplinarne Konteksty Pedagogiki Specjalnej, 2015, no. 8, pp. 9–33.

⁷ B. Szczupał, K. Chatzipentidis, *W poszukiwaniu drogi do emancypacji – godność osoby starszej i ageizm w świetle koncepcji praw człowieka oraz w perspektywie rozwoju współczesnego społeczeństwa*, Interdyscyplinarne Konteksty Pedagogiki Specjalnej, 2016, pp. 99–118.

⁸ I.M. Świłała, *Godność osoby starszej w nowej rzeczywistości społecznej*, Roczniki Teologiczne, 2017, Vol. 10, pp. 5–21.

encing the respect of the immediate circles. Treating a person with dignity means that they are a subject in every life situation, that they have freedom of choice and self-determination, cannot be used, and that their rights are respected. Dignity of a human being is expressed by ensuring their autonomy, freedom and equality, including in the sphere of economic and social rights.⁹ Unfortunately, there are also a number of negative phenomena which impact the situation of elderly people, which cause their exclusion, marginalisation and discrimination, and thus pose a threat to the fundamental value of self-dignity.

There are many examples of discrimination faced by elderly people, such as negative stereotypes regarding old age, worship of youth, widespread lack of reliable knowledge about old age, unemployment increasing competition in the labour market, specific needs of elderly people, procedures for sharing public funds, low education, loneliness, as well as poor organisation of work in institutions serving the elderly.¹⁰ The crisis of respect for the dignity of the elderly will progress more and more rapidly with the development of civilisation.

Elderly people with disabilities face many problems that affect their functioning in their everyday lives.¹¹ These include family problems (empty nest syndrome), retirement, changes affecting their health and bodies, excessive free time, economic and technical difficulties, dependence on third parties, daily routine, worsening health, loneliness, as well as staying in a social welfare home.¹² These factors are among the greatest threats to the self-dignity of older people.

⁹ T. Romer, *Godność człowieka w prawie pracy i pomocy społecznej*, [in:] *Godność człowieka a prawa ekonomiczne i socjalne. Księga Jubileuszowa wydana w piętnastą rocznicę ustanowienia Rzecznika Praw Obywatelskich*, Wydawnictwo Biura Rzecznika Praw Obywatelskich, Warsaw 2003, pp. 59–83.

¹⁰ P. Szukalski, *Uprzedzenia i dyskryminacja ze względu na wiek (ageizm) – przyuczyny, przejawy, konsekwencje*, *Polityka Społeczna*, 2004, no. 2, pp. 11–15.

¹¹ R. Kijak, Z. Szarota, *Starość. Między diagnozą a działaniem*, Wydawnictwo Centrum Rozwoju Zasobów Ludzkich, Warsaw 2013.

¹² K. Ziomek-Michalak, *Znaczenie rodziny w starzeniu się i w starości człowieka*, *Roczniki Teologiczne*, 2015, Vol. 5, pp. 175–194.

Helplessness of the elderly

Helplessness can affect people of all ages. It has its own individual dimension – it is subjectively assessed by an elderly person. At the same time, we can also distinguish helplessness in an objective dimension, which encompasses for example the existence of specific difficulties for older people in coping with particular aspects of life situations. A characteristic feature of contemporary everyday life is the fast-paced changeability and unpredictability. This is associated with great deal of difficulty in adapting to frequent changes and difficulties in finding one's place in reality. This leads to increasing dependence on others. The appearance of the first symptoms of helplessness should be a signal to the family, neighbours and social services in the broad sense of the term to undertake specific remedial actions.¹³

So far, measures geared towards elderly people with disabilities have had varying degrees of effectiveness. In many environments (such as rural) social work with the elderly is not carried out at all. Activities in this area carried out by local government institutions, governmental institutions and non-governmental organisations rarely form a cohesive system. Each entity operates according to its own standards and decides what actions are the most important for meeting the basic needs of elderly people on its own.

According to Tokaj, the multidimensional helplessness of the elderly should be accompanied by multifaceted support.¹⁴ A frequent cause of difficulties in old age are the so-called geriatric syndromes, such as dementia, depression, locomotion and balance disorders, hearing impairments, visual impairments, etc. A characteristic feature of geriatric diseases is their chronic, multi-causal nature and

¹³ M. Bogusz, S. Ostrowska, *Wybrane problemy polityki społecznej i zdrowotnej wobec osób starszych na poziomie lokalnym – sztuka partycypacji*, Prace Naukowe Uniwersytetu Ekonomicznego we Wrocławiu, 2016, no. 450, *Polityka ekonomiczna*, pp. 82–90

¹⁴ A. Tokaj, *Codziennosc, bezradnosc, pomoc. Trzy kategorie opisu sytuacji zyciowej czlowieka starszego*, *Auxilium Sociale*, 2005 no. 3–4, pp. 80–95.

difficulties in treatment. They most often restrict the activity of elderly people and their mobility, resulting in a gradual loss of independence.¹⁵ In addition, the lack of autonomy caused by these disorders can cause chronic stress and the emergence of other diseases and disorders. Disability in an elderly age can cause an additional burden causing a dissonance between the degree of everyday capacity and expectations of the elderly person, as well as general weakness of the body, resulting in a state of increased risk of the development of adverse health phenomena, such as bone brittleness, weakened immunity, general weakness. All these factors can lead to social isolation and feeling of loneliness, and as a consequence, a reduction in the quality of life. It is extremely important to strive for multi-pronged changes in the area of health, education and customs in order to change the negative image of old age and ensure every day, real support for this group.

Support for the elderly

The ageing of the population forces the rest of the population to face the challenge of fulfilling the needs specific to the group of elderly people. These are needs related to lifestyle, health and care, psychosocial sphere, social activity, economic activity, financial situation and education. Therefore, the tasks of many modern institutions include organising assistance for elderly people with disabilities in order to improve their life situation, health and physical fitness, care and assistance in basic life activities, long-term care and hospice, psychological support, sense of security, recreation and developing interests, as well as supporting and utilising the potential of the elderly.

Forms of assistance are an important element of the situation of elderly people with disabilities in contemporary times. In situations

¹⁵ A. Gutowska, *(Nie)pełnosprawna starość – przyczyny, uwarunkowania, wsparcie*, *Interdyscyplinarne Konteksty Pedagogiki Specjalnej*, 2015, no. 8, pp. 9–33.

where people are unable to act autonomously, it is essential that their dignity is protected by the state, implementing the provisions of the relevant legislation through appropriate social policies.¹⁶ Unfortunately, today's social situation may be a source of barriers in accessing important goods and values, jeopardising elderly people's ability to meet their needs, exposing them to multiple types of discrimination (concerning for example place of residence, age, gender and disability.)¹⁷ These barriers can often lead to the need for help and support for older people.

In Poland, family care is the dominant form of support, and in the cases of the lack of family, its inability to take care of the elderly person, or weakening of family ties, formal organisations or care institutions are obliged to provide assistance.¹⁸ The areas of support and social assistance addressed to the elderly include health care, social assistance, social insurance and social conditions. This support may be provided in the community assistance provided in the place of residence of the elderly people or institutional assistance, implemented through social welfare homes, which are institutions of permanent or temporary stay that can be used by these persons.¹⁹ Both forms of support – institutional and non-institutional – should be complementary and cannot be limited to fragmentary impacts in selected areas, ministries and systems.

A. Tokaj holds the opinion that the basic direction of all support activities for the elderly should be aimed at maintaining the activity

¹⁶ B. Mikołajczyk, *Międzynarodowa ochrona praw osób starszych*, Wydawnictwo Wolters Kluwer Polska Sp. z.o.o., Warsaw 2012.

¹⁷ B. Szatur-Jaworska, *Uczestnictwo osób starszych w sferze publicznej*, Biuletyn RPO, 2008, no. 65, p. 115–121.

¹⁸ M. Rajczykowska, *Środowisko terapeutyczne nowe podejście do projektowania domu senior*, Społeczeństwo i Edukacja. Międzynarodowe Studia Humanistyczne, 2015, no. 2, pp. 173–180.

¹⁹ W. Borczyk, D. Jachimowicz, W. Nalepa, *Partycypacja osób starszych w życiu publicznym – wybrane zagadnienia*, Nowy Sącz, Ogólnopolska Federacja Stowarzyszeń Uniwersytetów Trzeciego Wieku, Nowy Sącz 2015.

and independence of this group in order to satisfy everyday life needs and to integrate them with their immediate environment. Social policy addressed towards older people should take into account three basic principles: subsidiarity, comprehensiveness of assessment of needs and localisation.²⁰ These principles indicate that the quality of life of elderly people is the result of a balanced distribution of responsibility both among the state, the local environment and the family. The municipality is the main authority responsible for the implementation of local policies geared towards the elderly. Its basic responsibility in this respect results from the special position which it occupies in the structures of public administration and a privileged position among local government units. The activities of the poviats and voivodeships should complement and support initiatives taken at municipal level (from a local and regional perspective).

It is also worth noting that elderly people with disabilities are increasingly treated as subjects, while their needs are increasingly taken into account. Elderly people also strongly feel the need for respect, supporting their sense of dignity and usefulness. These needs can be met with the help of various institutions such as day-care centres, universities of the third age, senior citizens' clubs, self-help organisations, cultural organisations, voluntary work organisations, senior citizens' councils, as well as social time banks.²¹ Above all, the activity of the elderly meets the need to be useful and necessary, gives a sense of fulfilment, independence, makes it possible to pass on the wisdom of life and accumulated experience.²² As a consequence, elderly people feel a sense of stability, balance, safety, security, they can also take advantage of treatment, rehabilita-

²⁰ A. Tokaj, *Codziennność, bezradność, pomoc. Trzy kategorie opisu sytuacji życiowej człowieka starszego*, *Auxilium Sociale*, 2005 no. 3-4, pp. 80-95.

²¹ S. Scherger, J. Nazroo, P. Higgs, *Leisure activities and retirement: do structures of inequality change in old age?*, *Ageing and Society*, 2011, vol. 31, pp. 146-172.

²² M. Połusznna, *Aktywność rodzinna i społeczna osób starszych*, Nowiny Lekarskie, 2012, 81, 1, pp. 75-79.

tion and therapy. On the other hand, the lack of such activity may lead to a loss of acceptance on the part of the immediate social circles, resulting in loneliness and lack of self-respect.

Summary

The growing number of elderly people, including people with disabilities, is a major social, economic and political challenge. Contemporary reality creates many barriers and causes existential crises that worsen the quality of life of elderly people and diminish the respect for their dignity. The ageing process cannot be stopped, but it can be changed in such a way so that it becomes a good period in life. It is therefore essential to pay attention to the daily problems of this group, and to study the ageing of people with various disabilities and the emergence of disabilities in old age.²³ The increasing life expectancy is not always connected with satisfactory physical and psychological fitness and independence. It is also important to pay attention to the sense of dignity of the elderly, which helps to direct their lives in spite of changing circumstances, motivates, brings a sense of existence, sets moral directions, crystallises identity, strengthens staying true to one's ideals and values. The benchmark for dignified treatment is experiencing respect from one's immediate circles. It is essential to treat older people with disabilities as subjects, giving them the right to dignity, respect, self-determination, counteracting social marginalisation and ensuring social education aimed at overcoming stereotypes towards the elderly. It is important to promote attitudes that make respect for the dignity, freedom and equality of older people a reality. During this period of life, support and help are essential, but understanding, attentiveness, listening skills and respect are even more important. Thanks to

²³ A. Gutowska, *(Nie)pełnosprawna starość – przyczyny, uwarunkowania, wsparcie*, Interdyscyplinarne Konteksty Pedagogiki Specjalnej, 2015, no. 8, pp. 9–33.

such attitudes, elderly people with disabilities are more willing to participate in social life, work in various organisations to the best of their abilities, develop and be active.

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Educational activity of seniors as a predictor of successful ageing

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The article presents a paradigmatic change taking place in the theoretical approach to adult education. Against this background and in the context of contemporary conditions, the author points to the importance of learning from everyday experience and the role of educational activity in this process. The discussed issues were focused on the elderly.

KEY WORDS: educational activity, paradigmatic change, continuous learning, life-long learning, elderly people, post-modernity

Introduction

Adult education is a concept that is most often associated with institution, coercion, as well as measurable results that are expected in the labour market. It should be mentioned, however, that when talking about adult education, it is necessary to place this area alongside various educational processes – first of all, the activity of learning. Although this activity takes place during each educational process and should be considered crucial for human development, as a separate process, it does not gain due recognition in social assessment.

It should also be noted that adult education covers different age groups: early adulthood, middle adulthood and old age. None of these groups should be overlooked or favoured in the context of adult education. On the other hand, it is necessary to pay attention to the specific nature of educational needs or developmental opportunities of people from individual age cohorts. At the same time, it can be stated that education is an activity attributed to every adult person.

In the public space, adult education is popularised through various media, which is aimed at gaining an education. This state of affairs also confirms the conviction that old age is a period of life excluded from educational activity. The idea-concepts of adult education, promoted mainly by andragogues – continuous learning and lifelong learning – do not go beyond the world of academia, and they have different interpretations in the public opinion. Only Third Age Universities are presented as an educational solution for seniors. It should be mentioned that these are institutions for a small group of elderly people (mainly living in cities), and also that their mission is not an educational goal, although it also pursues such a goal. On the basis of what is happening in the public sphere, in the mass media, the conclusion can be drawn that older people are not seen as “participants in educational services” and that they do not have such needs as a result of retirement. In addition, seniors themselves do not relate educational activity to themselves, or at least they do not consider it an important determinant of their lives.

The author’s intention is to present against the background of theoretical concepts a reflection on the position that the traditional understanding of adult education, resulting from the socially established narrow interpretation of the concept of continuous learning should be rejected in favour of the concept of lifelong learning, which is the path to the development of contemporary humans and their functioning in a changing modernity. The article also refers to the characteristics of selected conditions of modernity, which determine the life of elderly people, to indicate that these are areas, among others, requiring educational activities.

Theoretical orientations implying adult education

Adult education is a sphere of human activity, which at present has a strong theoretical position, mainly in andragogy. In contemporary concepts that constitute adult education there are two parallel paradigms on which adult education is based: continuous learning and lifelong learning. Although both paradigms strongly emphasise the importance of educational activity in the whole life cycle of a person, each of them specifically addresses the issue of education and its implementation. The question arises: which of these paradigms takes on meaning in the postmodern period? It is therefore worth examining the assumptions that form the individual theories.

The concept of continuous learning has been setting teleological assumptions and the direction of adult education since the 1970s. It should be noted that from the very beginning, it had many creators and propagators. Its creation the thesis and conceptualisation theses arose mainly from international conferences under the auspices of UNESCO, as well as works of many authors of various nationalities, including Robert J. Kidd.¹

R. Kidd presented a comprehensive approach to lifelong learning by distinguishing three dimensions of education: education in length, education in width and education in depth. Education in length consists of all levels of school education – from kindergarten, through school to university level (currently this would be post-graduate studies). Education in width is carried out in extracurricular forms of learning and allows for achieving objectives of learning about different areas of life, science and culture outside formal education. On the other hand, education in depth refers to one's own activities and is expressed through the process of self-education and self-fulfilment.²

¹ Z. Wiatrowski, *Różne wymiary refleksji nad edukacją dorosłych*, [in:] *Stan i perspektywy rozwoju refleksji nad edukacją dorosłych*, ed. T. Aleksander, D. Barwińska, Instytut Technologii Eksploatacji – PIB, Krakow–Radom 2007, p. 109.

² J. Półturzycki, *Kształcenie ustawiczne i jego konsekwencje dla edukacji*, [in:] *Kształcenie ustawiczne Idee i doświadczenia*, ed. Z.P. Kruszewski, J. Półturzycki, E.A. Wesółowska, Wydawnictwo Naukowe Novum, Plock 2003, pp. 39–59.

The process of self-education appears in the framing of the idea of continuous learning presented by R. Kidd. It complements the holistic approach to education and distinguishes the – important for human development – activity of self-organisation of learning. Taking into account the characteristics of adulthood, it should be acknowledged that one's own educational activity is of particular importance and should occur as a natural tendency of the individual.

In later years, the idea of continuous learning was developed very widely, but not only by the andragogical community. Influential organisations have made a significant contribution to its practice: UNESCO, the European Commission, the World Bank, the Organisation for Economic Cooperation and Development (OECD).³

The concept of continuous learning is, in a sense, the resultant of the discourse between the organisations that determine its direction. This discourse is multi-threaded and results-oriented. As Mieczysław Malewski⁴ points out, „UNESCO, which considers itself the guardian of the European humanist tradition, emphasises the developmental and moral values associated with education, the World Bank emphasises the economic and market aspects of education, and the European Commission and the Council of Europe try to bring to the fore those dimensions of education which serve to strengthen European integration and build a sense of European identity among citizens of EU Member States”.

Taking into account the various influences on the shape of educational reality, it can be concluded that contemporary adult education is based on the assumptions of adult human development, human capital theory and the concept of human resources development. Ewa Solarczyk-Ambrozik, presents this issue in a slightly different, but excellent way: “[...] modern adult education is based on the paradigm of technological development and socio-cultural modernisation, and the promotion of the Western ideal of rationali-

³ M. Malewski, *O 'polityczności' andragogiki*, Edukacja Dorosłych, 2013, 1(68).

⁴ M. Malewski, *O 'polityczności' andragogiki*, Edukacja Dorosłych, 2013, 1(68), p. 15.

ty and individual fulfilment, and the main contribution to defining its character as an area of social research and practice is made by UNESCO works and publications [...].”⁵

The concept of continuous learning has been particularly inscribed in the educational practice of adults. Various forms of organising of adult education have emerged, and new ones are also developing (e.g. coaching, tutoring, mentoring). A system of education for adults was also created – from the level of primary school to higher education (university). Opportunities for people of all age cohorts (Third Age Universities for the elderly) to participate in education have also been ensured.

The idea of continuous learning has been defined as a complex of educational activities organised by institutions, but also by the individual themselves. However, in reality, its implementation mainly boils down to organising vocational education. The aim of education policy has been to adapt workers to the realities of the labour market, and this challenge is met in various forms of organisation offering education, further training or professional development. This imposed form of education rather than motivation to learn triggered a reluctance to engage in educational activity, and even negative emotions attributed to learning. Such an approach has also marginalised the process of self-education. Schools do not prepare their students for independent educational activities. The process of learning (self-education) is an area commonly underestimated and neglected.

The postulates of lifelong learning not only fit in very strongly with the scientific approaches to adult education, but have also become accepted in the social space. Unfortunately, adult education in the public perspective usually boils down to the processes of further education and professional development, so it is focused on professional goals. It is perceived mainly as a significant component in

⁵ E. Stolarczyk-Ambrozik, *Od uspołecznienia ‘mas’ do upodmiotowienia jednostek – od oświaty dorosłych do uczenia się przez całe życie*, Edukacja Dorosłych, 2013, 1(68), p. 38.

social stratification, changing the human *habitus*. It can be said that these theses have permanently taken root also in the consciousness of the present-day seniors, who received education in the years of crystallisation of the idea of continuous learning, or were professionally active and through gaining subsequent levels of education achieved various types of benefits, especially in their professional work, e.g. promotions, raises, etc. This approach has meant that other educational outcomes, such as development, better functioning in different areas, development of interests, have not been noticed. This situation led to the glorification of institutional education and, at the same time, to the omission of the self-education process.

The 1990s brought a change in the rhetoric of adult education researchers. It manifests itself in the fact that reflection on educational processes is focused on the individual and the learning process, and not, as before, on educational institutions and the education process.⁶

The term lifelong learning has not yet been clearly defined, even among andragogues. Therefore, the scope of meaning of this concept does not yet have a precise theoretical definition. The understanding of the idea can be related to the tendency that it initiates in education. Mieczysław Malewski points to two directions of changes introduced by the lifelong learning paradigm. The author presents them as follows: "First, the lifelong learning concept shifts the focus from educational institutions (teaching) to the learning individuals in local communities (learning). Secondly, he renounces professional scientific knowledge in favour of everyday experience, which is present in the daily interactions that constitute the worlds of people's lives."⁷

The concept of lifelong learning emphasises a different, specific understanding of learning. In its assumptions, an adult person is

⁶ M. Malewski, *Od nauczania do uczenia się O paradygmatycznej zmianie w andragogice*, Wydawnictwo Naukowe Dolnośląskiej Szkoły Wyższej, Wrocław 2010.

⁷ M. Malewski, *Od nauczania do uczenia się O paradygmatycznej zmianie w andragogice*, Wydawnictwo Naukowe Dolnośląskiej Szkoły Wyższej, Wrocław 2010, p. 47.

framed as a subject – as a person capable of organising their own education and assuming responsibility for it. There is no top-down (imposed) modelling of human development. An adult decides individually whether or not to participate in education. Education itself is also framed differently than in the paradigm of continuous learning. It is no longer treated as a good imposed on people, but it is given to them as a choice. In addition, by liberating itself from the institutional framework and allowing people to participate outside their area, education has extended its area to all areas of human life. Institutional education is no longer understood as the only way to human development, which is particularly important in the case of older people.

Nowadays, an adult has a wide range of possibilities in terms of fulfilling their educational needs. They can take part in already functioning formal education or constantly developing non-formal education. They also have the prospect of acquiring knowledge and skills on their own.

An important role, in line with the guiding principle of lifelong learning, is played by non-formal education, which is realised every day during the life of the individual through their activities in various areas (family, free time). It takes on particular importance in the present because the conditions of life are becoming more and more complex and it is necessary to learn to function within them. In addition, learning, the subject of which is everyday life, is also a significant carrier of human development.

It should be noted that the concept of lifelong learning and its application to older people can be considered appropriate to the situation of many seniors, as learning from everyday experience concerns every person. Therefore, educational activity, which differentiates the results of this process, is particularly important in this activity. This activity can manifest itself in very different ways, starting from the level of interest in a given issue through various forms taken: reading, mental games, tourism, interpersonal contacts, ordinary life situations, etc. It should be noted that the concept of lifelong learning imposes on individuals not only activity but also creativity in terms of their own development.

The involvement of older people in the learning process is diverse and presents itself specifically for each person. It depends mainly on how the person presents themselves in terms of interests, predispositions, ambitions and health. Achievement in self-education objectives will depend on the above factors.

Education as a lifelong process, encoded in human existence, is inscribed in in a dignified experience of old age. Olga Czerniawska is very precise about this issue: "Without education, old age has less chance of 'playing out' the full humanity. Without education, old age can destroy a person, ruin them physically and mentally, socially and spiritually."⁸

Old age is marked by many losses: decreased physical and mental fitness, loss of loved ones, changes in family and social roles. The situation connected with experiencing various types of losses or the perspective of losing one's life requires constant rediscovery of one's identity and rereading the meanings. The educational activity of the elderly is a way to understand oneself, one's old age, as well as giving satisfaction from learning and the educational results obtained. Among many others, a significant effect of education is also maintaining mental and physical fitness.

Selected areas of "uncertainty" for older people

The determinants of human life determine its duration to a large, both physically and psychologically. The historical period in which a person lives determines their possibilities of development and self-fulfilment in various dimensions. It is also an important predictor for the quality of life of older people.

The face of modernity, both the one referring to the surrounding reality and to social life, was shaped by the violent changes that took place at the end of the 20th century. Many of these transfor-

⁸ O. Czerniawska, *Drogi i bezdroża andragogiki i gerontologii*, WSHE, Łódź 2000, p. 178.

mations, due to their broad scope and intense character, are noticeable and recognisable by people living today. They have been clearly marked and meticulously described by sociologists in the literature on the subject. One can notice that the authors of sociological concepts present modern times through the prism of change and, due to its dimension, define them as late modernity, second modernity, or they call them postmodern. However, despite the heterogeneous naming, they are similarly characterised in the literature on the subject, and the name used results only from the acceptance or rejection of the thesis concerning the entry of humankind into the next phase of development. However, they share a common position on the emergence of very significant changes in the world, which have transformed the so-called modern world and set a new quality in almost all areas of human life.

The changes that took place during the 20th century are extensive, as they encompassed not only the physical space of human life, but also became a fundamental part of the sphere of social life and culture. At the same time, one has to admit that they are not a closed process, but they are still dynamic in nature, even though they escape human attention on a daily basis. In Poland, they result not only from civilisational changes, but also from political transformation, which resulted in a change of approach to many different social or economic issues. In the life attitude of a person living in new political and economic conditions, features related mainly to the economic aspect of life, such as entrepreneurship, creativity, independence, individualism, have taken on importance.

Modern times, due to technological progress and improvement of living conditions in social perception, are assessed as conducive to human existence. Against this background, however, the following questions arise: How do the current conditions fit into the lives of older people? Is this world really friendly or is it alien to older people?

The characteristics of the present day, determined by sociologists, do not indicate the stability of the conditions of human life. In sociological conceptualisations, much space has been devoted to the

exemplification of new threats and safety issues. The importance of the phenomenon was stressed by Ulrich Beck, who described the present mankind as a „risk society”.⁹ Anthony Giddens¹⁰ also referred to the issue of increased risk, which bases life in uncertain conditions on a mechanism of trust and reflection. The dangers described by the above authors are characterised by the fact that they are not well recognised, and their effects may be unpredictable. Some of them are already taking place, while others may still happen. Examples of the threats facing humanity today include environmental threats, terrorism, military threats, economic crises. Their distinguishing feature is their global dimension, as well as the fact that they can affect any person regardless of social status or material resources. In addition, they are very broad in scope, and it can also be said that modern threats cover many areas of everyday life up to the deeper foundations of human existence.

The well-known Polish sociologist, Zygmunt Bauman, described postmodernity through a metaphor of liquidity.¹¹ In this sociologist's view, liquidity is the overarching category in the assessment of reality and is transferred to different levels and spheres of human life. It is expressed in the fact that every area of human existence becomes blurred, fragmentary, impermanent, and in the reception of an individual, means instability and causes uncertainty. Therefore, it should be assumed that the life of modern humans is based on impermanent existential foundations. As Bauman writes: “The most acute and stubborn worries that haunt such a life are the fears

⁹ For more on this subject, see U. Beck, *Risk Society: Towards a New Modernity*, SAGE Publications Ltd., London 1992.

¹⁰ For more, see A. Giddens, *The Consequences of Modernity*, Polity Press, Cambridge 1990.

¹¹ The generalisations of Z. Bauman's concepts concerning the postmodern world contained in the article were formulated on the basis of the following books by this author:

Liquid Modernity, Polity Press, Cambridge 2000.

Postmodern Ethics, Wiley-Blackwell, Oxford 1993.

Liquid Life, Polity, Cambridge, 2005.

of being caught napping, or failing to catch up with fast-moving events, or being left behind [...] of missing the moment that calls for a change of tack before crossing the point of no return."¹²

Taking into account the factor of social change and the indicated symptoms accompanying the present, it can be concluded that liquid modernity requires a specific attitude on the part of the individual, which should be characterised by readiness to accept changes and the ability to cope with them.

Referring to the problem of changes, it can be noted that their scope and pace have a direct impact on human functioning, both in the psychological and functional areas. At the same time, it should be stressed that not all people react equally to a given situation and the same is true for personal references in relation to the dynamics changing in different areas of reality. There are people who are open-minded and willing to accept new experiences, but there are also those who have difficulty in doing so. It is also possible to speak of differences between people in this respect, taking into account the age factor. In the case of older people, unlike young people, the specificity is the predominance of adaptation processes over assimilation processes, which means that the modification of behaviour is not characteristic for this age group and adaptation to changes does not occur naturally and presents itself in them in a specific way.

When considering modernity and the effects of the changes that have taken place in reality, reference should be made to the phenomenon of globalisation, which is an essential feature of modernity in a broad way, leading to the disappearance of borders and the encroachment of what is in the world. The transformation of the political system has made this process possible and has inscribed itself in its character, which means not only transformations in the economic space, but also penetration through various areas of human existence, causing transformations in many aspects of social and personal life.

¹² Z. Bauman, *Liquid Life*, Polity, Cambridge 2005, p. 2.

The current of globalisation changes has a significant impact on the sphere of living nature of contemporary man. At present, he can no longer count on state support, because his structures are helpless in the face of a number of phenomena caused by globalisation and its impact on the life of an individual. This means that state organisations no longer provide sufficient support in many matters relating to human existence: social, caring, professional, health or personal life. This situation causes the person to remain completely alone in the face of various life situations. Zygmunt Bauman wrote about it as follows: "One of the most important aspects of post-modern transformations is the loss of the state's ability, need and will to lead spiritually (including morally)."¹³

If we consider the needs of older people, it should be noted that the above circumstances put them in a very difficult situation, because there are many people in this age group who need different types of guidance or support. In addition, it is difficult for older people to find a fit in the new rules of functioning of state structures. It must also be assumed that many of them are not familiar with the responsibilities of public bodies and are unable to obtain information in this area, and thus demand organised care or other assistance. In addition, it must be acknowledged that there is not yet a sufficiently developed network of facilities for the elderly.

A characteristic attribute of the present era is a permanent search for one's own identity. Variable living conditions and the uncertainty they create have led to the emergence of the concept of identity in a new sense. According to Z. Bauman, the earlier philosophical stance, which assumed that identity is discovered, has changed. Identity is now a goal and a constant aspiration, which over time undergoes modifications due to the ubiquitous changeability (including the changeability of plans).¹⁴

Searching for and constructing identity is not an easy task in the world set by liquidity and consumption. Bauman clearly noticed

¹³ Z. Bauman, *Postmodern Ethics*, op. cit., p. 151 ff.

¹⁴ For more, see Z. Bauman, *Dwa szkice o moralności ponowoczesnej*, Instytut Kultury, Warsaw 1994.

and pointed out that modern society is mainly a society of consumers, not producers. Consumption permeates various areas of life and becomes the driving force behind the aspirations and actions of the human race. He wrote about the rank and influence of this phenomenon: “[The market] relentlessly hammers home the message that everything is or could be a commodity, or if it is still short of becoming a commodity, that it should be handled *like* a commodity; it implies that things had *better be* ‘like commodities’ and ought to be viewed with suspicion, and better still rejected or avoided in the first place, if they refuse to fall in with the consumer-object pattern”.¹⁵ Consumption takes on very significant proportions in the life of society, so it grows to the rank of what the author calls consumerism. The sociologist clearly emphasises the character of this phenomenon of human existence and calls it the consumer syndrome. It is understood as “a batch of variegated yet closely interconnected attitudes and strategies [...] assumptions of the ways of the world and the ways of treading them [...]”.¹⁶

Consumerism has become a guiding idea for modern societies that ignores any previously adopted rules of conduct. The extent of the phenomenon and its dominant significance may be evidenced by the commodification of all areas of life. Marek Krajewski writes about this, stating that the object of sale can be anything that „is able to attract the customer’s attention, can become a commodity – pathologies, human misfortunes and tragedies, but also spiritual values, tradition, so-called personalities and individuals or family life and privacy.”¹⁷

It is not difficult to agree with the authors’ observations concerning consumerism, because each of us experiences its effects and influence on the perception of reality. Contemporary humans have to fit into the above conditions in order to make various life decisions. However, it should be noted that life „marked” by consumer-

¹⁵ Z. Bauman, *Liquid Life*, Polity, Cambridge 2005, p. 88.

¹⁶ Z. Bauman, *Liquid Life*, Polity, Cambridge 2005, p. 83.

¹⁷ M. Krajewski, *Konsumpcja i współczesność. O pewnej perspektywie rozumienia świata współczesnego*, Kultura i Społeczeństwo, 1997, no. 3.

ism promotes material values, which are often alien to the elderly. On the other hand, spiritual values, which are of great importance to them, are omitted. The current slogan of „everything for sale” is contrary to the ethics in the spirit of which today’s seniors grew up. It can therefore be presumed that they do not accept the current system of values based on consumerism as natural and close to them. The danger that consumerism poses is not only to accept this phenomenon as a value and to be uncritically influenced by it, but also to be exposed to all kinds of fraud. It has to be admitted that older people are quite credulous and give in to various forms of swindling: they can be persuaded to buy goods, even though they do not need them, they pay a much higher price than they should.

Consumption, which is recognised as a key social value, is certainly not the right direction for people’s aspirations. However, in addition to its many negative effects, there are some positive developments in the opportunities offered by the current market. People can purchase products or use various types of services depending on their needs. Within this wide range of services, many elderly people can also find something for themselves. It can be assumed that beauty or health-supporting products and the medical and tourist services sector play a very important role for this generation of people.

From the point of view of consumerism, it is also worth paying attention to the issue of the collection of financial benefits by the elderly, which encounters negative opinions in the context of the distribution of social goods. A lack of social understanding of the entitlements of older people and their needs is certainly very difficult for seniors to accept.

It should also be noted that there is a significant group of seniors who cannot find their place in the offer of the consumer market. It turns out that it has such a strong influence that such an individual may even feel excluded from social life. Z. Bauman writes about this issue: “In a society of consumers, it is above all the inadequacy of the person as a consumer that leads to social degradation and ‘internal exile’. It is this inadequacy, this inability to acquit oneself of the consumer’s duties, that turns into bitterness at being left being,

disinherited or degraded, shut off or excluded from the social feast to which others gained entry.”¹⁸

Identity is subject to change regardless of the individual's age. It is characteristic that at earlier stages of life, it is formed as a natural process within the framework of personality formation. On the other hand, in the period of old age, the main driver of its acquisition, reconstruction or modification are the changing circumstances of life, especially critical events or transformations in the cultural and social space, which require a response. There are many new issues with which humans are confronted in the present reality, but as an example one can cite in vitro fertilisation, euthanasia, homosexual relations, cloning. It is more difficult for an elderly person to adopt even a socially accepted stance or to remain neutral or indifferent to social issues. It must be acknowledged that they face many different issues that are incompatible with their system of values, which are dilemmas to be resolved. Critical events are also quite common motivators to shaping identity in this period of life. This is not a simple task, but one that also gives rise to many fears and frustrations.

Globalisation also involves the homogenisation of culture, and therefore the aspect of values that have been shifted beyond national borders. Changes in the axiological layer can cause a number of dilemmas, as they break with the traditional framing. The scale of the phenomenon is so large that it is possible to speak of a new adopted catalogue of norms, which concerns various areas of human life: family, life aspirations, social relations, etc. It is difficult for the elderly, brought up in traditional values and other conditions, to understand certain determinants of contemporary culture. This does not make everyday life easier for them because as we all know, culture has a great impact on people. It not only determines the space of their life, but it is also an adaptation mechanism and a system of values. It is therefore important that its aspects do not appear alien to older people.

¹⁸ Z. Bauman, *Work, Consumerism and the New Poor*, Open University Press, Maidenhead, Berkshire 2004, p. 38.

The consequences of globalisation for the cultural area include many elements, among which language deserves attention. It is worth stressing this aspect of reality, because there have been fundamental changes in this area, and this is a very important part of everyone's social life.

As Antonina Grybosiowa¹⁹ notes, there are currently two language subcodes. One of them is the Polish colloquial language, which is characterised by an abundance of vulgarisms, epithets and folk metaphors. The second is the official Polish language, which consists of many Latinisms, Anglicisms, technical and economic terminology.

Some positive aspects can also be seen in these language changes, but the fact that the language has been depreciated in many areas is particularly noteworthy. Not only is perfection in the use of one's mother tongue overlooked, but the use of concepts that violate moral norms and sacrum is also universally accepted. In interpersonal communication, the traditional catalogue of norms referring to the etiquette of conversing with women or the elderly, etc., is vanishing.

Both the language codes are foreign to elderly people who, through upbringing and education, have been prepared to value literary language and to respect language criteria. It is certainly difficult for them to come to terms with the relaxed rules of linguistic correctness and the adoption of a new language code. In addition, learning new terms, which are essential in everyday life, may not be an easy task for them.

The value highly appreciated in the life of every person is the family. If we take into account the modern family, we should first of all notice the disappearance of multi-generational families and the effects of this state of affairs on the quality of intergenerational rela-

¹⁹ A. Grybosiowa, *Dynamika zmian językowych o podłożu kulturowym u progu XXI wieku (na materiale polskim)*, [in:] <http://docplayer.pl/24358064-Dynamika-zmian-jezykowych-o-podlozu-kulturowym-u-progu-xxi-wieku-na-materiale-polskim-zmiany-w-swiadomosci-mowiacych.html> [access: 1.07.2018].

tions. Living in a multi-generational family was connected with living together, which, in turn, helped to build bonds between its individual members. In such a family, there were mutual obligations. Older people could count on the help of younger family members, and for their part, they offered care for grandchildren. In this way, the intergenerational integration was tightened. The fact that families give too little attention and time to the elderly is a common situation nowadays. They focus mainly on their own families and professional life, which consume their time and despite good intentions, it is difficult for them to find opportunities for more frequent contacts with their parents. This situation causes many elderly people to experience a sensation of misunderstanding and loneliness.

Contemporary conditions are complex. On the one hand, we can talk about the progress of civilisation and its benefits in the form of technological or scientific progress, and on the other hand, about the social risks that have arisen as a result of it. The current reality is so difficult and diverse that in the circumstances of promoted individualism or consumerism it is quite difficult to find a friendly and familiar living space for the elderly. The only people who can fit into the indicated circumstances are those find their place in the social hierarchy, and the factors conducive to this are wealth, education, physical and mental fitness despite their age, as well as educational activity. It is thanks to education that it will be possible to adapt to various conditions of the present day and to make conscious use of its many benefits.

Conclusions

It is just as important for older people to take up education as it is for the younger generations. This type of activity cannot be abandoned due to advanced age. It should be noted, however, that measurable results of education may vary slightly, due to different needs of people in different age groups. In addition to other results,

working people will also expect results that are related to their work. Older people who have retired will be guided mainly by cognitive interests, as well as issues related to everyday life or existential issues.

It should be made clear that educational activity can accompany people to a greater or lesser extent, as life is also the content of learning. Learning emphasises human dignity and is a tool for understanding the world and one's own person, as well as for improving oneself at all ages.

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Seniors in the media world

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These days, the media education process starts at a very early stage of life and lasts throughout it. Older people are still in a worse position in this respect. In order to find their place in the information society, they have to master the IT and media skills and competences that enable them not only to use new forms of education (such as e-learning, distance learning, blended learning), but also to an ever-greater extent to handle everyday affairs. (such as making payments, booking tickets, taking care of official matters without having to wait in long lines), or even communicate with other people. Education – computer and Internet training – and non-institutional support play a key role in this respect. Among the most frequently cited reasons for not using technology, researchers list the lack of motivation, access to media and the Internet, as well as lack of competencies and awareness of how ICT (information and communication technology) can be used. The main barriers to the dissemination of new technologies in society are not hard – such as the lack of infrastructure or financial constraints, but soft barriers related to the lack of knowledge, awareness of needs or skills.

KEY WORDS: media, new technologies, ICT, skills, competencies, old people, senior citizens

Introduction

These days, the media education process starts at a very early stage of life and lasts throughout it. Older people are still in a worse position in this respect. In order to find their place in the infor-

mation society, they have to master the IT and media skills and competences that enable them not only to use new forms of education (such as e-learning, distance learning, blended learning), but also to an ever-greater extent to handle everyday affairs. (such as making payments, booking tickets, taking care of official matters without having to wait in long lines), or even communicate with other people. It should be stressed that "the lack of competencies in use negatively correlates with the willingness of potential new users to take an interest in technologies."¹ Education – computer and Internet training – and non-institutional support play a key role in this respect. Among the most frequently cited reasons for not using technology, researchers list the lack of motivation, access to media and the Internet, as well as lack of competencies and awareness of how ICT (*information and communication technology*) can be used. The main barriers to the dissemination of new technologies in society are not hard – such as the lack of infrastructure or financial constraints, but soft barriers related to the lack of knowledge, awareness of needs or skills.² "New technologies became a fundamental link in the development of the young generation ..."³, but we should ask ourselves the question how does an elderly person find themselves in this new social reality? What are the problems and opportunities for seniors in connection with the use of new technologies? What educational activities in the field of ICT tools are undertaken for the benefit of the elderly? To what extent are new technologies adapted

¹ K. Stachura, *Wymiary cyfrowych nierówności. Uwagi o problemie technologicznej nieobecności*, [in:] *Nieobecność społeczna. W poszukiwaniu sensów i znaczeń*, Z. Galor, B. Goryńska-Bittner (eds.), Wydawnictwo Wyższej Szkoły Nauk Humanistycznych i Dziennikarstwa w Poznaniu, Poznań 2012, p. 264.

² D. Batorski, *Technologie i media w domach i w życiu*, [in:] *Diagnoza społeczna 2015. Warunki i jakość życia Polaków*, J. Czapiński, T. Panek (eds.), Rada Monitoringu Społecznego, Warsaw 2015, pp. 373–395, http://www.diagnoza.com/pliki/raporty/Diagnoza_raport_2015.pdf [access: 13.06.2018].

³ K. Wasilewska, *Zaangażowanie seniorów w zakresie technologii informacyjno-komunikacyjnych na tle umiejętności młodszego pokolenia*, *Zeszyty Naukowe Wydziału Elektroniki i Informatyki Politechniki Koszalińskiej*, 2015, no. 7, p. 101.

to the needs of senior citizens? In order to look for answers to these questions, we will analyse the available literature and research results related to the use of ICT tools by the elderly.

Changes occurring in societies

Scientists and scholars do their utmost to describe the technological changes and shifts taking place within societies with such notions as network society;⁴ information society;⁵ knowledge society;⁶ post-industrial society;⁷ post-modernity;⁸ late modernity;⁹ second modernity, risk society;¹⁰ third wave.¹¹ Another very important aspect of transformations are demographic changes and the shift occurring in the population age structure, which determine many changes taking place in societies and actions taken. The generation born in 1961–1984 is called Generation X, functioning in the world of media, which McLuhan referred to as hot media – press, radio, television. The generation born in 1977–1997 is referred to as Gener-

⁴ M. Castells, *The Rise of the Network Society*, 1996, Polish edition: *Spółeczeństwo sieci*, Wydawnictwo Naukowe PWN, Warsaw 2008.

⁵ T. Goban-Klas, P. Sienkiewicz, *Spółeczeństwo informacyjne: szanse, zagrożenia, wyzwania*, Wydawnictwo Postępu Telekomunikacji, Krakow 1999, <http://informacja.cyfrowa.wsb.edu.pl/pdfs/SpoleczenstwoInformacyjne.pdf> [access: 3.07.2015]; S. Juszczak, *Człowiek w świecie elektronicznych mediów – szanse i zagrożenia*, Wydawnictwo Uniwersytetu Śląskiego, Katowice 2000.

⁶ P.F. Drucker, *Mysli przewodnie Druckera*, Wydawnictwo MT Biznes, Warsaw 2002.

⁷ A. Touraine, *The Post-Industrial Society. Tomorrow's Social History: Classes, Conflicts and Culture in the Programmed Society*, Random House, New York 1971; D. Bell, *The Coming of Post-Industrial Society*, Basic Books, New York 1973.

⁸ Z. Bauman, *Liquid Modernity*, Polity Press, Cambridge 2000; Polish edition: *Płynna nowoczesność*, Wydawnictwo Literackie, Krakow 2006.

⁹ A. Giddens, *Nowoczesność i tożsamość. „Ja” i społeczeństwo w epoce późnej nowoczesności*, Wydawnictwo Naukowe PWN, Warsaw 2001.

¹⁰ U. Beck, E. Grande, *Europa Kosmopolityczna. Społeczeństwo i polityka w drugiej nowoczesności*, Wydawnictwo Naukowe Scholar, Warsaw 2009.

¹¹ A. Toffler, *The third wave*, Bantam Books, New York 1980.

ation Y – the representatives of this generation function mainly in the world of computers, Web 1.0 Internet – characterised by low use of tools enabling creating and generating own content on the Internet (for example reading and commenting on blogs, discussions on forums, participation in discussion groups, promoting one's own activity on the Internet). Generation Z is a generation of people born in 1995–2010. Their world is dominated by social networking sites, mobile phones, web games and Web 2.0 Internet. People born after 2010 are referred to as the Alpha Generation, believed to function in the world of electronic gadgets and smartphones.¹² “It is one of the first generations to experience a new, technology-led system of upbringing, education, play and entertainment.”¹³ The world of new technologies has been present in their lives since birth and it is as natural for them as paper editions of books, newspapers, or writing traditional letters is for seniors.

With every year, the group of seniors constitutes a larger sub-population. According to the Central Statistical Office (GUS), between 2000 and 2017 in Poland their numbers increased by over 2.3 million.¹⁴ “The fact that we live longer and in better health is a great success for modern society”¹⁵ and at the same time it poses a major challenge, not only for social policy, but also for medicine, pharmacology and education. Changes in lifestyles, behavioral pat-

¹² M. Gruchola, *Nowe formy zachowań społecznych wobec i pod wpływem mediów oraz nowych technologii. Analizy porównawcze*, Państwo i Społeczeństwo, 2017, vol. XVII, no 3, pp. 123–133.

¹³ M. Gruchola, *Nowe formy zachowań społecznych wobec i pod wpływem mediów oraz nowych technologii. Analizy porównawcze*, Państwo i Społeczeństwo, 2017, vol. XVII, no 3, pp. 132.

¹⁴ *Ludność. Stan i struktura oraz ruch naturalny w przekroju terytorialnym w 2017 r. Stan w dniu 31 XII*, Główny Urząd Statystyczny, Warsaw 2018, <https://stat.gov.pl/obszary-tematyczne/ludnosc/ludnosc/ludnosc-stand-i-struktura-oraz-ruch-naturalny-w-przekroju-terytorialnym-w-2017-r-stand-w-dniu-31-xii,6,23.html> [access: 21.05.2018].

¹⁵ M. Ferry, R. Baker, *Strategie regionalne a starzenie się społeczeństwa*, Komitet Regionów-Age Concern England, Brussels 2006, p. 2, http://ec.europa.eu/regional_policy/archive/conferences/demographicchallenge_jan07/doc/presentations/ageproofing_toolkit_pl.pdf [access: 21.05.2018].

terns, relationships and communication of older people open up new opportunities for them, but also cause the need for continuous education, including in new technologies. An important aspect of the information society is “to educate the public towards further development so that everyone can take full advantage of the opportunities offered by the means of mass communication and information.”¹⁶

The generation of seniors is called the generation of Digital Immigrants – they are people who came into the digital age and the world of computers as adults. This has often been accompanied by great anxiety and uncertainty. Not because they do not need any facilities or that they do not need to use the latest technologies, but because they are a novelty for them, something that needs to be learned, which at the same time destroys the traditional way of functioning. Such a change requires time and the development of new working patterns.¹⁷ It is often difficult for them to find themselves in an ICT environment, in a society where the ability to access, collect and process information has become a paramount value.

Use of ICT tools by elderly citizens

The age of users continues to be one of the main indicators of access to technology. Research shows that the most excluded group are people over 55 years of age, in particular those over 65 years of age. In 2017, among the 55–64 age group, regular computer users accounted for 46.8% of the respondents, and among people aged

¹⁶ The definition comes from the website of the Office of the Committee for European Integration: <http://archiwum-ukie.polskawue.gov.pl/www/serce.nsf/0/6A1F328341480FEAC1256F6A0038762F?Open> and is used in the terms and conditions of competitions in defining the notion of information society in projects implemented by the Digital Poland Project Centre.

¹⁷ G. Small, G. Vorgan, *iMózg. Jak przetrwać technologiczną przemianę współczesnej umysłowości*, Vesper, Poznań 2011.

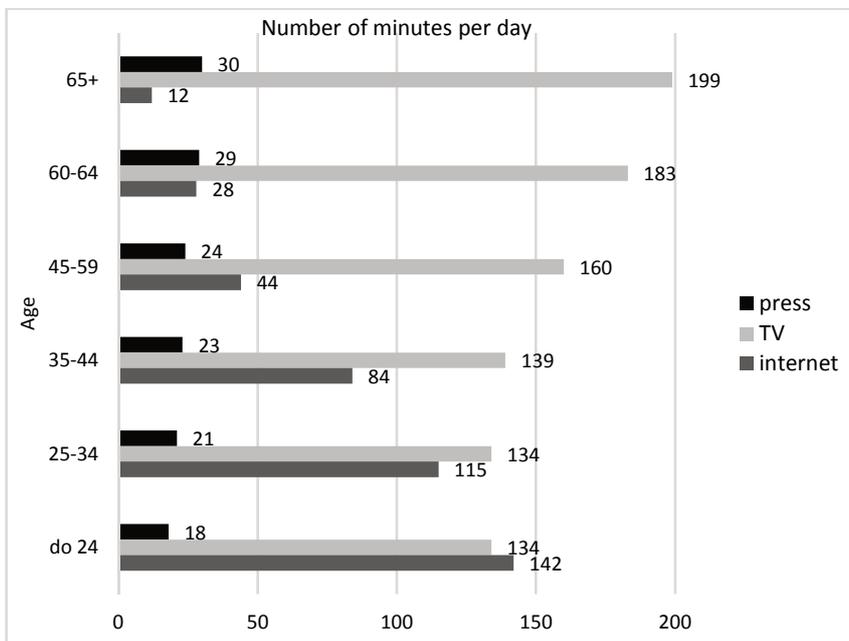


Fig. 1. Time spent during the day by respondents on reading press, watching the TV and using the Internet in 2015

Source: D. Batorski, „Technologie i media w domach i w życiu Polaków”, [in:] *Diagnoza społeczna 2015. Warunki i jakość życia Polaków*, J. Czapiński, T. Panek (eds.), Warsaw 2015, p. 390.

65-77 only 25.6% used computers on a regular basis. Only 19.6% of respondents in the 55-64 age group, and only 8.6% of respondents in the 65-74 age group used Internet for shopping. As far as digital literacy is concerned, only 20.2% of people aged 55-64 were able to transfer files between a computer and another device, with only 9.4% respondents between the ages of 65-74 being able to do so. Only 10.1% of respondents aged 55-64 and only 4.7% of respondents aged 65-74 were able to change the settings of the operating system or software ensuring the safety of their devices. An even smaller percentage of respondents in these groups was able to install software or applications on devices (9.6% - 55-64 years; 4.7% -

65–74 years).¹⁸ People living in Poland spend 4 hours a day on average perusing various media. This time is distributed among the various media – press, radio, television, the Internet – and is strongly linked to age. Older people still prefer to watch the TV (the older, the more time they spend in front of the TV during the day) while younger people prefer to use the Internet. People up to 24 years of age declared spending the most time using the Internet. As the Figure 1 shows, the readership of the press is not very diversified, seniors devote more time during the day to this activity.¹⁹

The number of Internet users is systematically growing year by year in every age group. In 2015, every fourth retiree and about every third pensioner used the Internet. It is worth noting that over the period of two years (2013–2015) a 5.3% increase in the age group 60–64 years was observed in the group of users, along with a 3.8% increase in the group of users over 65 years of age.²⁰ On the other hand, NBP research shows that less than 3% of seniors declare using mobile banking. PKO BP reports that mobile banking is used by 2% of people aged 65+ and 5% of people aged 55–64.²¹

A survey conducted by the European Commission – the Digital Economy and Society Index (DESI) – shows that only 44% of Poles

¹⁸ *Spółeczeństwo informacyjne w Polsce. Wyniki badań statystycznych z lat 2013–2017*, Central Statistical Office, Warsaw-Szczecin 2017, <http://stat.gov.pl/obszary-tematyczne/nauka-i-technika-spoleczenstwo-informacyjne/spoleczenstwo-informacyjne/spoleczenstwo-informacyjne-w-polsce-wyniki-badan-statystycznych-z-lat-2013-2017,1,11.html> [access: 13.06.2018].

¹⁹ D. Batorski, *Technologie i media w domach i w życiu Polaków*, [in:] *Diagnoza społeczna 2015. Warunki i jakość życia Polaków*, J. Czapiński, T. Panek (eds.), Warsaw 2015, p. 390

²⁰ D. Batorski, *Technologie i media w domach i w życiu*, [in:] *Diagnoza społeczna 2015. Warunki i jakość życia Polaków*, J. Czapiński, T. Panek (eds.), Rada Monitoringu Społecznego, Warsaw 2015, pp. 373–395, http://www.diagnoza.com/pliki/raporty/Diagnoza_raport_2015.pdf [access: 13.06.2018].

²¹ M. Bednarek, *Zagubiony senior w bankowości mobilnej. Specjalne infolinie w Orange i doradcy w PKO*, Wyborcza, 2017, 23rd of June, <http://wyborcza.biz/biznes/7,158582,21998635,zagubiony-senior-w-swiecie-bankowosci-mobilnej-specjalne-infolinie.html> [access: 18.06.2018].

have basic digital competences, which include the ability to use office software, e-mail and instant messaging software. It also draws attention to the fact that people with low education or income levels as well as the elderly, retired and unemployed, are less active users of the Internet. Although usage rates among these groups are growing, in each of them about 4 out of 10 people do not use the Internet on a regular basis. This means that the risk of digital exclusion in this group is particularly high.²²

Table 1. Computer use - PIAAC survey

Age	Lack of experience in computer use (as declared by respondents)	Lack of basic computer skills despite the declaration of computer use (failed computer use test)	Lack of information about the level of digital literacy (refusal to solve tasks using a computer)	Sufficient computer use skills (enabling the respondents to solve tasks using a computer)
16-24	1%	19%	9%	28%
25-34	4%	22%	19%	33%
35-44	13%	21%	22%	19%
45-54	32%	19%	25%	12%
55-65	50%	20%	25%	7%

Source: M. Palczyńska, "Wykorzystanie technologii informacyjno-komunikacyjnych" [in:] *Umiejętności Polaków - wyniki Międzynarodowego Badania Kompetencji Osób Dorosłych (PIAAC)*, Warsaw 2013, p. 118.

In almost every aspect of digital literacy, 17-24 year olds are the best performers in the surveys conducted.²³ PIAAC survey shows

²² *Human Capital - Digital Inclusion and Skills*, Digital Economy and Society Index Report 2018, Human Capital, http://ec.europa.eu/newsroom/dae/document.cfm?doc_id=52247 [access: 12.10.2018].

²³ *Spółczesność informacyjna w Polsce. Wyniki badań statystycznych z lat 2013-2017*, Central Statistical Office, Warsaw-Szczecin 2017, <http://stat.gov.pl/obszary-tematyczne/nauka-i-technika-spolczesnost-informacyjna/spolczesnost-informacyjna/spolczesnost-informacyjna-w-polsce-wyniki-badan-statystycznych-z-lat-2013-2017,1,11.html> [access: 13.06.2018].

that 82% of respondents declared lack of experience in computer use, and the majority of them comprised people aged 45–65, while only 1% of respondents aged under 24 declared the same. Less than 7% of respondents aged 55–65 demonstrated computer skills sufficient to solve tasks using a computer. The best performers in this category were people aged 25–34 (Table 1). Thus, the age of the users still remains the main indicator of not only access to technology, but also of experience in its use.

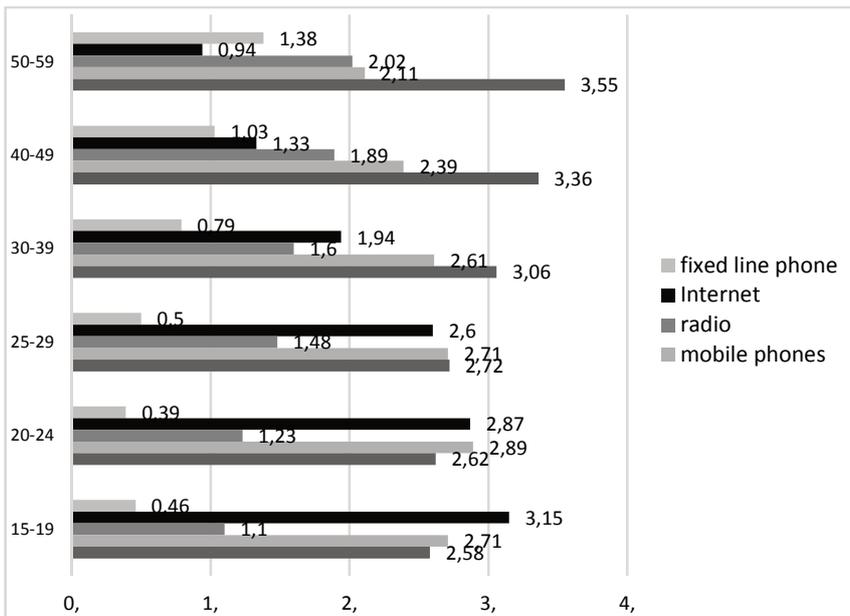


Fig. 2. The importance of media in different age groups

Source: own study based on *World Internet Project Poland 2012*.

Preferences for the selection of traditional sources of information, such as books, papers, radio and television among the elderly are confirmed not only by the World Internet Project survey

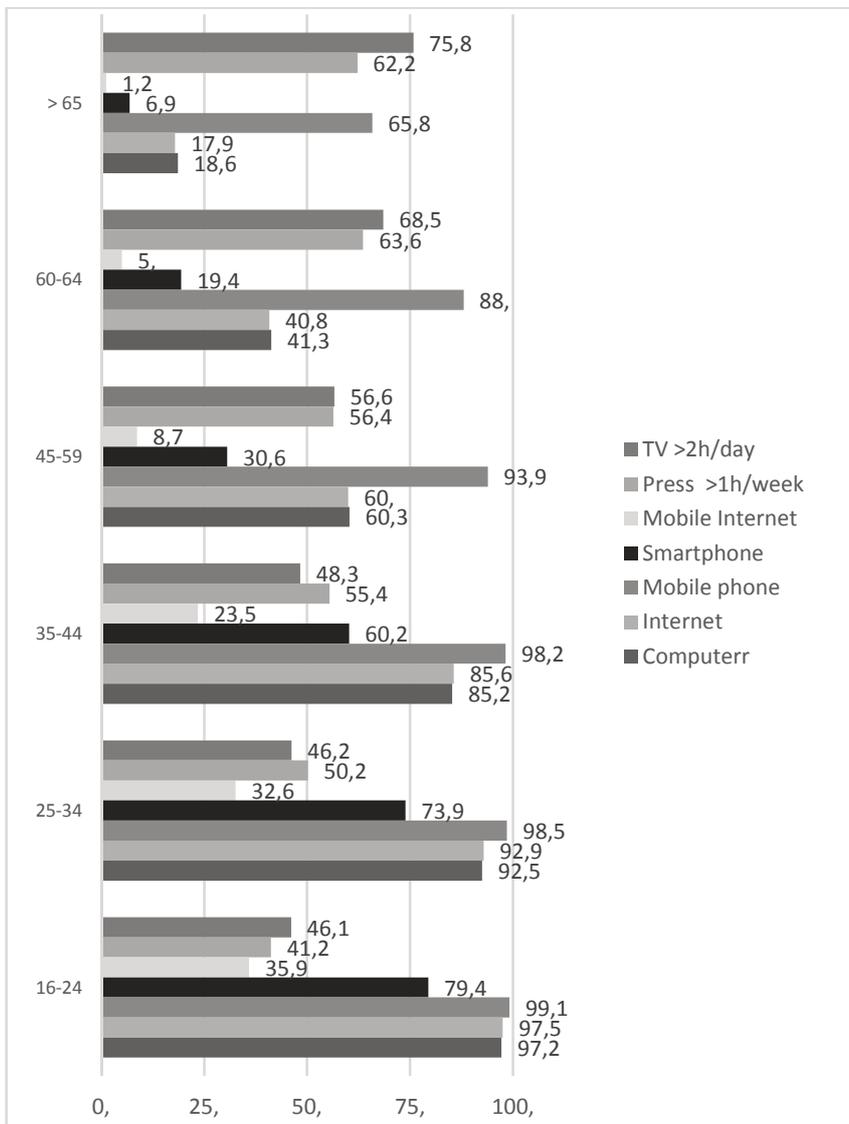


Fig. 3. Use of technology and media in different age groups

Source: D. Batorski, "Technologie i media w domach i w życiu Polaków" [in:] *Diagnoza społeczna 2015. Warunki i jakość życia Polaków*, J. Czapiński, T. Panek (eds.), Warsaw, 2015, p. 383.

(Figure 2), but also by the social diagnosis study carried out 3 years later (Figure 3). For the elderly, television broadcasting is by far the most important, while the younger the person, the more emphasis they put on the use of the Internet.

The social diagnosis study additionally distinguished the use of computers and smartphones. However, in this case too, there is a strong tendency for younger people to use new technologies. The elderly tend to use the press and television, although there is also a strong tendency to use cell phones.

Despite the ever-increasing number of senior citizens using the Internet and new technologies, they are still the group endangered the most with digital exclusion. It should also be noted that older people using ICT tools treat them as tools to facilitate work and life, and not, as in the case of young people, as an equal reality.²⁴

Soft barriers to the use of ICT tools by seniors

Jan van Dijk distinguished a number of types of access to new technologies: motivational, functional, competence, material and physical.²⁵ Research among elderly people shows that problems with the use of new technologies are related to the motivational and competence aspects.²⁶ Elderly people are distrustful of new technol-

²⁴ K. Barani, M. Hołda, *Osobowość i jakość życia, a korzystanie z Internetu przez seniorów*, [in:] *Senior zalogowany*, ed. B. Szmgiełska, Wydawnictwo Uniwersytetu Jagiellońskiego, Kraków 2014, after: J. Gacka, *Polscy seniorzy w sieci: wirtualna złota jesień? Korzystanie przez osoby dojrzałe z internetu i nowych technologii*, *Konteksty Społeczne*, 1 (9)/2017, p. 87.

²⁵ J. Dijk, *Społeczne aspekty nowych mediów*, Wydawnictwo Naukowe PWN, Warsaw 2010, after: A. Niemczyk, *Seniorzy wobec nowych technologii*, *Studia Ekonomiczne. Zeszyty Naukowe Uniwersytetu Ekonomicznego w Katowicach*, 2016, no. 303, pp. 102-113.

²⁶ Cf. e.g. D. Batorski, *Technologie i media w domach i w życiu*, [in:] *Diagnoza społeczna 2015. Warunki i jakość życia Polaków*, J. Czapiński, T. Panek (eds.), Rada Monitoringu Społecznego, Warsaw 2015, pp. 373-395, http://www.diagnoza.com/pliki/raporty/Diagnoza_raport_2015.pdf [access: 13.06.2018]; M. Mucha, *Demogra-*

ogies “using them in a way analogous to the previous use of previously owned devices (for example telephone), they are less mobile in the virtual world, they prefer text content over multimedia, they prefer linear and serial thinking and information processing, and they better understand longer content.”²⁷

Seniors are not able to achieve the same level of media literacy as young people. Many options and ICT applications are not adapted to their needs and capabilities. They also often feel anxiety, discomfort and fear of using them. *Can they do it? Won't they break anything?* Very often, even the operation of a mobile phone surpasses their capabilities and thus they require help of third parties. According to Natalia Bojarska and Monika Dawidowska, this fear of using new technologies may result from the fact that seniors “are not able to remember the information necessary to live in an alternative reality. One can get the impression that they give room to shine to younger generations, because it is the generation of their children and grandchildren whom they consider to be the proper users of the new technologies. They are inclined to think that they can live without the Internet, because they lose more than they gain from learning it to the extent that would enable further, satisfactory use.”²⁸ Digital competences give great opportunities to manage

ficzne uwarunkowania konsumpcji – seniorzy na rynku dóbr i usług w Polsce, Prace Naukowe Uniwersytetu Ekonomicznego we Wrocławiu, 2017, no. 501, pp. 87–95; T. Zalega, *Konsumpcja osób starszych w Polsce*, *Nierówności Społeczne a Wzrost Gospodarczy*, 2015, no. 42 (2/2015), pp. 152–173; *Społeczeństwo informacyjne w Polsce. Wyniki badań statystycznych z lat 2013–2017*, Central Statistical Office, Warsaw–Szczecin 2017, <http://stat.gov.pl/obszary-tematyczne/nauka-i-technika-spoleszenstwo-informacyjne/spoleczenstwo-informacyjne/spoleczenstwo-informacyjne-w-polsce-wyniki-badan-statystycznych-z-lat-2013-2017,1,11.html> [access: 13.06.2018].

²⁷ J. Gacka, *Polscy seniorzy w sieci: wirtualna złota jesień? Korzystanie przez osoby dojrzałe z internetu i nowych technologii*, *Konteksty Społeczne*, 1(9), p. 86.

²⁸ N. Bojarska, M. Dawidowska, *Zamiast zakończenia. O zróżnicowaniu internetowego krajobrazu*, [in:] *W sieci i poza siecią. Typologia relacji i strategie przystosowawcze wokół cyberprzestrzeni*, ed. K. Stachura, Wydawnictwo Uniwersytetu Gdańskiego, Gdańsk 2010, after: M. Szpunar, *Senior w środowisku nowych mediów*, [in:] *Seniorzy w świecie nowych technologii. Implikacje dla praktyki edukacyjnej oraz rozwoju społec-*

one's own development, give an opportunity for access to information, knowledge and self-development. However, seniors often exclude themselves from the group of people using new technologies by giving them up, believing that they lack the right skills and qualifications. Lack of interest, fear and anxiety associated with situations requiring new knowledge and skills, as well as the lack of confidence in one's own abilities determine the sense of inadequacy to live in a world dominated by information and communication technologies. Taking up learning to use these tools late in life is also associated with low self-esteem and the fact that their family often does a lot of work for them, which results in a lack of confidence in their own skills and development opportunities.²⁹ People without access to ICT face social isolation and increased distance from the rest of society. Seniors' fear of new technologies and changes is described by many researchers. Elderly people say things such as "I am afraid of change. For a long time, I resisted all novelties, so I didn't spend time on the Internet. When I stumble upon anything new, I'm always afraid that I won't know something and that I'll have to learn something new." "Older people are more nervous, so they'll get upset before they type something", "These names, all these ways of looking for things, I'm absolutely not attracted to them. I don't want to learn it", "You know, Olbrychski doesn't even use the phone because he doesn't want to learn."³⁰ "The worst fears are the fear of something new and the fear of breaking the device."³¹

zeństwa informacyjnego, Ł. Tomczyk, A. Wąsiński (eds.), Biblioteka Gerontologii Społecznej, 2013, no. 1–2, p. 38.

²⁹ A. Bąk, A. Jaszczak, *Rzeczywiste kompetencje seniorów w zakresie korzystania z Internetu*, [in:] *Senior zalogowany*, ed. B. Szmigielska, Wydawnictwo Uniwersytetu Jagiellońskiego, Kraków 2014 after: J. Gacka, *Polscy seniorzy w sieci: wirtualna złota jesień? Korzystanie przez osoby dojrzałe z internetu i nowych technologii*, Konteksty Społeczne, 1(9)/2017, p. 87.

³⁰ J. Ambrosiewicz, I. Szyłke, *Społeczne, kulturowe i technologiczne uwarunkowania (nie)korzystania z Internetu*, [in:] *W sieci i poza siecią. Typologia relacji i strategie przystosowawcze wokół cyberprzestrzeni*, ed. K. Stachura, Wydawnictwo Uniwersytetu Gdańskiego, Gdańsk 2010, after: M. Szpunar, *Senior w środowisku nowych mediów*, [in:] *Seniorzy w świecie nowych technologii. Implikacje dla praktyki edukacyjnej oraz rozwoju*

Educational activities

Education plays a key role in e-inclusive activities and lifelong learning is taking on a new importance. Changes in the psychological and physical sphere of elderly citizens make it difficult to adapt to new technologies and learning. Reduction of brain mass, as well as degeneration of synaptic connections result in slower reaction times, longer learning time, as well as slower assimilation of new information. However, as Gary Small's study carried out using the so-called functional nuclear magnetic resonance pointed out,³² surfing the Internet and searching for information on the web creates new connections in the brains of people over 50 years of age, which proves that the human brain is capable of developing even in old age. American scientists recommend training the brain in order to prevent brain ageing process by surfing the web, since "browsing the Internet using search engines is a better way of exercising the brain for people over 50 than reading books, and the power of the web is comparable to solving jigsaw puzzles or crosswords. The reason for this is that the decision-making process when reading the book is reduced to a dilemma: close it or continue reading, while navigating on the Internet, the user constantly makes decisions about the information of interest to them."³³

społeczeństwa informacyjnego, Ł. Tomczyk, A. Wąsiński (eds.), Biblioteka Gerontologii Społecznej, 2013, no. 1-2, p. 44.

³¹ M. Sulik, *Jesień życia kobiety – aspekty edukacyjne*, [in:] *Edukacja wobec starości – tradycja i współczesność*, ed. A. Stopińska-Pająk, Uniwersytet Śląski, Katowice 2009, after: M. Szpunar, *Senior w środowisku nowych mediów*, [in:] *Seniorzy w świecie nowych technologii. Implikacje dla praktyki edukacyjnej oraz rozwoju społeczeństwa informacyjnego*, Ł. Tomczyk, A. Wąsiński (eds.) Biblioteka Gerontologii Społecznej, 2013, no. 1-2, p. 44.

³² G. Small, G. Vorgan, *iMózg. Jak przetrwać technologiczną przemianę współczesnej umysłowości*, Vesper, Poznań 2011.

³³ J. Morbitzer, *Seniorzy w społeczeństwie informacyjnym*, [in:] *Seniorzy w świecie nowych technologii. Implikacje dla praktyki edukacyjnej oraz rozwoju społeczeństwa informacyjnego*, Ł. Tomczyk, A. Wąsiński (eds.), Biblioteka Gerontologii Społecznej, 2013, no. 1-2, p. 26.

Over the years, seniors were discriminated against in access to computer and Internet education, and their knowledge has been based on information from younger family members. Recent years have brought many changes related to elderly people's education and lifelong learning. Nowadays, not only Universities of the Third Age, but also libraries, NGOs, associations and foundations offer the opportunities to learn about IT and media. A number of measures are being taken to educate older people. Government grants, as well as subsidies from local government, private or EU funds enable carrying out projects aimed at seniors.³⁴ Meetings with representatives of academia are held, during which seniors can listen to speeches on the information society, the purpose of using new technologies, as well as security in the cyberspace. Senior citizens are the addressees of many books and brochures devoted to the skills of using new technologies. Learning is encouraged by factors such as pressure, a strong need for information or contact, curiosity, as well as social support and awareness of the opportunities offered by new technologies.³⁵ The most important aspect of using ICT tools is mo-

³⁴ Among the activities aimed at information and media education of the elderly we may mention: "Digital Senior" carried out by the Kielce Chapter of the Polish Scouting Association, "Safe IT Academy - equal opportunities on the labour market", carried out by NASK academies together with the Warsaw School of Information Technology; "Pass it Forward - Senior for Culture" carried out in 2014 and 2015 by NASK; "Computer and Internet for Senior Citizens", a computer course organised by the High School Complex No. 2 in Siedlce; „@ctive 60+", carried out by the Zaczyn Foundation within the framework of digital education projects; "E-competencies without barriers", carried out by Warmińsko-Mazurski Zakład Doskonalenia Zawodowego in Olsztyn within the framework of the Digital Poland Operational Programme. "E-Senior Academy" initiated in 2006 by UPC Polska as part of the "In One Community" pro-social programme. These are just a few examples of actions aimed at raising digital competences of seniors and counteracting digital exclusion.

³⁵ K. Stachura, *Wymiary cyfrowych nierówności. Uwagi o problemie technologicznej nieobecności*, [in:] *Nieobecność społeczna. W poszukiwaniu sensów i znaczeń*, Z. Galor, B. Goryńska-Bittner (eds.), Wydawnictwo Wyższej Szkoły Nauk Humanistycznych i Dziennikarstwa w Poznaniu, Poznań 2012, pp. 262-277.

tivation,³⁶ which is accompanied by the willingness to purchase the appropriate devices. In many cases an effective form of learning how to use ICT tools is education, as well as support from the family, usually grandchildren. This is an excellent lesson both for seniors who learn how to use the tools, as well as for grandchildren who learn patience and humility. Most importantly, it is a way to establish closer intergenerational relationships, an opportunity for grandchildren to get to know the stories told by their grandparents. The use of ICT tools offers many benefits to every age group, and in the case of seniors, the Internet and mobile telephony enable communication with their loved ones. This is particularly important in the case of elderly with mobility impairments, illness or disability. Lower dynamics, fatigue, worsening motor skills, slowing down, as well as worsening agility and flexibility often cause older people to withdraw from active life. The Internet allows them to find information on health care, social assistance, leisure time management, finding additional work, dealing with official matters without having to leave home, shopping or even comparing prices. It gives them an opportunity to search for cultural offer, as well as look for information on topics of interest without having to leave home. It also makes it possible to reduce, for example, the cost of telephone calls by using instant messaging to communicate with loved ones, and to connect to several people at the same time and enrich it with the video of the caller. This is extremely important given the low incomes of retirees and financial difficulties.

³⁶ In the 1990s and at the beginning of the 21st century, the main focus of research on digital exclusion was access to infrastructure, the Internet, as well as financial hardships (the so-called hard barriers.) Currently, it is believed that the skills of using ICT tools, as well as the ability to benefit from their use by increasing the sense of independence is more important than simply access to infrastructure (cf. Stachura 2012; Batorski 2015; Polańska 2012).

Improper adaptation of ICT tools to the needs of the elderly

Seniors face many difficulties when dealing with new technologies. One of the main problems is the limitations associated with visual perception and shaking hands while using the keyboard or mouse. Programming TV channels is often an insurmountable barrier and requires support and help from third parties. Progressive miniaturisation – incorporating more and more possibilities in smaller devices – is a real challenge for seniors. Touchscreens or voice control of devices cause additional difficulties for the elderly.

The unsuitability of ICT tools for older people hinders their use. The new generation of media is too complicated for them to handle. Interfaces are often described by specialised vocabulary, often unknown to seniors. There is no room or possibility to adapt the software to their needs, for example by increasing the contrast, enlarging the font or adapting websites to text-to-speech software. Many people over the age of 60 have problems with impaired visual acuity, reduced vision in low light or reduced field of vision. Their visual, auditory, olfactory, tactile, kinesthetic analysers are weakened, while synaptic connections degenerate.³⁷ Device manufacturers are trying to meet the needs of older people and are increasingly offering phones with limited functionality, larger fonts on the display or large buttons. Special devices, applications or software dedicated to this age group also helps overcome the limitations resulting from sight impairments. The main recipients and users of new technologies are young people and manufacturers usually address their offer to them in the first place. However, there is a noticeable increase in campaigns targeting older people, who are treated as active and

³⁷ A. Kowalewska, *Wybrane układy i funkcje organizmu człowieka ważne dla procesów uczenia się*, [in:] *Biomedyczne podstawy kształcenia i wychowania*, Z. Izdebski, K. Komosińska, A. Kowalewska, B. Woynarowska, Wydawnictwo Naukowe PWN, Warsaw 2010, after: Ł. Tomczyk, *Edukacja osób starszych. Seniorzy w przestrzeni nowych mediów*, Difin, Warsaw 2015.

conscious users of information and communication technologies. The list of entities that aim their offers towards seniors include banks. Although they do not offer special mobile applications for the elderly, they try to adapt their offer to their needs, for example mBank has established a special group of agents whose task is explaining how the application and services work in simple terms; Orange has a special helpline for seniors; PKO BP has agents who inform and show customers how to use the iPKO website and the IKO mobile application at its branches.³⁸

Conclusions

In modern times, we as the people created a technical society, in which its everyday functioning and safety are increasingly determined by technology.³⁹ On the one hand, the development of technology, information and communication tools contributes to the improvement of the quality of life, facilitates everyday tasks, but on the other hand it leads to divisions, digital exclusion, marginalisation of people and even entire social groups. In the absence of adequate support, education and, above all, motivation, the digital divide will widen. Over time, people whose media competence is at a higher level will enter old age. However, the development of technology will be much faster than the replacement of generations. Accelerating progress in the field of technology, ICT makes more and more elderly people who use ICT tools do not keep up with their development. That is why education in this area is so important.

³⁸ M. Bednarek, *Zagubiony senior w bankowości mobilnej. Specjalne infolinie w Orange i doradcy w PKO*, Wyborcza, 2017, 23rd of June, <http://wyborcza.biz/biznes/7,158582,21998635,zagubiony-senior-w-swiecie-bankowosci-mobilnej-specjalne-infolinie.html> [retrieved: 18.06.2018].

³⁹ P. Sztompka, *Socjologia. Analiza społeczeństwa*, Wydawnictwo Znak, Krakow, 2002, after: Ł. Tomczyk, *Edukacja osób starszych. Seniorzy w przestrzeni nowych mediów*, Difin, Warsaw 2015.

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Early detection of autism spectrum disorders – risk symptoms, initial diagnosis, screening

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The diagnosis of autism within the first two years of a child's life is burdened by many difficulties. Even though many children belonging within autism spectrum disorders is characterised by similar traits typical for this disturbance, they are characterised by a high variability of the exhibited abilities and the dynamics of changes. Significant are also difficulties spanning specific symptoms that may in various children differ in intensity and level. The most significant symptoms for early recognition of ASD are deemed to be emotional and social deficits, disturbances in the development of speech and communication as well as atypical behaviour in the form of limited, repetitive behaviour patterns. In the first as well as the second year of life, the most commonly confirmed early signs of ADS refer to the lack of behaviour indicating the child's readiness to form social relations and to social communication, including in particular its reactions to its own name, limited eye contact, atypical facial expressions in social situations, the lack of emotional adaptation, limited interest in social impulses and poor vocalisation, as well as limited abilities to imitate, establish a common field of attention and the expression of attachment to the next of kin. In the second year of age, the atypical behaviour is manifested more clearly and may, although it must not necessarily, shine through in all areas typical for autism. The knowledge of these atypical behaviour patterns is used for the construction of screening tools. Early diagnosis is key for the efficient intervention, rehabilitation and therapy of a child.

KEY WORDS: autism spectrum disorders, autism risk symptoms, social communication and general communication disturbances, stereotypical, limited behaviour patterns, early detection of autism, initial diagnosis, screening tests

Introduction

Despite the fact that many children with Autism Spectrum Disorders (ASD) exhibit similar properties that are characteristic for this disorder, however, in the end they are characterised by a great variety of the exhibited abilities and by the dynamics of changes. Developmental changes influence the expression of symptoms¹. The nosological categorisation and diagnosis of a child as being autistic is quite complex, in particular due to the differences in terms of various specific symptoms, which in various children might differ by intensity and level². Both axial as well as secondary symptoms may express differently and emerge in various combinations³. A significant difficulty is found in the fact of uneven moment of emergence of the first symptoms (from birth until the 36th month), the number of these and their intensity over time, the circumstances, in which they emerge most frequently (including the influence of environmental factors), as well as the general psychological and physiological development of the child, frequently determined by co-existing disorders (comorbidity) and mental retardation⁴. According to the most recent data, 70% of persons with autism spectrum disorders may have one co-existing disturbance, and 40% of this population – two or more co-existing disturbances⁵. Despite the

¹E. Pisula, *Autyzm. Przyczyny, symptomy, terapia*, Published by Harmonia, Gdańsk 2010, p. 73.

²A.J. Cotugno, *Terapia grupowa dla dzieci z zaburzeniami ze spectrum autyzmu. Rozwijanie kompetencji i umiejętności społecznych*, Published by Fraszka Edukacyjna, Warszawa 2011, s. 13.

³M. Piszczek, *Kwestionariusz oceny kompetencji emocjonalno-społecznej (KOKE-S) wysoko funkcjonujących autystów i dzieci z zespołem Aspergera (część pierwsza), „Rewalidacja”*. Publication for teachers and therapists 2010, no. 1(27), s. 48.

⁴J. Bleszyński, *Autyzm a niepełnosprawność intelektualna i opóźnienie w rozwoju. Skala Oceny Zachowań Autystycznych*. Published by HARMONIA UNIWERSALIS, Gdańsk 2011, s. 57; B. Winczura, *Autyzm, autyzm atypowy a schizofrenia wczesnodziecięca*, [in:] B. Winczura (ed.) *Dzieci z zaburzeniami łączonymi. Trudne ścieżki rozwoju*, Published by Impuls, Kraków 2012, s. 86.

⁵*Diagnostic and statistical manual of mental disorders. Fifth edition, (DSM-5)*, American Psychiatric Association, APA, Washington DC 2013.

neurobiological background of autism spectrum disorders, no biological markers were determined until now that would permit their usage in daily clinical diagnosis. The diagnosis is made based on the clinical image characteristic for ASD, the structured interview, for the purpose of confirmation or exclusion of possible comorbidities, as well as additional biochemical, genetic and imaging analyses, despite the fact that none of these individually may determine the ultimate diagnosis of autism spectrum disorders⁶. Despite much research on the dynamics of development of autism spectrum disorders, we still have very limited knowledge on the development of children with ASD in the first few months of their lives. Early evaluation of disturbances in little children is usually introspective and is most frequently based on information acquired from parents/close caretakers of these children. Despite the fact that these opinions are usually apt, perhaps even precise, it is difficult to pin down whether they always reflect the objective state of affairs. Numerous studies are being undertaken to determine the criteria of the best possible recognition of autism spectrum disorders in children at an early stage of development. Irrespective of the fact that symptoms of ASD shine through in the first two years of a child's life, proof concerning the time of emergence of the initial symptoms and their character, their intensity, remains limited⁷.

Early symptoms of autism spectrum disorders

According to the DSM-5, the diagnosis of autism spectrum disorders requires the presence of clinical symptoms of ASD at an early stage in life, however, their lack at a later stage does not exclude

⁶ A. Rynkiewicz, M. Kulik, *Wystandardyzowane, interaktywne narzędzia do diagnozy zaburzeń ze spektrum autyzmu, a nowe kryteria diagnostyczne DSM-5*, „Psychiatria” 2013, 10, no. 2, s. 42.

⁷ M. Skórczyńska, *Wczesne diagnozowanie autyzmu – perspektywy i dylematy*, [in:] B. Winczura (ed.), *Autyzm Na granicy zrozumienia*. Published by Impuls, Kraków 2009, s. 56; E. Pisula, *Autyzm. Przyczyiny...*, op. cit., s. 81.

ASD diagnosis⁸. Studies show that the first signs of autism are noticeable between the sixth and 12th month of life. The most children to be diagnosed with autism in time is able to still make relatively correct eye contact and develop a social smile even in the sixth month of life, however, their frequency and quality change between the sixth and 12th month of life⁹. In this time, symptoms begin to appear such as: The lack of a proper reaction to their own name, no emotional interplay with other persons, the failure to show attachment, poor range of vocalisations, stereotypical behaviour patterns, atypical reactions to sensory stimuli, atypical exploration of objects. Development may also stop or recede¹⁰. The key areas for early diagnosis of ASD are deemed to be difficulties in social contacts and in communication, as well as specific, limited, repeating behaviour patterns, all of which remains in correlation with the diagnostic criteria of the DSM-5¹¹.

Difficulties in making social relations

The majority of observations show that the beginnings of emotional and social development in little children, in whom autism is suspected, may be disturbed, even though they also may be highly differentiated. In some of these, disturbances in the abilities of making emotional contact may be observed even before they conclude their sixth month of life. No exchange of content-adapted social actions and verbal messages or verbal and non-verbal messages occurs between the child and their next of kin¹². Particular disturb-

⁸L. Meng-Chuan, M.V. Lombard, B. Chakrabarti, S. Baron-Cohen, *Subgrouping the Autism "Spectrum"*: Reflections on DSM-5. PLOS Biology, 2013, 11(4), pp. 1-7.

⁹A. Steiner, T.R. Goldsmith, A.V. Snow, K. Chawarska, *Practitioner's Guide to Assessment of Autism Spectrum Disorders in Infants and Toddlers*, "Journal of Autism and Developmental Disorders" 2012, 42(6), s. 1184.

¹⁰A. Rynkiewicz, M. Kulik, *Wystandardyzowane, interaktywne...*, op. cit., s. 42.

¹¹*Diagnostic and statistical manual of mental disorders. Fifth edition*, (DSM-5), 2013

¹²E. Pisula, *Małe dziecko z autyzmem, diagnoza i terapia*, Published by Gdańskie Wydawnictwo Psychologiczne, Gdańsk 2005, s. 32.

ances are seen in the area of social communication, mostly its non-verbal aspects. The earliest symptoms (indications) of autism spectrum disorders are:

- limited eye contact (disturbance arises before the sixth month of life),
- lack of interest in people, ignoring them, short time of looking at people (disturbance emerges around the end of the first year of life),
- lack of ability to alternately participate in interactions and limited abilities to initiate and support interactions (disturbance arises before the sixth month of life),
- no reaction to parent messages directed at the child (disturbance arises before the sixth month of life),
- no smile reaction in social situations, no other forms of exhibition of joy (before the sixth month of life),
- no emotional adjustment, emotional synchrony, no adaptation of facial expressions to the situation (disturbance arises before the sixth month of life),
- no reaction to the own name (disturbance emerges between the 8th and 10th month of life),
- no pointing (disturbance emerges between the 8th and 12th month of life),
- no demands to be held and hugged (disturbance emerges after the sixth month of life),
- no following a person or object with the eyes (disturbance emerges at the break between the first and second years of life),
- no complex social behaviours that would fuse observation, facial expressions, tone of voice and gestures (disturbance emerges after the sixth month of life),
- no understanding of socially-valid gestures (e. g. “bye-bye”) (disturbance emerges at the break between the first and second years of life) (Baranek, Volkmar, Chawarska and Klin; Maestro, Muratori, Cesari, Pecini, Apicella, Stern)¹³.

¹³ E. Pisula, *Od badań mózgu do praktyki psychologicznej AUTYZM*, Wydawnictwo GWP, Sopot 2012.

J. Osterling and G. Dawson have in their observations discerned four characteristic modes of behaviour, within the scope of which over 90% of children with autism aged 12 months differed from 10-month-old babies developing normally and 12-month-old babies with developmental retardation. They included:

- no looking towards others,
- no reactions to the own name,
- no pointing, no showing or giving objects¹⁴.

Similar results were achieved in the research conducted by G.T. Baranek¹⁵. Among discrete symptoms of autism in babies aged nine to 12 months, included were:

- weak visual orientation (including non-social stimuli),
- delayed reaction to the own name,
- avoiding being touched by others.

Distressing behaviour patterns in children in the first year of life that may strongly correlate to a later diagnosis of autism include:

- limited social reactivity (e. g. reacting to the own name, looking at people, behaviour related to the creation of a common field of attention),
- atypical behaviour patterns related to sensory adjustment (e. g. frequent putting objects in the mouth, uncommon visual attention patterns, increased irritability)¹⁶.

The most significant diagnostic indicator seemed to be the failure to look at other people and no reactions of the child to the own name. This problem is also noticed by parents, as it contributes to difficulties in the social communication with the child. With respect to reactions to the name, it can be observed that it must be repeated

¹⁴J. Osterling, D. Dawson, *Early recognition of children with autism: A study of first birthday home videotapes*, "Journal of Autism and Developmental Disorders" 1994, 24, s. 250.

¹⁵G.T. Baranek, *Autism during infancy: a retrospective video analysis of sensory - motor and social behaviors at 9-12 months of age*, "Journal of Autism and Developmental Disorders" 1999, vol. 29, no. 3, s. 220.

¹⁶S. Goldstein, J.A. Naglieri, S. Ozonoff S. (ed.), *Diagnoza zaburzeń ze spektrum autyzmu*, Wydawnictwo Uniwersytetu Jagiellońskiego, Kraków 2017, s. 162.

many times, before the child turns their attention to the person pronouncing it. Such a delay, and at times even a lack of reaction, is considered to be one of the informative signals about a possible threat of autism already in babies aged eight-nine months. Significant is also the discovery that already in the 12th month of life, between autism-risk group children and children developing properly, differences are seen in the area of complex communication behaviour patterns – such as the fusion of cooing with pointing towards or expressing words and pointing¹⁷.

Around the end of the first year of life, noticeable is also the lack of play related to imitation (e. g. playing “peek-a-boo”, waving “bye-bye” when parting). This correlates closely with the inability to imitate gestures and disturbed development of social skills in the child¹⁸. It was noticed that these children seem uninterested or not aware of the interpersonal aspects of relations with others. Even if they can be engaged to participate in certain types of activities, they still take on a passive attitude within such participation¹⁹. They do not observe what others are doing. They are not interested in the activities that others perform. They do not imitate the behaviour of others because they are not aware of what is going on with others. They do not share their interests, desires, with others²⁰.

In the second half of the first year of life, the children from the autism spectrum risk group were also observed to have difficulty establishing a common field of attention. They are expressed in the

¹⁷E. Werner, G. Dawson, J. Munson, J. Osterling, *Variation in early developmental course in autism and its relations with behavioral outcome at 3–4 years of age*, “Journal of Autism and Developmental Disorders” 2005, 35, s. 340–348.

¹⁸G. Jagielska, *Objawy autyzmu dziecięcego*, [in:] J. Komender, G. Jagielska, A. Bryńska (ed.), *Autyzm i zespół Aspergera*, Wydawnictwo Lekarskie PZWL, Warszawa 2009, s. 33–50.

¹⁹Pisula E., *Autyzm – fakty, wątpliwości, opinie*, Published by WSPS, Warszawa 1993.

²⁰B. Blok, Z. Brzeska, B. Ignaczewska, *Diagnoza i wspomaganie rozwoju dziecka z autyzmem w Specjalnym Ośrodku Rewalidacyjno-Wychowawczym dla dzieci i młodzieży z autyzmem*, [in:] T. Serafin (ed.), *Wczesne wspomaganie rozwoju dziecka od chwili wykrycia niepełnosprawności do podjęcia nauki w szkole*, published by the Polish Ministry of National Education and Sport, Warszawa 2005, pp. 171–198.

limited ability of the child to receive social impulses, the lack of interest in people and the lack of reaction to when somebody calls the child by name²¹. Infants from the autism spectrum risk group do not follow the index finger of the parent with their eyes, even if the child is aided in locating the direction of the gaze with a physical suggestion, for instance, when the child's arm is touched before showing or when the child is called by name. There are children, who in the end look in the indicated direction, but without exchanging glances with the parent and without visible emotional expression²². They are not able to direct the attention of another to specific objects or events, or monitor the attention of another or notice what the other person wants to show²³. Children with autism do not see the relation between looking at something and wanting to have it, manipulate it out of curiosity. They have difficulty reading the content of information contained in the direction of a gaze²⁴.

M. Sigman et al.²⁵, as a result of observations and conducted research, have discerned the main atypical behaviour patterns of children in social development until the 18th month of age. They have concluded that these are warning signs for an early detection of autism. They included among these:

- the inability to participate in social interactions,
- failure to establish a common field of attention (pointing, following with the glance),
- limited ability to imitate,
- disturbed recognition of emotions and emotional synchrony,
- limitations in expressing attachment.

²¹ E. Pisula, *Autyzm. Przyczyny, symptomy...*, op. cit., pp. 85–87.

²² M. Skórczyńska, *Wczesne diagnozowanie autyzmu...*, op. cit., pp. 45–46.

²³ E. Pisula, *Autyzm u dzieci. Diagnoza, klasyfikacja, etiologia*, Wydawnictwo naukowe PWN, Warszawa 1999.

²⁴ K. Markiewicz, *Charakterystyka zmian w rozwoju umysłowym dzieci autystycznych*, Wydawnictwo Uniwersytetu Marii Curie-Skłodowskiej, Lublin 2007, pp. 96–99.

²⁵ M. Sigman, A. Dijamco, M. Gratier, A. Rozga, *Early detection of core deficits in autism*, "Mental Retardation and Developmental Disabilities Research Reviews" 2004, 10, pp. 221–233

In general, it is difficult to say what exactly causes the first distress in the family. Usually, the symptoms gain momentum only when minor observations begin to multiply, even when none of these does not seem significant. A diligent analysis of family video recordings had shown that from the temporal perspective, initially subtle symptoms become obvious, significantly clear already at the end of the first year of life.²⁶ The first disturbed social skills of a child in the contact with the mother are evaluated to be a significant signal announcing the development of autism.²⁷ The disturbing emotional and social symptoms most frequently reported by parents of small children are:

- high emotional irritability,
- the preference of loneliness,
- ignoring others, in particular next of kin.

The child seems not to be interested in physical contact with the mother, it even defends itself from her, recedes from her, even demonstratively pushes her back²⁸. It usually does not like modes of play that involve hugging or frolicking. There exists a large group of children that do not allow any kind of physical contact at all. The typical problem is the lack of or limited eye contact, frequently described as the so-called “empty” gaze. The child exhibits limited interest in the human face, the perception and voice of the mother²⁹. It doesn't fix its gaze on the mother's face, it does not follow her with the look, its gaze wanders in space, it does not react to her image, in particular to her smile or her gestures, with emotional animation. Characteristic are disturbed facial expressions (“mask-like

²⁶ U. Frith, *Autyzm. Wyjaśnienie tajemnicy*, Gdańskie Wydawnictwo Psychologiczne, Gdańsk 2008, p. 32.

²⁷ H. Jaklewicz, *Autyzm dziecięcy*, [in:] A. Popielarska, M. Popielarska (ed.), *Psychiatria wieku rozwojowego*, Wydawnictwo Lekarskie PZWL, Warszawa 2000, p. 118.

²⁸ E. Pisula, *Wspomaganie osób z zaburzeniami należącymi do autystycznego spektrum w perspektywie psychopatologii rozwojowej*, [in:] J. Trempała (ed.), *Psychologia rozwoju człowieka*, Wydawnictwo PWN, Warszawa 2011, p. 449.

²⁹ J. Bleszyński, *Autyzm a niepełnosprawność intelektualna...*, op. cit., p. 61; D. Senator, *Przejawy autyzmu w pierwszym roku życia*, „Pediatria Polska” 2006, no. 2, p. 128.

face”), the lack of expression accompanying a look, rare smiling and the typical inability to assume a body position indicating the readiness of and the will to be taken in the arms³⁰. The social smile appears rarely, at times it looks artificial, as if pasted on. The child does not react when called by name, with parallel attention to other ambient sounds³¹. A visible deficit are also difficulties in the imitation of emotional conditions of others. The inability to share joy, sadness, pain, fear with others. In times of distress, threat, it does not seek comfort in the next of kin, and does not offer it, even seeming as if unaware that it is at all possible, ignores or wrongly interprets the emotional behaviour patterns of their next of kin, does not express care about the feelings and emotions of others. It does not differentiate between the next of kin and objects it is fascinated with. It decidedly prefers remaining in a world of objects than a world of people. This is accompanied by an observed short time of looking at people³². The child never or rarely shifts its gaze from the object to the fact of the person. Studies that analysed the direction of the gaze of children indicated that children with this disorder less frequently look in the eyes of the figures they are watching, but more frequently follow their moving lips and the remainder of the body³³.

Observed are also specific, limited forms of making contact with people. Some children take on strange postures when in contact with others, e. g. always stand sideways, with their back to any person standing closely, remove themselves from others to a significant distance, squint, cover their eyes. At times, to make contact, they utilise objects of significance to them, e. g. blocks, balls, a piece of cord³⁴. Typical is also the lack of vocal-emotional expression, like

³⁰L. Wing, *Związek między zespołom Aspergera i autyzmem Kanner, [in:] U. Frith (ed.), Autyzm i zespół Aspergera*. Warszawa; Wydawnictwo Lekarskie PZWL, Warszawa 2005, p. 117.

³¹D. Senator, *Przejawy autyzmu...*, op. cit., p. 129.

³²P. Randall, J. Parker, *Autyzm. Jak pomóc rodzinie*, Gdańskie Wydawnictwo Psychologiczne, Sopot 2010, pp. 99, 146.

³³Pisula E., *Wspomaganie osób z zaburzeniami...*, op. cit., p. 448.

³⁴Pisula E., *Matę dziecko z autyzmem...*, op. cit., p. 69.

“ooo”, “uu”, an empty or limited range of interaction gestures, e. g. waving “bye-bye” with the hand and the lack of proper gestures and expressing emotions through body position. As a consequence, observed is a limited range of social behaviours joining the gaze, facial expression, the tone of voice and gestures. The child rarely exchanges messages with the partner when playing together. It prefers playing alone, without contact with people, with the play usually being sensory-motor and/ or ritual in character³⁵. The child usually engages in relations because it wants to satisfy its desires, e. g. it wants to get a toy, a treat, frequently utilising for this purpose the hand of the person standing next to it (treating the hand of the adult as a tool, a prosthesis, to achieve its goal)³⁶. Parents indicate that their child is overly calm, quiet, withdrawn from relations, exhibits limited activity and that it is not interested in its environment³⁷.

An analysis of video recordings from first birthdays of children to later be diagnosed with autism had revealed that these children differ from healthy peers in many characteristic traits. Observed was mainly the lack of reactions to their own name, no proto-declarative pointing, not observing the faces of others when they point to an object. A high degree of risk of emergence of autism is related to behaviour patterns that shine through between the 18th and the 24th month of life. These include:

- isolation,
- no interest in children, not imitating them,
- no co-shared attention, no proto-declarative pointing,
- no bringing and showing to parents of various objects that interest the child,

³⁵ Pisula E., *Wspomaganie osób z zaburzeniami...*, op. cit., p. 449; E. Wiekiera, *Strategia postępowania z dziećmi autystycznymi, Przekład z „Engagement”, Poradnik praktyczny dla rodziców*, Wydawnicwo Krajowe Towarzystwo Autyzmu Oddział w Krakowie, Kraków 1995, p. 13.

³⁶ H. Jaklewicz, *Autyzm dziecięcy...*, op. cit., p. 119.

³⁷ E. Pisula E., *Autyzm u dzieci. Diagnoza, klasyfikacja, etiologia*, Wydawnictwo PWN, Warszawa 2000, p. 117.

- no reaction of a child who is called. A study conducted by S. Maestro, F. Muratori, A. Cesari et al. showed that 87% of children to be diagnosed with autism at a later age clearly exhibited these disturbances in development and behaviour³⁸.

Gradually, along with the progress of development, the child shows further disturbing signs. Around the second year of age, the problems most frequently indicated by parents/ close caretakers of children to later be diagnosed with autism are: the child does not have close relations with others in the family, does not greet, does not react spontaneously to the parent, close taker when they see them, expresses emotions weakly or not at all, or does this in an atypical manner, does not use gestures to make social contacts, is not able to initiate play with toys, when instructed by an adult it can play with objects, however, it does so rarely of their own accord, is not interested in children or may even avoid them, does not react to verbal or non-verbal attempts at making contact with it, has limited abilities of imitation and does not participate in games involving imitation³⁹, does not express readiness to play together with children, is not interested in social play, attachment to others gains atypical forms, mainly as attachment to routines related to certain persons, however, it has no traits of typical emotional and social attachment⁴⁰.

The dynamics of course of disturbances in the social development children from the autism risk group shows significant variability and multiple faces. There is no child showing all symptoms, and in turn their limited intensity must not necessarily mean that in the future the child will be diagnosed with ASD. There are also children, in which the symptoms of autism spectrum disorders are obscured by additional problems, for instance, attention deficits,

³⁸ G. Jagielska, *Objawy autyzmu dziecięcego...*, op. cit., p. 42.

³⁹ E. Pisula E., *Autyzm u dzieci...*, op. cit., s. 118; A. Wolski, *Diagnoza autyzmu u małego dziecka – implikacje do pracy w rodzinie, „Rewalidacja”*. Publication for teachers and therapists, 2010, no. 2(28), p. 24.

⁴⁰ E. Wiekiera, *Strategia postępowania...*, op. cit., p. 13; A.J. Cotugno, *Terapia grupowa dla dzieci...*, op. cit.

psychological and motor hyperactivity, disturbances of fear and others. Diagnostic problems obviously show in extreme cases. If a child is characterised by a low level of cognitive abilities, it is difficult to state, whether the emotional and social disturbances correspond to its mental age, or are these more intense than in case of its other developmental abilities⁴¹. In addition, certain behaviour patterns, in terms of which small children with ASD differ from their correctly-developing peers are related to mental or speech retardation. Ever more frequently, as well, there emerges a group of children with mild or atypical symptoms of autism⁴². Disturbances in the socio-emotional sphere are of key importance for the clinical image of autism spectrum disorders, whereby the manifestation of symptoms changes with age and with the child's development. Delays in terms of social abilities are stronger predictors of an autism diagnosis than of delays in communication ability⁴³.

Speech and communication disturbances

One of the most frequent symptoms in children suspect of autism are disturbances in the development of speech and communication. The first diagnostic step in this regard is an audiometric evaluation. Hearing damage occurs more frequently in children, who were hospitalised in intense neonatal care wards. Screening tests of newborns permit early detection of reduced hearing sharpness⁴⁴. Analyses of video recordings indicate that already in the first twelve months of life, babies diagnosed with autism had deficits in communication. Most parents indicate no development of speech or delayed speech development as the first cause of their concern. In

⁴¹ U. Frith, *Autyzm. Wyjaśnienie...*, op. cit., p. 33.

⁴² M. Skórczyńska, *Wczesne diagnozowanie autyzmu...*, op. cit., p. 56.

⁴³ S. Goldstein, J.A. Naglieri, S. Ozonoff (ed.), *Diagnoza zaburzeń...*, op. cit., p. 25.

⁴⁴ M. Skórczyńska, *Autyzm a opóźnienie rozwoju*, [in:] B. Winczura (ed.), *Dzieci z zaburzeniami łączonymi. Trudne ścieżki rozwoju*, Published by Impuls, Kraków 2012, p. 15.

a study conducted by E. Coonrod and W.I. Stone included a group of parents (44 persons) of children aged 24–36 months, including 22 children diagnosed with autism and 22 children diagnosed with developmental delays (DD), this problem was indicated at 72–98%. In other studies by the same authors, delayed speech development was a cause of concern for 91% of parents of autistic children and 77% of parents of children with developmental delays. Parental concern is also caused by a significant reduction in the progress of development (e. g. no first words appearing after the cooing period) or a loss of skills gained formerly by the child. In 20–35% of cases, regression is indicated, in the form of loss of words, vocalisations or non-verbal communication skills (e. g. through gestures or eye contact)⁴⁵.

Already in the first year of a baby's life, observed may be particular difficulties in pre-verbal communication. Studies conducted by Ch. P. Johanson and S.M. Myers (2007) indicate that this is: the lack of alternating vocalisation between the baby and the parent, the lack of reaction to the voice of the mother, father or any other next of kin, no vocal/ emotional expressions like „ooo“, „uu“, a delayed range of cooing (after the ninth month of life, or a lack thereof until the 12th month of life), poor vocalisation, disturbed language prosody, minor or lacking repertoire of gestures (e. g. waving “bye-bye”, finger-pointing), no gaze directed at others, no coordination between the gaze, facial expressions, gestures and the sounds produced⁴⁶.

Considering the limited communication function, children experiencing early development of autism in the pre-verbal phase utilise atypical modes of communication. They do not exhibit interest in the spoken word or any other sounds, they make the impression, as if they had hearing problems. The cry of a baby from the autism risk group seems to be devoid of expression. Cooing does not emerge

⁴⁵ M. Skórczyńska, *Autyzm a opóźnienie...*, op. cit., p. 23.

⁴⁶ M. Skórczyńska, *Wczesne diagnozowanie...*, op. cit., p. 48; E. Pisula, *Wspomaganie osób...*, op. cit., p. 449.

at all or emerges much later, it is less varied, lacking expression, without modulation that would be akin to a conversation. These babies do not use their voice to attract attention to them. A significant group of children does not speak at all, and in those that utilise speech, its development is usually not only delayed, but also impaired⁴⁷. According to P.A. Filipek et al. (1999, 2000) the following may be considered signs of delays in the development of speech in babies from the autism risk group:

- no pronunciation of words by the baby showing comprehension after the first year of life,
- no construction of simple sentences after the second year of life (no two-word sentences pronounced spontaneously after the 24th month of life),
- no development of speech that serves communication with others,
- regression in the development of speech or social abilities at any age⁴⁸.

Babies suspect of autism communicate mainly or exclusively for the purpose of control of behaviour of others when they want to ask for something or reject something. There is no communication directed at turning somebody's attention to an object, a phenomenon or person. This deficit is a characteristic trait of autism and is not symptomatic for children with development delays. Babies in this group of disturbances have difficulties acquiring conventional and symbolic aspects of communicating⁴⁹.

Apart from this, they never or rarely intentionally use gestures or vocalisations to convey an information to someone, and have difficulty communicating messages using their gaze. They do not try to express their emotions through facial expressions, they do not nod when agreeing to/ with something, nor do they smile to aid social communication. They also do not respond to such signals

⁴⁷ H. Jaklewicz, *Autyzm dziecięcy...*, op. cit., p. 119.

⁴⁸ Skórczyńska M., *Wczesne diagnozowanie...*, op. cit., p. 41.

⁴⁹ Skórczyńska M., *Autyzm a opóźnienie...*, op. cit., p. 24.

directed at them. Coping with the lack of skills necessary to satisfy their needs, they sometimes use the body of another person (most frequently the hand) as an object, for instance, they guide the object they desire, pushing the hand in that direction. At times, the role of communication is fulfilled by aggressive behaviour, by screaming or crying⁵⁰.

The majority of autistic babies make the impression as if they did not comprehend what was spoken to them. Observed are disproportions between the readiness to repeat words, name objects, and the capacity to comprehend. According to reports of parents, approximately 25% of children aged 12 or 18 months express individual words. The first signs of comprehension of words in half of autistic children do not emerge before they reach the mental age of two years and six months. The capacity to comprehend words on a level characteristic for a child aged 16 months is reached by autistic children already at a mental age of four years. In terms of expression of words alone, the difference is smaller, and the delay fits in the range of eight to 19 months⁵¹. T. Charman et al., conducting studies on reactions of autistic babies to three types of messages (their own name, a prohibition ("no") and a statement ("this is mum/ dad")) indicated that just half of autistic children aged less than two reacted to their own name, 70% would respond correctly to the prohibition of „no”, and 30% understood the message “this is mum/ dad”. Only 30% of children aged two years imitated words, and 15% were able to name objects. It was only at the age of four years that almost all studied autistic children reacted to their own name and understood the meaning of the word “no”. Just over 80% of children would repeat words, but still only 52% would name objects⁵². In general, speech comprehension in autistic children is

⁵⁰ Pisula E., *Autyzm. Przyczyny...*, op. cit., pp. 43–44.

⁵¹ Pisula E., *Małe dziecko...*, op. cit., p. 36.

⁵² Pisula E., *Zaburzenia komunikacji u dzieci z autyzmem*, [in:] *Kiedy mózg pracuje inaczej... – postrzeganie, ruch, emocje, komunikacja*, „Zeszyty Naukowe” 6 for the International Conference organised by the Polish Foundation for Disabled Children „Promyk Słońca”, Wrocław, December 5th, 2008, p. 43.

significantly delayed. At a later time, the child may experience various levels of impairment, beginning with a total lack of speech comprehension, through the comprehension of instructions within a specific context or speech supported by gestures, all the way to discrete disturbances concerning the understanding of abstract concepts, metaphor, jokes⁵³.

Approximately 25–30% of children with ASD start pronouncing their first words around the first year of life, but frequently between the 15th and 24th month of life they stop speaking, and their verbal expression boils down to a few messages, mainly those that aim at satisfying their current needs. This regression may also encompass the loss of the ability to communicate through gestures (waving, pointing, etc.) or social communication abilities (eye contact, reactions to praise). The regression may be gradual or sudden, it may overlap with subtle, pre-existing developmental delays or an atypical course of development (e. g. uniquely intense interest for certain objects or other stimuli that are not social in character in the first year of life). The regression in the development of speech is related to the child's withdrawal from social contacts and protection against changes, the rigidity of behaviour, sleep disturbances or problems eating⁵⁴.

In approximately $\frac{3}{4}$ of children with autism that utilise speech, echolalia may be observed⁵⁵. Such speech does not entail any sort of intention of communication and entails the immediate or delayed repetition of words, the first or last syllables or sentences pronounced by someone else. At times, the child may repeat *a sentence directed at them or heard by it in the grammar form and in the tone of voice, in which it was formulated*, for instance “would you like a piece of candy?”. Echolalic statements are repeated by the child with precise intonation and melody in which they were pro-

⁵³G. Jagielska, *Objawy autyzmu dziecięcego...*, op. cit., p. 39.

⁵⁴M. Skórczyńska, *Wczesne diagnozowanie...*, op. cit., pp. 48–49.

⁵⁵J. Bleszyński, *Czy echolalia w autyzmie jest problemem komunikacyjnym?*, [in:] B. Winczura (ed.), *Autyzm. Na granicy zrozumienia*, Wydawnictwo Impuls, Kraków 2009, p. 106.

nounced. They are unrelated to the situation and do not fit in the context of the conversation going about the child⁵⁶. In an autistic child, echolalia may remain the main mode of expression and continue throughout its life. This means that the child is unable to independently create a statement, and such statements may be understood as please, protest or confirmation of something. Accordingly, the interpretation of such messages is not simple and requires good knowledge of the child. The speech of autistic children frequently includes so-called language stereotypes. The child repeats certain words, phrases, the content of advertisements, fragments of films, in particular children's stories or television programmes, multiple times. Such statements by the child usually do not serve communication and their functions are closer to other stereotypical behaviour patterns. The differences in speech also apply to atypical intonation, tempo, the rhythm of the statements and the limited and uneven vocabulary. Additionally, characteristic are difficulties with using personal pronouns. They refer to themselves "you" or "he", they make mix up pronouns describing others. Such mistakes may emerge throughout the development of speech in healthy children, but in autistic children they transgress typical developmental and temporal time frames⁵⁷. Some autistic children have trouble introducing statements to functional speech. For instance, they have memorised the names of colours, shapes, numbers or letters, but they are unable to indicate them unless asked in a manner that is different than usual. They master speech in a schematic and rigid way. Learning the meanings of words, they tie them to specific objects, for instance, the term "man" may be related to a specific person, and "cat" to a specific cat⁵⁸.

The level of development of speech and communication abilities are one of the indicators of the further course of development of the child. The earlier and the better speech develops, the better the de-

⁵⁶ H. Jaklewicz, *Autyzm dziecięcy...*, op. cit., pp. 119–120.

⁵⁷ E. Pisula, *Autyzm. Przyczyny...*, op. cit., p. 52.

⁵⁸ M. Skórczyńska, *Wczesne diagnozowanie...*, op. cit., p. 48.

velopment prognoses are. In a small group of children, where slight delays/ impediments in speech are observed, autism may remain undiscovered all the way until pre-school age, at which time difficulties in making social relations with peers will become visible⁵⁹.

Stereotypical, repetitive behaviour patterns

Children with the autism spectrum may demonstrate atypical behaviour in various areas, e. g. strange mannerisms, unique bonds with objects, obsessions, compulsions or stereotypical behaviour. approximately 5% of parents express distress because of stereotypical behaviour patterns of their children. Even though they notice this atypical behaviour of the child early, however, many of them are unable to precisely describe its character and causes. Most frequently they name such behaviour in the context of fits of bad mood, excessive liveliness, the lack of co-operation, not playing with toys, excess sensitivity to certain stimuli⁶⁰. Parents indicate that their children frequently endlessly repeat the same movements. This is most frequently: flapping arms, specific movements of hands or fingers (snapping the fingers, clapping), rocking sideways or back and forth, throwing up the arms, spinning around, walking along a circle, hitting [something] with the head, waving the hands close to their face. Even though these activities constitute a form of self-stimulation, they need not necessarily always be for them a source of joy itself, just the opposite. The statements by parents indicate that a certain group of children, when performing these activities, frequently shows signs of distress, crying, screaming. In certain cases, stereotypical movements of children may be a reaction to stress from contact with the environment, in which the child develops daily⁶¹.

⁵⁹ E. Pisula, *Autyzm. Przyczyny...*, op. cit., p. 53.

⁶⁰ E. Pisula, *Mate dziecko z autyzmem...*, op. cit., pp. 61–62.

⁶¹ P. Randall, J. Parker, *Autyzm. Jak pomóc...*, op. cit., p. 61.

Most stereotypical movements, however, are sufficiently burdensome that they hinder and prevent the execution of daily activities and learning new skills. Stereotypical movements, even though they are highly characteristic for a minor group of children from the autism risk group, they are not a specific property, as they are also present in children with significant mental disabilities and/ or severe sensory disturbances. Even correctly-developing babies, in particular before they master the skill of speaking fluently, may transitionally flap their arms when excited or frustrated. Stereotypical behaviour patterns related to ASD in early years of life of children emerge as indicators of such behaviour. Until the conclusion of the twelfth month of life, stereotypical movements are present along with general distress and focus mainly on movements of hands and the head. The activity of such children most frequently entails repetitive regular motions, e. g. scratching of their quilt or cot, knocking on an object, rocking back and forth or even hitting their head on hard padding⁶². After the twelfth month of life, stereotypical behaviour patterns intensity, when the environment is disturbed or when the routine changes. This behaviour covers mainly jumps and spinning around, however, also knocking on objects and making them spin. There emerges intense fear in situations changing the stereotypical routines present until that time. Stereotypical play, lonely play is mainly joy. The child plays most frequently with mechanical toys that may be spun around or knocked on⁶³. Usually, it repeats the same activities, aligns blocks, cars or other toys or just their fragments in rows. Noticeable is the lack of spontaneous activity. It was determined that the difficulties in controlling own activity are particularly clear in autistic children during free play.

Around the second year of life, stereotypical behaviour patterns emerge much more clearly, and their repertoire expands decidedly. The focal point in the child's behaviour is taken up by: moving of the hands or fingers (waving, fanning, flapping) in the peripheral

⁶² M. Skórczyńska, *Wczesne diagnozowanie...*, op. cit., p. 50.

⁶³ J. Bleszyński, *Autyzm a niepełnosprawność...*, op. cit., p. 97.

areas of the field of view, persistent staring at a specific object attracting attention, walking on toes and/ or long-term smelling or licking of inedible objects. Instead of soft, plush toys, they prefer hard objects such as: pens, flash-lights, keys, figurines, cords, parts of toys, e. g. car wheels, doll legs. They also insist on holding these objects the entire time, even though they are used by the children for playing rarely. Behaviour signifying fear and highly expressive reactions gain momentum. Longitudinal studies of children in the risk group conducted by C. Lord discovered that in over 87% of children diagnosed as autistic at three years of age, the parents described the presence of mannerisms spanning movements of arms and hands and specific sensory interests at two years of age⁶⁴. The author notes that such behaviour, however, is simpler to discern in three-year-olds than in two-year-olds diagnosed with autism. The parents of older children notice these deficits more frequently than parents of younger children. It is unknown, whether this happens because the children are unable to cope with them, or because autistic disturbances increase more significantly between the age of two and three years⁶⁵.

Fascination of specific objects and using them not as intended, even to the point of obsession, may be noticed in autistic children. If these objects are consciously removed or lost, the children may express deep distress or even fits of rage. At times, obsessive interest applies to bus routes, train timetables, numbers or figurines. Over 60% of children express attachment to the daily routine and rejects any changes to rituals they know in their closest environment. This applies, for instance, to activities related to going to bed, visiting stores always in the same order, travelling to specific places always along the same route, or drinking from a specific cup. They insist on having a fixed plan of the day. Behaviour is characterised by a lack of flexibility. In case of attempts at the introduction of any changes, even minor ones, not noticeable for others, the children may react

⁶⁴ M. Skórczyńska, *Wczesne diagnozowanie...*, op. cit., pp. 50–58.

⁶⁵ E. Pisula, *Autyzm u dzieci...*, op. cit., p. 54.

suddenly, expressing distress, screaming, crying⁶⁶. The child's protests may quickly take the form of aggressive behaviour. These include hitting [something] with the head, biting hands, putting fingers in ears and eyes, scratching the body, etc. This behaviour may lead to significant injuries. They may be caused, among others, by frustration caused by ineffective attempts at communication, the distress experienced in a new environment unknown to the child or due to being bored, tired, due to lack of sleep, due to hunger or pain⁶⁷.

Fixed, stereotypical behaviour in children with the autism spectrum may change as the child develops, and may take on various forms. The limited range of behaviour patterns remains related to the level of mental development of the child. Children characterised by a more limited level of development more frequently smell, lick or touch objects, and children characterised by a higher level of intellectual development more frequently repeat complex activities and prefer other forms of activity. There is also data indicating that stereotypical behaviour is significantly more frequent in little children with autism than in their peers with other developmental or behavioural disturbances or in children from the risk group but not diagnosed with autism. All kinds of atypical modes of behaviour of a child are highly troublesome and tiring for its environment. They cause difficulties in the area of upbringing and increase the level of stress in the child's family. They also constitute an external, easily noticeable sign of atypical development and thus stigmatise. A frequent descriptor of such behaviour of a child is "weirdness". An analysis of the limited behaviour patterns in little children aged less than two years had shown that their presence may be highly useful in diagnosing autism⁶⁸. Repetitive, stereotypical behaviour patterns and a limited and schematic repertoire of behaviour are treated as one of the axial properties of ASD.

⁶⁶ P. Randall, J. Parker, *Autyzm. Jak pomóc...*, op. cit., pp. 101-102.

⁶⁷ M. Skórczyńska, *Wczesne diagnozowanie...*, op. cit., p. 51.

⁶⁸ E. Pisula, *Autyzm. Przyczyny...*, op. cit., pp. 56-57.

Descriptions of behaviour of little children suspect of autism are also significant because of the fact that their general level of activity is usually different from what may be observed in other children. At times, the children are dominated by almost total passivity. It seems totally removed, characteristic is the lack of curiosity, interest in its environment, both the physical as well as the social. Parents indicate frequently that the child, when set down at a specific point, remains there, not making attempts at moving, playing or following a caretaker who is walking away. A second, significantly different image of activity of the child may be excess hyperactivity, hypermobility, connected to the inability to focus attention on anyone or anything even for a moment. The child is constantly in motion, it runs, jumps, climbs furniture. Its activity seems chaotic, devoid of any objective and changes all the time. It is accompanied by a high level of excitement, adjusted through physical expression, but this activity at the same time serves self-stimulation. It is frequently accompanied by fits of rage and aggression, screaming in public places, reactions of fear and panic. Such a mode of behaviour of the child is frequently mistaken with the attention deficit and hyperactivity disorder (ADHD). It must be noted, however, that in a minor group of children it is possible for these two disturbances to coexist⁶⁹.

Autistic children may exhibit symptoms indicating disturbances in sensory integration. However, they do not differentiate children with ASD from children with other developmental disturbances⁷⁰. A characteristic trait of the dysfunction of sensory integration are wrong responses to the sensory stimuli that they experience. Typical symptoms of sensory disintegration in little children with autism include, among others: hypersensitivity or hyposensitivity to the touch, to light, to sound, to motion, to taste and to smells (e. g. sen-

⁶⁹E. Pisula, *Małe dziecko z autyzmem...*, op. cit., p. 53.

⁷⁰M.L. Kutscher, J. Glick, *Zaburzenia integracji sensorycznej*, [in:] L.M. Kutscher, T. Attwood, R.R. Wolff (ed.), *Dzieci z zaburzeniami łączonymi*. Published by K.E. LIBER, Warszawa 2007, pp. 168–169.

sory factors related to eating: colour, texture, taste may lead to a highly restrictive diet of the child); concentration disorders, an uncommonly low or high level of activity, frequent inactivity or withdrawal, the inability to cope with frustration, with self-satisfaction, intense, disproportionate reactions to changes to the situation or unknown places, impulsive behaviour, difficulty shifting from one activity to another⁷¹.

In recent years, more and more information is emerging concerned with other disturbances in the motor development of children as an indicator of autism risk. Such deficits apply to major and minor motor functions, the maintenance of balance, the speed of movement, the maintenance of the body position of the child and the motor functions of the speech system. Studies of motor activity of children from the autism risk group were conducted by O. and P. Teitelbaum, and have shown that this development shows significant disturbances entailing mainly the asymmetry of body motions. Researchers believe that the recognition of indicators of such disturbances in babies aged between six and eight months is fully possible. They have shown that in children, in whom autism spectrum disorders were diagnosed, asymmetry of movements during lying and crawling, the maintenance of the asymmetric tonal neck reflex outside of the proper time of development and the lack of defensive movements when the child would be losing balance could already be observed in the first months of life. In addition, in these children, rolling from the back onto the stomach, crawling, sitting up and the gait do not develop in the correct time⁷². Motor disturbances may constitute one of the earliest signals of incorrect development of a child with autism, even before visible social or communication deficits show. It must be stressed, however, that despite long-term research in this area, it was not possible to determine a typical pattern of motor dysfunctions for autism, or the fact that not all chil-

⁷¹ M. Skórczyńska, *Wczesne diagnozowanie...*, op. cit., pp. 52–53.

⁷² O. Teitelbaum, P. Teitelbaum, *Czy twoje dziecko ma autyzm? Jak rozpoznawać najwcześniejsze oznaki autyzmu*, Published by Harmonia Universalis, Gdańsk 2012.

dren from the autism risk group may show such divergences from the development norm⁷³.

Sleep and appetite disturbances, aggression and self-aggression, problems with bodily functions, high emotional lability (fits of anger, screaming, crying without tears) are signs that frequently accompany the development of autism spectrum disturbances in small children⁷⁴.

Early detection of autism spectrum disorders

The recognition of symptoms of autism before the second year of life of the child remains an exceedingly difficult task. Most clinicians indicate that the behaviour of children before the conclusion of the second year of age may not be sufficiently clear to establish a diagnosis of autism. In such a small child, symptoms encompassed by current diagnostic criteria may not always fully show. In addition, disturbances that belong to the autism spectrum are characterised by significant dynamics in development. The development of these children is very varied, not only in terms of speed, but also the frequency of emergence of the individual phases of development. This applies to cognitive abilities, deep social deficits, the ability to communicate as well as other problems accompanying the axial symptoms. In addition, some modes of behaviour differentiating autistic babies from their correctly-developing peers are probably related to mental disabilities or speech disturbances. If a child is mentally disabled, the autism symptoms may be assumed to be indicative of disability. Hence, the differentiation between autistic children with mental disabilities from children characterised by the same level of disability, but without autism, is more difficult than differentiating them from children in the intellectual norm⁷⁵.

⁷³ E. Pisula, *Od badań mózgu...*, op. cit., pp. 43–45.

⁷⁴ H. Jaklewicz, *Autyzm dziecięcy...*, op. cit., p. 118; G. Jagielska, *Objawy autyzmu...*, op. cit., pp. 48–49.

⁷⁵ E. Pisula, *Autyzm u dzieci...*, op. cit., p. 53.

Until now, it was not possible to determine algorithms serving the diagnosis of ASD in babies below the first year of age that would be based on empirical proof⁷⁶. According to the current state of knowledge, the earliest moment when autism could be recognised is the eighteenth month of life. This is indicated by analyses of records from control inspections conducted by paediatricians (differing significantly from the results of assessments of twelve-month-old children), as well as by results of research conducted in this area. In clinical practice, we have at our disposal various diagnostic tools for screenings. Most frequently, these tools are useful for application for the general population of children covered by basic health care services. They could aid the detection of ASD in very young babies, however, they do not permit the differentiation of ASD from other developmental disturbances. Additionally, not all of the available diagnostic tools permit the determination of the risk of autism in very small children below the 18th month of age⁷⁷.

The most useful tools for early ASD screenings in little children are considered to be the Checklist for Autism in Toddlers – CHAT (from the 18th month of life) developed by S. Baron-Cohen, J. Allen, Ch. Gillberg⁷⁸, and its modified version, the Modified Checklist for Autism in Toddlers – M-CHAT (from the 24th until the 30th month of life). G. Baird et al.⁷⁹, conducting for many years control studies on the usage of the CHAT for screenings of the general population have discovered its high usability (most children not to get a positive result of the CHAT did not receive an autism diagnosis later)

⁷⁶ A. Steiner, T.R. Goldsmith, A.V. Snow, K. Chawarska, *Practitioner's Guide to Assessment...*, op. cit., p. 1185.

⁷⁷ M. Skórczyńska, *Wczesne diagnozowanie autyzmu...*, op. cit., p. 41.

⁷⁸ S. Baron-Cohen, J. Allen, Ch. Gillberg, *Can autism be detected at 18 months? The needle, the haystack, and the CHAT*, "British Journal of Psychiatry" 1992, 161, pp. 839–843.

⁷⁹ G. Baird, T. Charman, S. Baron-Cohen, *A screening instrument for autism at 18 months of age: A 6-year follow-up study*, "Journal of the American Academy of Child and Adolescent Psychiatry", 2000, 39, pp. 694–702.

and its positive prognostic value (most children not to complete the CHAT was later diagnosed to be autistic). During the conducted research, however, it came to light that this is a tool that is less sensitive to the more subtle symptoms of autism, as children later diagnosed within the AS or with atypical autism were not detected at 18 months of age in CHAT tests. Wanting to improve the diagnostic sensitivity of the tool, in the year 1999 D.L. Robins, D. Fein, M.L. Barton, J.A. Green⁸⁰ had introduced modifications to it, proposing a modified version – the M-CHAT, which excluded observation by a medical practitioner, and expanded the number of questions aimed at parents. At the same time, they improved their practical usability for screening tests of 24-month-old children. Another useful screening tool for children aged 24–36 months is the interactive Screening Tool for Autism in Two-Year-Olds – STAT⁸¹. The diagnostic criteria for this tool are closely tied with later discovery of the ASD. These are the lack of reactions to the own name or a limited frequency of these, the inability to follow an indication or gaze, an indication for reasons other than a plea and undertaking play based on imitation. This test was created on the basis of empirical proof showing that autism spectrum disorders may be diagnosed at the age of two years, because these children present specific deficits in terms of social competences spanning imitation, functional play and directing attention. Based on clinical and scientific observations, selected were activities that best differentiate the group of children with autism from the control group⁸².

⁸⁰ D.L. Robins, D. Fein, M.L. Barton, J.A. Green, *The Modified – Checklist for Autism in Toddlers: An initial study investigating the early detection of autism and pervasive developmental disorders*, “Journal of Autism and Developmental Disorders” 2001, 31(2), pp. 131–144.

⁸¹ W.L. Stone, E.B. Lee, L. Ashford i wsp., *Can autism be diagnosed accurately in children under 3 years?*, “Journal of Child Psychology and Psychiatry” 1999; 40(2), 219–226; W.L. Stone, E.E. Coonrod, O.Y. Ousley, *Brief report: Screening tool for autism in 2-year-olds (STAT): Development and preliminary data*, “Journal of Autism and Developmental Disorders” 2000, 30(6), pp. 607–612.

⁸² A. Rynkiewicz, M. Kulik, *Wystandardyzowane, interaktywne...*, op. cit., pp. 43–44.

Due to the complex and specific mode of progress of development processes and their mutual ties in the population of children with autism spectrum disorders, it is necessary for the diagnostic process or the model of early detection of autism to be conducted in many stages. Clinical trials have shown that only systematic observation of the child, using suitable diagnostic tools (even their multiple use at the right times) provide the basis for an ultimate diagnosis⁸³. This is a priority aspect of diagnosis, conditioning the early commencement of therapy, and at the same time providing a perspective to reduce the child's difficulties and preventing disturbances that could emerge as so-called secondary disturbances. We have at hand an ever higher volume of data indicating that early intervention for children with autism spectrum disorders brings positive results⁸⁴.

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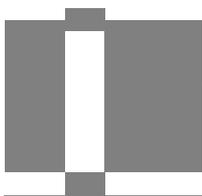
⁸³ M. Skórczyńska, *Wczesne diagnozowanie...*, op. cit., p. 52.

⁸⁴ J. Ball, *Autyzm a wczesna interwencja. Rzeczowe pytania, życiowe odpowiedzi*, Wydawnictwo Harmonia Universalis, Gdańsk 2016.

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Play in autistic children in therapeutic wards – instrumental or autotelic?

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Play is a typical and natural activity in children, which introduces it to the real world. It plays an uncommonly important function, thanks to the which the little person learns and gains information about their environment, the properties of objects, social relations or other rules. This area is different in children with autism. In most cases, play is accompanied by significant deficits, and the burden of focus of revalidation influences remains on the development of areas that are more disturbed, such as communication, disturbances in social interactions or behaviour hindering functioning. In course of therapeutic work, we sometimes forget the seemingly trivial activity that the playing of a child may be in view of adults. Considering this, it is worthwhile to take a look at the role ascribe to play by specialists over the years, and what it looks like in autistic children.

KEY WORDS: autism, child, children playing, play in children, development, types of play, social skills

The issue of autism as a social phenomenon

The child does not play because it is a child, but it plays to become an adult

Lev S. Vygotsky

Autism is a comprehensive disturbance of development, the fundamental basis of which is neurobiological. There are currently in the world two valid classifications serving a diagnosis. One is the DSM-5 classification of the American Psychiatric Association published in the year 2013 and the ICD-10 International Statistical Classification of Diseases and Related Health Problems valid since the year 1996 and still utilised in Poland, developed by the WHO (ICD-11 is now at an advanced stage of preparation by the WHO). Both of these tools include certain differences in diagnostic criteria and the naming of diseases. Quoting A. Rynkiewicz and M. Kulik, "the DSM-5 classification unifies all diagnostic units in a single unit called the Autism Spectrum Disorder (ASD). (...) The "Spectrum" applies to differences in the presentation and intensity of symptoms within a group of patients with ASD and indicates a continuum between the general population and the persons diagnosed with it¹. According to the ICD-10, the diagnosed units that are the subject of the process of assessment in order to gain aid in the education system due to the need of special education, are: autism, Asperger syndrome or atypical autism². In order to maintain consistency, this article will use the term 'ASD' with respect to all disturbances, fusing all the mentioned issues.

Over the last ten years, the topic of autism has been researched and analysed in multiple respects, beginning with constantly-improving research responding to many questions, through an ev-

¹ A. Rynkiewicz, M. Kulik (2013), *Wystandardyzowane, interaktywne narzędzia do diagnozy zaburzeń ze spektrum autyzmu a nowe kryteria diagnostyczne DSM-5*, *Psychiatria*, vol. 10, no. 2, <https://journals.viamedica.pl/psychiatria/article/view/35880/25969>

² In certification practice, atypical autism is also deemed to be autism; it does not fulfil all diagnostic criteria of child autism.

er-increasing number of publications, all the way to broadly propagated knowledge. Societal awareness is improving, and the numbers of children, youths and adults diagnosed with this disorder are rising. As indicated by the report published by United States-based organisations dealing with monitoring development threats in persons within the ASD³, the estimated percentage of diagnoses made is higher than in historic reports. Research conducted in eleven states in the United States had shown that in one of 59 children at the age of eight years, ASD was identified⁴. In Europe and in Poland, such detailed statistical data is not available, however it is assumed that ASD is diagnosed in one in 100 children⁵. The first studies that are supposed to estimate the prevalence of ASD in Europe are conducted in twelve countries by Autism Spectrum Disorders in the European Union since the year 2016, and the final result is yet to materialise⁶.

In order to take a closer look at the spectrum of issues of the prevalence of ASD in Poland, and to indicate the weight of this issue, statistical data was utilised that contain information on the number of pupils covered by support in education, meaning, those that hold certificates confirming the need for special education issued by public psychological and educational support facilities due to autism, Asperger Syndrome. The process of increase of the number of certificates issued is presented by fig. 1.

The data presented in the diagram applies to all types of education facilities that were obligated to file reports to the Polish Educa-

³ Funded by the Centers for Disease Control and Prevention (CDC), United States Department of Health and Human Services.

⁴ Community Report from the Autism and Developmental Disabilities Monitoring (ADDM) Network, <https://www.cdc.gov/ncbddd/autism/addm-community-report/documents/addm-community-report-2018-h.pdf> [access: 12.05.2018].

⁵ Certain epidemiological differences may stem from the sheer fact of referring to two various classifications: DSM in the United States and ICD in Europe, Poland as well.

⁶ http://asdeu.eu/wp-content/uploads/2016/09/Poster-ASDEU-Prevalence_AE-Congress.pdf

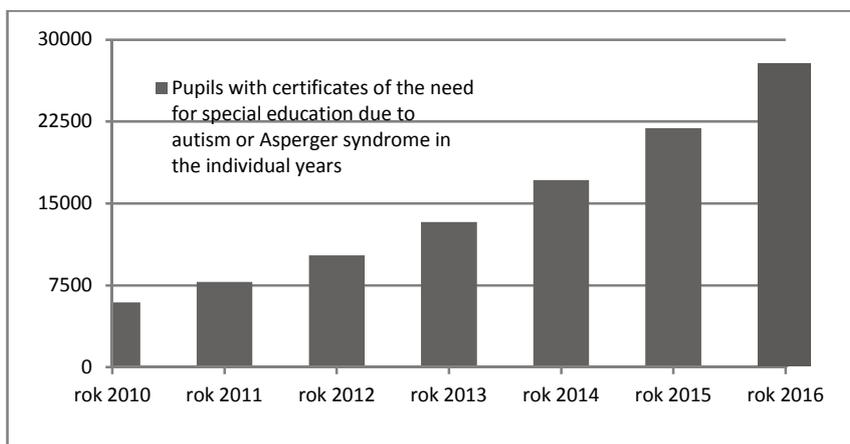


Fig. 1. Pupils with certificates of the need for special education, issued by public psychological and educational support facilities due to diagnoses of ASD in the years 2010–2016 (own work based on data of the Polish Education Information System)⁷

tion Information System on September 30th of each year. It must be stressed that these apply to the field of autism and Asperger syndrome, and do not contain information from the field that includes pupils with compounded disabilities, which may include pupils experiencing autism and intellectual disability. In the year 2016, data collected in the Polish Education Information System indicated that the number of children holding certificates on the need for special education due to autism or Asperger syndrome remaining in pre-school education facilities amounted to almost 10 000.⁸ As play is the fundamental activity of a child in the pre-school age, and within the autism spectrum its development is disturbed, the issue of play will be the focal point of the further part of this study.

⁷ SIO <https://cie.men.gov.pl/sio-strona-glowna/dane-statystyczne/niepelno-sprawnosci-dane-statystyczne/> [access: 16.05.2018].

⁸ SIO <https://cie.men.gov.pl/sio-strona-glowna/dane-statystyczne/niepelno-sprawnosci-dane-statystyczne/> [access: 16.05.2018].

The characteristics of play in an ASD child

The specifics of life of an ASD child, as well as the properties characterising it, differ in terms of the volume of prevalent behaviour patterns, their intensity and quality, as well as the cognitive and communication skills or intellectual capacity. Considering the breadth of the properties, the usage of the term “autism spectrum disorders” established by Doris Allen in the year 1988 seems to be justified⁹. Studies conducted by Lorna Wing in the 1980s “have shown a prevalence of autism at 4–5 cases per 10 000 people. At the same time, following the same study in terms of the autism continuum, this ratio increases to 21 per 10 000”¹⁰. The observation of such a group of children permitted the determination of three characteristic spheres, which, described in detail, were included in the diagnostic classifications described above. The spheres differentiated between by L. Wing, in which all the analysed children exhibited disturbances, are:

- Difficulties in participation in alternating social interactions;
- Difficulties in communication with the environment;
- A specific, limited pattern of imagination, which influences, among others, the rigidity of play¹¹.

Play has a significant role within a child’s development. It is a prime and uncommonly important activity of the child, which brings it closed to gaining knowledge about the world that surrounds it. Analysing the thoughts of psychologists on play, one can distinguish the following properties that characterise it:

- It is a social phenomenon, it emerges and develops under the influence of the environment and the child’s own activity.
- It is historic in character – it changes and develops depending on the conditions, in which a child develops. The content and topics of play may change.
- It is a reflection of the reality explored by the child¹².

⁹ E. Pisula (2005), *Małe dziecko z autyzmem. Diagnoza i terapia*, GWP, Gdańsk.

¹⁰ Ibidem.

¹¹ E. Pisula (2005), *Małe dziecko z autyzmem. Diagnoza i terapia*, GWP, Gdańsk.

¹² M. Przetacznikowa, H. Spionek (1982), *Zabawa jako typowa forma działalności małego dziecka*, [in:] M. Żebrowska, ed., *Psychologia rozwojowa dzieci i młodzieży*, Warszawa, PWN.

Play constitutes the foundation of social interactions that are shaped in actuality from a very early period in life. The child, engaged in play, learns life skills that are necessary for functioning in the adult world. In course of development, the child goes through various stages of play ascribed to various age groups. In the first months of life, it mostly engages in play using its own body and in the manipulation of objects, it then moves to constructional, topical play to achieve at the age of six years the skill to understand verbalised rules of social play¹³. Thanks to play, symbolic thinking develops in children, imagination is started up, toys may represent real objects. The child learns to act/ work with an object, it checks, how it can be used and the properties it has. Through topical play, it tries out various scenarios that it implements, it learns relevant modes of behaviour and interpersonal relations¹⁴. In view of Lev Vygotsky, all imagination-related play are the highest form of play that leads to the development of imagination as well as abstract thinking¹⁵. A child developing properly does not ponder on the meaning/ significance of its play. It feels the instinctive need of interacting with the world, with people, the need to create, act out, experience the reality that surrounds it. Observing a child, which e. g. struggles again and again endlessly to construct a pyramid of building blocks that keeps collapsing or a four-year-old girl, who is cooking spaghetti of water, paint and pieces of crêpe paper for her dolls – it is clearly visible, what foundations for future development are formed at that time.

Playing skills are different in children with autism spectrum disorders. *“An autistic child is not interested in their environment at all or is interested in it to a very limited extent; it does not study or explore it.*

¹³ J. Cieszyńska, M. Korendo (2014), *Wczesna interwencja terapeutyczna. Stymulacja rozwoju dziecka. Od noworodka do 6 roku życia*, Wydawnictwo Edukacyjne Kraków.

¹⁴ J. Moor (2006), *Śmiech, zabawa i nauka z dziećmi o profilu autystycznym*, Łódź-Warszawa, Wydawnictwo Mała Litera, Wydawnictwo Cyklady.

¹⁵ E. Filipiak (2015), *Nauczanie rozwijające we wczesnej edukacji według Lwa S. Wygotskiego. Od teorii do zmiany w praktyce*, Akademia Centrum kreatywności, Bydgoszcz.

*It does not play with toys in the typical manner, as they are intended to be played with*¹⁶. Play in this group is most frequently „weird”, meaning, its form and/ or course is surprising, atypical. The child may play using entirely different objects or utilise objects in an atypical way. Instead of a teddy bear, the child does not let go of pliers, a spoon is used to knock on furniture, the child may tear up and throw around paper tissues, split a newspaper into bands, spend time in the bathroom watching the laundry spin around in the washing machine, make objects rotate, stare at shadows on the wall for many hours, etc. Toys are used schematically, e. g. a jigsaw puzzle is arranged the other way around, with the image facing to the floor, images from an Old Maid card game are arranged in vertical, precisely even stacks, and toy cars are arranged one behind another to form an uncommonly long line. Frequently, any change introduced to the arrangement by a parent, teacher or therapist results in anger, aggression or self-aggression¹⁷. Among children with ASD, characteristic is the lack of play utilising imitation, the lack of the need to cooperate with peers during play. The level of intensity of difficulties will depend on diverse factors, which are listed, among others, by J. Moor. These include, among others:

- Difficulties in speaking and communication, characterised by delays in the development of speech, flaws, lack of speech comprehension, etc.;
- Difficulties in reading and interpreting non-verbal messages, such as facial expressions, body position, the tone of voice, etc.;
- Errors in interpersonal contacts, the dislike for and inability to share space, sharing own experiences;
- Problems activating imagination, reading thought-up situations, which could result in the obsessive repetition of a single activity¹⁸.

¹⁶ A. Bryńska, G., Jagielska J. Komender (2009), *Autyzm i zespół Aspergera*, Wydawnictwo Lekarskie PZWL, Warszawa.

¹⁷ The examples quoted in the article stem from own therapeutic practice.

¹⁸ J. Moor (2006), *Śmiech, zabawa i nauka z dziećmi o profilu autystycznym*. Łódź-Warszawa, Wydawnictwo Mała Litera, Wydawnictwo Cyklady.

Looking at the way ASD children play, noticeable is the fact that the decisive majority of activities are self-stimulation, patterns, the lack of planned activity or the complete lack of usage of toys as they were intended to be used. An autistic child more eagerly chooses activity with an object than with another person, or perhaps with the necessity to respect any sorts of social contracts, rules or conventions. It gains much more pleasure from rolling a vehicle back and forth, looking at the wheels turning, than from parking the toy at a toy parking lot, loading building blocks on to a friend's truck or racing along a track¹⁹. A girl is playing with a stuffed owl toy, but she flaps its wings in her field of vision or moves them over her lips. A boy is arranging a puzzle, but the pieces are arranged vertically and horizontally according to colours or sizes, and not e. g. according to categories or in suitable openings; he is playing with a toy plane, but only rotates its rotor and does not pretend to be flying the machine, etc. Examples of such activities may be listed ad infinitum.

Children with ASD decidedly more frequently lack play that uses imitation, topical play or play using imagination. It is difficult for children with autism to imagine that a block may be a plane, that a bean bag may be a fish, that a ball may be an orange. "*In studies of Baron-Cohen, only 20% of autistic children were able to play using imitation (playing through imitating). These skills were displayed by 80% of children with Down syndrome*"²⁰. Play in children with ASD can be functional play, which means that they can play with toys as they are intended to be used, or that it may frequently be sensomotory play. The child is interested in the sensory properties of a toy: it smells it, licks it, it puts it in its mouth, watches it from various angles. However, children with autism also exhibit other types of play. In this group of children, functional, constructional play may also emerge, as can imitation play or symbolic play²¹. The skills of

¹⁹ E. Pisula (2013), *Konteksty Pedagogiczne*. 1/2013. http://kontekstypedagogiczne.pl/wpcontent/uploads/konteksty_pedagogiczne_1.pdf#page=17 [access: 10.05.2018].

²⁰ Ibidem.

²¹ E. Pisula (2005), *Mała dziecko z autyzmem. Diagnoza i terapia*, GWP, Gdańsk.

a child will largely depend on its communication skills, intellectual capacities or the developed theory of mind²².

Watching children with autism in a group of peers, one can clearly notice that they do not enter into interactions with other boys or girls in the group. Frequently, the interests of children with autism are completely different from the interests of their peers without disturbances. A large group of children exhibits from very early years an interest or even fascination with letters and numbers. They memorise them quickly, recognise them at every stage, they can arrange them in a specific order, they can be uniquely tied to a selected number (e. g. 4, 5 or 8 may be uniquely fascinating for a specific child). The child recognises a specific digit from a very early age, carries it along as if like a talisman, loves puzzles or toys with numbers, clocks, calendars, buses or trams marked with a specific number. It reads a book, but only a specific page that has a specific number. The situation is similar to an obsession with letters. A small child exhibits from a very early age an uncommon fascination with e. g. television shows (the symbol with the logo and name of a channel, e. g. TVN or POLSAT). It watches inscriptions, recognises them, finds them in the TV guide, at an early stage it attempts to copy the letters, fuse them into a whole. It could also observe and recognise the names-labels of stores, chain restaurants or stores. The child reads names, arranges them from blocks or letters. Characteristic are also the tendencies towards arranging, recreating or repeating the alphabet. Particularly frequently may be observed interest for foreign language (e. g. English) songs for children, where the alphabet is pronounced in full. As they age, these interests need not change, but this may not necessarily translate into functional skills, e. g. the child does not utilise these fascinations to learn to read. Frequently, the superordinate objective is not getting to know letters or numbers, but the act of arranging and fitting them together itself. At times, however, letters let the child arrange words, names that are uniquely important to them. The child

²² Ibidem.

arranges titles of films, names of mobile phones, words from the remote control, like: play, stop, names of dinosaurs, much less frequently their own name or names of others from the family. In addition, the categories of interests follow a pattern, repetition and foreseeability, a world, which is safe and satisfying for children with ASD²³.

The awareness of the difficulties experienced by children with autism during play causes an increase in the interest by scientists in this form of activity, even though there seems to be disagreement between the need for structure of training of complex skills with the need for stimulation of spontaneous play behaviour. Literature includes topical suggestions that attempt to integrate these two diverging objectives: the *Floor Time* concept of Grennsman or the IPG (*Integrated Play Group*) Model of Wolfberg and Schuler²⁴, along with a few others, however, in this study, important is the perception of the play of a child not through the perspective of any sort of objective, hence, a therapeutic model, but as an autotelic activity: activity of play as an experience, which – as may be assumed – is very much missing from the structured life of an autistic child. This constitutes a deficit that needs to be dealt with primarily through education work, so that it would not need to be dealt with so intensely through therapy, which should rather be interventional in character. Within the therapeutic process, children with autism are most frequently offered modes of play that are educational: manipulation, didactic or movement-based play. In home situations, parents as well – guided by therapists – focus more strongly on the therapeutic process, stress the development of didactic skills within the area of play rather than the spontaneity of behaviour. It would be worthwhile to change this, and out of this was born the idea of a research

²³ Own observations. Conf. as well: Charbicka M. (2015), *Dziecko z Zespołem Aspergera*, Difin.

²⁴ J. Lantz (2001), *Play time: An examination of play intervention strategies for children with autism spectrum disorders*. The Reporter, 6(3), pp. 1–7, 24, [online] <https://www.iidc.indiana.edu/pages/Play-Time-An-Examination-Of-Play-Intervention-Strategies-for-Children-with-Autism-Spectrum-Disorders> [access: 11.01.2018].

projects expanding knowledge about the play in a child with ASD as an activity that is required in itself. However, this primarily requires an analysis of the specifics of play in these children.

Own research methodology

The observation of play in children with ASD, of their spontaneous behaviour patterns or interactions took place over the span of ten months during classes conducted on the premises of the therapeutic pre-school facility for children with autism in Łódź. The group of 12 children attending the preschool are aged 2–8 years. All the children were accepted into the preschool on the basis of certificates confirming the need for special education issued due to autism. Some of the pupils have certificates of compound disabilities: autism and intellectual disability. Observation only took place during spontaneous and unorganised activity of pupils, most commonly during so-called education and care classes, when the child has ‘free time’ for itself. During this time, the children had free access to toys, and adults did not impose any tasks on them. During observation, notes were made on the behaviour of children, what the children did, how did they behave, what activities they chose²⁵. The second column includes behaviour of children developing typically (children of the employees, siblings), who appeared during the classes at the preschool, where the research was conducted. The uncatagorised observations were described in methodological categories as event samples. It was natural and confidential, meaning, the children did not know they were being watched, but they were used to the constant presence of the therapist as a natural situation during their stay at the preschool.

The list of observed activities during play is presented in table 1.

²⁵ The observations were conducted at the Therapeutic Preschool for Children with Autism in Łódź, Poland.

Table 1. Summary of activities of children at the therapeutic preschool – examples of modes of play observed in children with autism and in children developing typically, observed during spontaneous activity (source: own research)

Child age	Number of children with ASD observed	Activities most frequently chosen by children with autism during free play	Activities most frequently chosen by children developing typically during free play
2–3 years	2	Plays with a musical and light toy, switching it on multiple times and repeating this activity, puts plastic fruit into a pot and mixes them for a long time, repeats this activity numerous times, when it cannot cope, it pulls the hand of an adult, not making eye contact, climbs a chair and a table, physically very active, frequently uses toys based on sound and light, obsessively turning them on, licks toys, puts them into the mouth;	Explores the space, is interested in all suggested activities, enters the tunnel following a ball, seeks support in the mother if it fails to do something, puts circles on a pyramid, handles it to an adult to put them on together, mixes bulk material in a container, distributes it into boxes, builds a tower, arranges a pyramid, puts in containers, from smallest to largest;
3–4 years	2	Walks around the hall without purpose, puts toys in the mouth, hums, murmurs, steps on toys that spilled out on the floor, places hands apart and looks up against the light, puts arms in the mouth, knocks a block on the floor, on the door;	Scribbles with crayons, listens to the books being read, watches pictures, eagerly paints, plays with the toy kitchen and pots, distributes onto plates, gives out to adults, constructs a track for wooden trains, makes balls and cylinders out of plasticine, names them (snake, fish, etc.);
5–6 years	6	Plays with plastic and fabric fruit, keenly watches its favourite cartoon, kneads plasticine, joins various elastic masses together, runs around the preschool room without purpose, jumps, jumps on a ball, arranges a simple jigsaw puzzle, sings songs from the cartoon, repeats entire phrases; Throws up objects and toys, makes them spin in the hand;	Plays with Lego blocks, builds structures: bases, castles, garages, makes dinosaurs out of plasticine, plays board and clue games, draws with crayons and colours according to topics that interest it, such as animals, dinosaurs, engages adults from the family to join in, does sword-fights, climbs furniture, hides and demands that he be sought;

con. tab. 1

Child age	Number of children with ASD observed	Activities most frequently chosen by children with autism during free play	Activities most frequently chosen by children developing typically during free play
7-8 years	2	Sits or lies on the floor, reads books sometimes, takes out and arranges a simple jigsaw puzzle for younger children, does not initiate play, expects adult suggestions, plays with numbers putting them in order; most eagerly lies there and rocks back and forth, cuts paper, newspapers into little pieces without purpose, puts plastic toys into a pot, often puts toys, objects in the mouth, does a 25-piece jigsaw puzzle.	Collects figures and objects from its favourite film, expressively discusses its favourite heroes, wants to play with an adult to recreate scenes from the film, thinks up and constructs a space ship using the objects that surround them; Draws scenes from favourite films and with favourite heroes, thinks up images.

An amendment to the observation study of children remaining at the preschool were information on the group of children with ASD, assessed using the ADOS-2 tools²⁶. These studies were conducted among children diagnosed with autism that took part in the Polish ADOS-2 adaptation and validation programme and in the control group of children developing typically. This tool is used throughout the world as the so-called „gold diagnostic standard” in

²⁶ Autism Diagnostic Observation Schedule-2, a tool for diagnosing and for evaluation of signs of autism. In the years 2013–2016, Poland saw the execution of a research project aimed at validating the tool and adapting it to Polish norms. The project was conducted under the leadership of prof. dr hab. Ewa Pisula and dr Izabela Chjnicka from the Faculty of Psychology of the University of Warsaw, as part of a research grant awarded by the Polish State Fund for the Rehabilitation of the Disabled, co-financed by resources of the University of Warsaw. The project included organisations working for persons with ASD. The author is one of the therapists included in the research. Descriptions of results for children covered by own therapy utilised with consent of the project leaders, according to the conditions of participation in it.

discerning disturbances in development of children²⁷. The ADOS-2 is a standardised and partially structured observation protocol useful in clinical diagnosis as well as utilised for the needs of scientific research. The tool is composed of four modules, the choice of which is conditioned upon the age and language competences of the person studied, as well as a toddler module used to study very young babies. The individual modules in the age groups are foreseen for smaller children focus on assessing such skills as:

- language and communication;
- mutuality of social interactions;
- play;
- stereotypical behaviour patterns and fixed behaviour and interest patterns;
- other behaviour diverging from the norm²⁸.

The diagnostic algorithm includes specific tasks that were assigned to two categories. For the purposes of the present article, utilised were studies performed using modules one and two. Module one is foreseen for children aged 31 months and older, the language development of which is in the pre-verbal stage or where a few single words are found. Module two is used to diagnose children using sentences, most frequently at the pre-school age. Both modules include tasks for part C of the protocol, applicable to play. Both studies evaluate "Functional play with toys as well as imagination/ creativity²⁹. These positions are evaluated during play using toys - miniatures representing real objects. The child plays spontaneously, symbolically, pretending. The evaluation is made at a score

²⁷ I. Chojnicka, E. Pisula (2017), *ADOS-2 Polska adaptacja*, Pracownia Testów Psychologicznych Warszawa.

²⁸ I. Chojnicka (2012), *Polska wersja narzędzia obserwacyjnego do diagnozowania autyzmu ADOS*, *Psychiatria Polska* 2012, vol. XLVI, no. 5. https://www.researchgate.net/profile/Izabela_Chojnicka/publication/235439532_Polish_version_of_the_ADOS_Autism_Diagnostic_Observation_Schedule-Generic/links/54895eac0cf268d28f0921b2.pdf [retrieved: 05.05.2018].

²⁹ E. Pisula, I. Chojnicka, *ADOS-2 Protokół do diagnozowania zaburzeń ze spektrum autyzmu*. Polish edition 2017. Hogrefe WPS USA.

Table 2. Results of observations of children assessed with the ADOS-2³⁰

Module type/ age range, age	Observation results for ASD children	Observation results for non-ASD children
ADOS-2 module T 18-30 months	Spins the wheels of a car, rubs its hand with a rough building block, observes the spinning wheels, not interested in the ball, the bubbles, quickly changes interest in the toys, no words;	Looks at various toys, shows them to the mother, engages mother to play, watches the purse, the items that match it, puts them in the purse, shows the book with the animals to the mother, pretends to talk on the phone, a few words, mum, doll, what? Hides behind the mother or seeks comfort in her
ADOS-2 module T 18-30 months	Arranges building blocks and cars in a row, puts toys in its mouth, spins the wheels on the car, interested in toys that play a short while, walks over the toys; No words	Watches the toys with interest, gives them to the mother, engages mother to play, climbs onto the mother in situations of fear, brings to the mother the doll and spoon with the plate, feeds the mother and the doll;
ADOS-2 module 1 3-4 years	Jumps on the coloured circles, lists colours, counts the bears in a cause-and-effect toy, walks around the room in a circle, names animals in a book, counts building blocks, speaks a few words;	Takes out pots, puts pieces of wool on them, distributes cutlery on plates, gives out to adults, puts in front of the doll, pretends to be eating, inspects whether all the adults are participating in the play, looks at all toys, hand cause-and-effect toys to the caregiver, engages the caregiver and diagnostic technician in the play. No verbal speech
ADOS-2 module 1 4-4, 8 years	Lies on the floor and cries most of the time, most interested in toys that play or make sounds, walks on the toys, short-term interest in each toy, puts the toys in the mouth, short-term play with cause-and-effect toys; No speech	Watches all items with interest, shows to mum from afar, puts building blocks on the truck, engages mother and diagnostic technician in the play, repairs the car, pretends to be making a call on the phone Asks questions about the toys that it shows to the mother
ADOS-2 module 2 5-7 years	Interested mainly in sound-based cause-and-effect toys, puts the phone in the mouth, arranges the vehicles in a row and spins the wheels on the car.	Watches the toys with interest, plays with the car, loads building blocks onto the car, transports them and uses them to build a tower, comments on what it's doing, repairs the car, engages the diagnostic technician to play along, asks questions about the toys, is interested in everything.

Source: own research.

³⁰ Mentioned earlier.

of zero to three, where zero indicates patterns of a specific activity. Evaluated is the flexible and creative use of toys, ideas to use them symbolically, topical play (e. g. birthday) and spontaneity³¹. A comparison of play activities in both groups studied by the ADOS-2 in the validation project is presented in table 2. The observation of event samples using the standard technique was also natural, confidential. Table 2 lists the studies of five children with a diagnosis of autism, referred to as ASD, and five children from the control group, referred to as non-ASD.

The information contained in the table includes the records from the observation sheets for children during the task that is present in all three of the presented modules. This attempt assumes the free play of a child, and in the first two modules is conducted in the beginning of the study, and in module two – halfway throughout the activities performed by the child. As the samples show, table 1 and 2 stresses differences in play between a typically-developing child and an ASD child. Visible are also certain characteristic traits of play in ASD, which are comparable across both studies. In this scarce sample, one can clearly see the divergences in the group of children with ASD.

Summary

One could devote a lot of space to play in children with ASD, because this is a broad and theoretically as well as practically promising area of research. Comparing it to play in their peers, beside the described atypicality, one may conclude on a fundamental aspect: play is a social act. Children play with other children and derive pleasure from this as well as learn to explore the world. Their play changes and evolves with age and with the acquisition of new skills.

A child with ASD plays most frequently in an atypical manner, does not interact with its peers, has no direct capability to gain the

³¹ Ibidem.

skills that are shaped during play in typical development. Hence, how can it function in a world of children if it has no plane of understanding with them? If play plays such an important role for children, and in case of ASD if it exhibits such a significant deficit of key competences, would it not be worthwhile to devote more time in the process of therapy to develop it? I stress again – this concerns play as an autotelic activity, not an instrumental one, hence frequently even pseudo-play.

Analysing the process of therapeutic influences aimed at the child during early intervention, both therapists, specialists, educators, teachers as well as parents pay much attention to therapy. They frequently focus on therapy as on structured educational influences, and ascribe great – perhaps excess? – importance to the development of such specific skills as, for instance, the recognition of shapes, letters, colours, numbers, etc. A little child with ASD fits together identical images, recognises differences, emotions, develops its graphomotor skills, learns to read, count, be good... this is supposed to replace play. Does it not expand the deficit in spontaneity? These questions naturally require further, broader research, but the collected observations substantiate this distress.

Play is therapeutic in nature for autistic children, hence, it is eagerly used in therapy the ability to play, however, recedes to the background, as play will continue to be associated with therapy. As a result, an ASD child masters much educational content that it might never use in life. Similarly later, when it goes to school, it turns out that it cannot interact with a peer because children at this age still play: they chase each other, play tag, hide-and-seek, nudge peers – sometimes joking, sometimes they argue, but in a moment they again exchange the cards they have, boast of new Lego figures or stickers with characters from a popular film. These activities are based on spontaneous social exchange. At the same time, a child with autism is frustrated at a break, because it is unable to achieve a presence within its group of peers. It does not know how to interpret the behaviour of others and what to do in its free time, because from its earliest age it was “supported by adults”,

who accompany it at every step, with ready activity algorithms. Out of helplessness and in tension, hence, it jumps in a corner or runs around without purpose, flapping its arms.

Analysing the gains brought about by “true”, spontaneous play in children, perhaps they should also be introduced into therapeutic schemes for little children diagnosed with autism spectrum disorders, also for the purpose of establishment of specific play skills. *“Children learn to play, and this is what learning should look like within the framework of early intervention programmes”*³². It needs to be remembered, however, that in autism the area of social competences develops wrongly. Hence, object literature stresses the role of influences in concert with the child – even if this concerns the organisation of the space of activity... on the floor. Therapeutic experience shows that it is not always easy to “bring” the parent to floor level, which is fantastically reflected in the intent of the already-mentioned Floor Time method. The floor, but also the garden, a lawn, can be a symbolic space of opening of the environment of/ for play³³. J. Ball stresses that *“(...) what a child experiences, and what is supposed to teach, should focus around play. (...) The environment of play should be the first and most important environment of the child”*³⁴.

During the process of therapy of a child with autism, the therapeutic session should be conducted in such a way so as to reduce the level of fear and maintain a high level of motivation of the child. Only then it may learn, fully using this process. Therapists should ensure that *“therapy is as nice and natural as possible. (...) It should be fun and friendly, and at the same time it should let the child learn”*³⁵.

There are many areas of deficits in autism. In each child, they will take on different forms and different levels of intensity of prop-

³² J. Ball (2016), *Autyzm a wczesna interwencja. Rzeczowe pytania, życiowe odpowiedzi*, Gdańsk, Wydawnictwo Harmonia Universalis.

³³ M. Charbicka (2017), *Integracja sensoryczna przez cały rok*, Difin, Warszawa.

³⁴ Ibidem.

³⁵ J. Knapp, C. Turnbull (2017), *Kompletny program terapii SAZ dla osób z zaburzeniami ze spektrum autyzmu w wieku rozwojowym od 1 roku do 4 lat. Podręcznik terapii...*, Gdańsk, Wydawnictwo Harmonia Universalis.

erties. In light of contemporary research on the key issue of social skills and the theory of mind of children with autism, the developmental significance of play seems a very plausible hypothesis³⁶, even though it still requires further research. However, the issue should be considered, at what stage should spontaneous play be introduced into the therapeutic process. I believe that it is worthwhile to convince primarily the parents to try out this idea, because it is frequently they that have it difficult to understand that a small child learns its life through play, no just sitting at a table. The need to shape specific play skills frequently applies to the parent as well, who, burdened by the role of co-therapist, changes its modes of behaviour with respect to the child – not even realising it. Parents included in work with an autistic child in just such a role are burdened by responsibility for measurable development effects, in light of which they are frequently unable to develop or lose the ability to spontaneously play with children. Perhaps they should be helped along to find it again...

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³⁶ K.H. Armstrong et al., *Evidence-Based Interventions...*, as quoted; Begeer S., Gevers C., Clifford P. and oth., (2011), *Theory of Mind Training in Children with Autism: A Randomized Controlled Trial*, Joournal of Autism Developmental Disorders, 2011 Aug; 41(8).

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The significance of stress in parents of a child with Autism Spectrum Disorders

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The literature review focuses on the importance of stress in parents of a child with autism spectrum disorders, which significantly affects family life. The main cause of the burden are accompanying difficulties that are the part of disorder. This applies to specific reactions such as fits of anger, self-harm, psychomotor agitation, eating disorders, sleep disorders and other troubles which require almost 24-hour care. This review assesses several research studies that deal with the issue and which can be examples of good practice.

KEY WORDS: stress, family, Autism Spectrum Disorders, child

Introduction

Pervasive development disorders (including ASD, Autism Spectrum Disorders) belong to the most significant mental development disorders in children. They fuse in themselves many specific symptoms (problems with social interactions, communication, stereotypical and repetitive behaviour) as well as non-specific ones that for the most part influence the general functioning of the family. The

term 'pervasive' expresses the fact that they permeate all aspects of life, and that hence the development of a child is deeply disturbed in many respects. The concept of autism spectrum disorders is more precise, as the original manifestation is rather (spectral) diversity than the intertwining of many areas (ever-present)¹.

The new version of the DSM, DSM-5, made the identification of disability more effective through the removal of speech development delays from the area of symptoms, leaving two areas – social communication disturbances and stereotypical, rigid behaviour². This is confirmed by the study of Tsai³, according to which 9–54% of cases diagnosed according to DSM-5 does not fulfil the diagnostic criteria for autism spectrum disorders. The diagnosis of disorders could in particular be made more precise by the level of gravity and further details such as the presence or lack of mental disability, speech impairments or a genetic illness.

Persons with significant signs of autism require almost round-the-clock care, as significant deficits in the individual aspects of family life, in particular the child itself, are very limiting (APA)⁴. Almost 70% of persons with autism develop another mental disease that in practice goes undiagnosed and which weakens their psycho-social activity⁵.

According to Janzen⁶, parents are frequently able to interpret the behaviour of their children. They are able to guess the signals indicating an elevated level of stress and the possibility of intensification of unwanted behaviour. In general, we say that when stress

¹ K. Thorová, *Poruchy autistického spektra*, Praha, Portál, 2006

² M. Hrdlička, V. Komárek eds., *Dětský autismus*, Praha, Portál, 2004.

³ Tsai L.Y., Impact of DSM-5 on epidemiology of Autistic spectrum disorder. In *Research of Autism spectrum disorders*, 2014.

⁴ American Psychiatric Association (APA). Diagnostic and statistical manual of mental disorders – 5th edition. Arlington: VA, American Psychiatric Publishing, 2013.

⁵ NICE. Clinical guideline 128. Autism diagnosis in children and young people. Recognition, referral and diagnosis of children and young people on the autism spectrum, 2011.

⁶ J.E. Janzen, *Autism, facts and strategies for parents*, Texas, Therapy skill builders, 1999.

increases, intensity increases as well, causing a chain reaction in behaviour. This could shine through in the following:

- 1) physical symptoms (frustration, disquiet, tiredness, changes in breathing),
- 2) repetitive verbal or motor behaviour (repetition of questions related to time or events, spinning fingers, rocking),
- 3) disorganised behaviour,
- 4) symptoms of apathy, the loss of motivation, covertness, closing eyes, banging the table with the head,
- 5) signs of protest (fleeing, destroying objects),
- 6) emotional outbreaks (laughter somebody is injured, shouts),
- 7) self-harm (hitting oneself on the head, hitting oneself with a fist),
- 8) aggression (pinching, scratching, punching, kicking).

The Autism Society with its seat in the state of Maryland (United States) indicates that stress in families of children with autism spectrum disorders is a daily routine (Autism Society). This applies to normal behaviour such as shopping, bathing, preparing food, spending free time, the course of which remain on a completely different level than in the case of families of children without these disturbances⁷. According to the University of Wisconsin, the level of stress in parents of children with autism is comparable to stress of war veterans⁸.

⁷J. Bimbrahw, J. Boger, A. Mihailidis, *Investigating the efficacy of a computerized prompting device to assist children with autism spectrum disorder with activities of daily living*. In *Assistive technology*, 2012; Hong E., Ganz J., Ninci J., Neely L., Gilliland W., Boles M., *An evaluation of the quality of research on evidence-based practices for daily living skills for individuals with ASD*. In *Journal of autism and developmental disorders*, 2015. Labosh K., *Stress: Take a load off*. In *Autism advocate*, 2005; Weaver L.L., *Effectiveness of work, activities of daily living, education and sleep interventions for people with autism spectrum disorder: A systematic review*. In *American Journal of Occupational Therapy*, 2015.

⁸M.M. Seltzer, J.S. Greenberg, J. Hong, L.E. Smith, D.M. Almeida, C. Coe, R.S. Stawski, *Maternal cortisol levels and behavior problems in adolescents and adults with ASD*, In *Journal of Autism and Developmental Disorders*, 2010.

Benson⁹ indicates that parental depression is related to the gravity of autism spectrum disorders in children. He speaks of proliferation of stress, which was discovered in 68 parents of children with autism spectrum disorders. Proliferation of stress is the tendency of stressors to give rise to further stressors in other areas of life. According to the regression analysis, depression in parents may be related to increased symptoms in their children, as well as the proliferation of stress, which influenced the emergence of stronger symptoms in children and of depression in parents. Benson¹⁰ also notes that informal social support reduces the level of stress in parents, but that its proliferation is directly related to the gravity of the condition of the child, significantly influencing the development of the mental disorder in the parent.

As indicated above, care for a child with autism spectrum disorders brings with itself great burdens that impact negatively on the physical and mental health of the family as well as other people caring for the child¹¹. In this context, much research focuses rather on the quality of life of the parents¹² than on the stress itself.

The burdens that the parents of a child with autism spectrum disorders must cope with are frequently not aligned with the stud-

⁹P.R. Benson, *The impact of child symptom severity on depressed mood among parents of children with ASD: The mediating role of stress proliferation*. In *Journal of autism and developmental disorders*, 2006.

¹⁰Ibidem.

¹¹J.B. Gorlin, C. McAlpine, A. Garwick, E. Wieling, *Severe childhood autism: the family lived experience*. In *Journal of pediatric nursing*, 2016.

¹²M. Hrabovecká, *Kvalita života rodičov detí s autizmom*. In *E-Psychologie*, 2015; R.L. McStay, D. Trembath, CH. Dissanayake, *Maternal stress and family quality of life in response to raising a child with autism: from preschool to adolescence*. In *Research in developmental disabilities*, 2014; D. Mugno, L. Ruta, V.G. D'arrigo, L. Mazzone, *Impairment of quality of life in parents of children and adolescents with pervasive developmental disorder*. In *Health and Quality of Life Outcomes*, 2007; L.C. Lee, R.A. Harrington, B.B. Louie, C.J. Newschaffer, *Children with autism: Quality of life and parental concerns*. In *Journal of autism and developmental disorders*, 2008.

ies that we find in the context of handling them, or with specific possibilities of coping with them¹³.

Wang¹⁴ concentrated his research on children from 368 families that show autism spectrum disorders from the People's Republic of China and compared them to families of children with other developmental disorders. Both groups experienced a high level of burdens, but the most commonly applied strategy in raising children with autism spectrum disorders was exactly planning. In the sample of Chinese families, however, these were dominated by fears for the future of their children due to factors typical for the People's Republic of China – the lack of qualified specialists working with children with autism spectrum disorders, no possibility of educating these children, the financial burden for rehabilitation, education and in the end the fear of the parents as to what will happen to their children after they die.

Bilgin and Kucuk¹⁵ have conducted a survey based on a semi-structured interview with 43 mothers from Turkey, focusing on their experiences, their lives, their support options, the strategies of managing burdens and educational capabilities. In the Turkish family system, solidarity and mutual support are common values, but the difficulty of some stressful situations in the life of a child with

¹³ M.J. Baker-Ericzen, L. Brookman-Frazee, A. Stahmer, Stress levels and adaptability in parents of toddlers with and without autism spectrum disorders. In *Research and Practice for Persons with Severe Disabilities*, 2005; B.A. Boyd, Examining the relationship between stress and lack of social support in mothers of children with autism. In *Focus on Autism and Other Developmental Disabilities*, 2002; N.O. Davis, A.S. Carter, Parenting stress in mothers and fathers of toddlers with autism spectrum disorders: Associations with child characteristics. In *Journal on Autism and Developmental Disorders*, 2008; C.D. Hoffman, D.P. Sweeney, D. Hodge, M.C. Lopez-Wagner, L. Looney, Parenting stress and closeness: Mothers of typically developing children and mothers of children with autism. In *Focus on Autism and Other Developmental Disabilities*, 2009.

¹⁴ P. Wang, C.A. Michaels, M.S. Day, Stresses and coping strategies of Chinese families with children with autism and other developmental disabilities. In *Journal of Autism and Developmental Disorders*, 2011.

¹⁵ H. Bilgin, L. Kucuk, Raising an autistic child: Perspectives from Turkish mothers. In *Journal of child and psychiatric nursing*, 2010.

autism spectrum disorders may also influence the cultural attitudes of religious origin. Perceiving autism from the point of view of multiculturalism as a significant factor in the life of a family is discussed within a broader spectrum by Dyches¹⁶.

Janzen¹⁷ indicates that one of the most fundamental rules of care for a child with autism spectrum disorders is understanding its behaviour. It is exactly the difficult-to-handle behaviour of the child that causes additional reactions that are part of the disorder and cause the most stress in the parents. According to Janzen¹⁸, the most important strategies of coping with such behaviour are: preventive care and preventing the worsening of behaviour. The achievement of these objectives is ensured by parents, teachers, assistants, mentors, siblings or persons acting as facilitators. In order to better understand the level of burden in course of care for a child with autism spectrum disorders, Janzen¹⁹ had determined four levels of stress, in which he described primarily the objective and task of the facilitator himself:

1. *When the stress increases and unwanted behaviour intensifies.*

Objective of the facilitator: reduce the stress and avoid a crisis.

Task of the facilitator: identify the behaviour indicating such a stress reaction (disquiet, rocking, redness of the face, change of breathing rhythm or behaviour); be able to notice such a reaction/information; react to the problem and suggest a solution; provide assistance in solving the problem, avoid the crisis.

*Good practice*²⁰: important is getting to know the motivational factors of a child (toy, food, activity, person) in order to prevent the tension from escalating, and to have them handy.

¹⁶ T.T. Dyches, L. Wolder, R.R. Sudweeks, F.E. Obiakor, B. Algozzine, Multicultural issues in autism. In *Journal of autism and developmental disorders*, 2004.

¹⁷ J.E. Janzen, *Autism, facts and strategies for parents*. Texas: Therapy skill builders, 1999.

¹⁸ Ibidem.

¹⁹ Ibidem.

²⁰ Under the heading of Good practice, the author of the article presents her experiences from practice that have proven themselves during work with a child with

2. *When the child is hypersensitive or out of control; crisis level.*

Objective of the facilitator: protect people

Task of the facilitator: if there is time for this, take the child to a location where it will have the possibility of calming down, if there is no time for this, remove the persons to another place to protect them from potential danger; quickly solve the problem and let go of the load; remain calm and redirect the interest of the child elsewhere; give way and leave more space for the child; stop talking; do not forget that the child is in a state of panic and that in that moment it is not able to think; protect people; try to avoid damage and injuries; a cautious approach or having permanent protection handy is necessary (in this case, it is not an intervention programme or time for learning. In a state of crisis, the child neither able to think nor learn.).

Good practice: the effort leading to a reduction of the potential threat to the child (if it has a tendency to self-destruct) from other children, removing it to a different room, directly burdening the child with your own body and strength, or removing everything in the direct neighbourhood as far away from it as possible; reflect its behaviour (as an intention of communication, making contact).

3. *Calming and minimising the escalation of behaviour.*

Objective of the facilitator: aid the child in returning to its prior activities.

Task of the facilitator: remain close, calm and quiet, one should not make any demands of the child; if the child begins to calm down, support them with the words: "This is good, remain calm, everything will be all right..."; if the child is completely calm, prepare for it some kind of further task: „When the bell rings, it's time for..."; it's good to support the next task with some visual sheet, an object, a table with daily activities.

Good practice: after the passage of increased tension, fluidly move on into another activity and continue the daily routine, the

autism spectrum disorders. However, always consider the current condition of the child and the intensity of disturbances.

transition to a different activity [should be] supported by an information sheet, motivate the child to change its activity, let the child know your emotions immediately after its behavioural attach (consider – depending on the progress of the condition).

4. *Calm and stable behaviour, a condition of balance.*

Objective of the facilitator: maintain the level of tension of the child at such a level that it is alert, but not at a level that would cause it to lose control; teach it new skills when it is in a state of calm and when it is able to learn.

Task of the facilitator: foresee and prevent possible problems in such a way so that the child could be prepared for new and unknown situations; continuously observe its level of tension; if an unforeseen problem emerges, attempt to solve it as quickly as possible, reduce the tension and in this manner prevent a crisis; teach the child new skills spanning the prevention of recurring problems, e. g. plea for help, teach it relaxation techniques so that it is able to express its need for a break, continuously evaluate and improve the organisation of space, materials, the daily routine, individual activities, the daily life style, and connect necessary expectations with the needs of the child, be able to organise an environment suitable for learning.

Good practice: getting to know the components of a child's motivation as a mode for progress; the significance of the relation with the child; know its phobias, joys and functioning in ordinary life (communication with parents).

New research²¹ shows that 99% of adults with autism and their caretakers indicated that stress is important for them, whereby 93% of them add that it is very difficult or even impossible to find effective help in controlling stress. It was furthermore concluded that:

- 98% of parents (caretakers) state that it is difficult or impossible to find efficient support for their children,
- 81% adults with autism state that stress has significant or even very significant influence on the self-esteem confidence,

²¹ Research Autism. *Beating stress in autism*, [online]. London 2017.

- 74% adults with autism state that stress has significant or even very significant influence on sleep,
- 95% parents (caretakers) state that stress has significant or even very significant influence on the upbringing or work of their children,
- 88% parents (caretakers) state that stress has significant or even very significant influence on the behaviour of their children,
- 86% adults with autism state that stress has significant or even very significant influence on their mental health,
- 84% parents (caretakers) state that stress has significant or even very significant influence on the relations of their children,
- 63% adults with autism spectrum disorders state that their current strategies of managing stress are ineffective.

Additionally, tension and stress are frequently considered to be synonyms. Stress defines borderline forms of tension states, in which the threat to life or individual integrity requires an exceptional activation of the system of self-control. Lazarus and Folkman²² describe stress as a *“specific relationship between a person and the environment, which in view of persons makes excess demands exceeding their capabilities and threatening their health”*. Along with the inability to cope with this relationship or adaptation, there emerges the risk of weakening of physical and mental health, which significantly intervenes in changes to the structure and dynamics of work that causes stress situations²³. According to Strmeň, Raiskup²⁴, tension is a factor influencing the body that stresses demands that interfere with the balance in the body, stimulating work aimed at its restoration. The mentioned authors stress higher requirements related to

²² R.S. Lazarus, S. Folkman, *Stress, appraisal and coping*. New York, Springer, 1984, p. 19.

²³ M. Bratská, *Zisky a straty v záťažových situáciách alebo príprava na život*. Bratislava: Práca, 2006, p. 305.

²⁴ L. Strmeň, J.Ch. Raiskup, *Výkladový slovník odborných výrazov používaných v psychológii*. Bratislava, IRIS, 1998.

sensory, mental, independent processes and capacities of man. Stress and tension emerge when the measure of burdening factors is higher than the measure of a person to handle the situation²⁵.

The evaluation of burdens in the care for a child with autism spectrum disorders never reflects the experiences of parents, who as a result of these daily disturbances find themselves in difficult situations. On the basis of numerous studies mentioned above, it may be concluded that the diagnosis significantly influences the quality of life of the family. The case is not just the internal family environment (siblings, partner relations and their intimacy, spending free time, etc.), but also support and understanding from the external environment (closest family, society), which in the 21st century exhibits stereotypical reactions and marks these children as misbehaving and badly educated.

The burden of the family encompasses a certain stigma, difficulties in managing the child's behaviour, challenges related to care, social isolation and mentioned altered dynamics within the family. An enormous volume of factors, with which the family of a child with autism spectrum disorders copes leads to everyday battles, which intersect at a single point – the need of support.

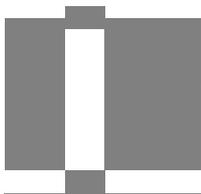
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²⁵ R. Šerfelová, *Závaž opatrovateľa počas starostlivosti o zomierajúceho*. Martin, JLF UK, 2012.

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Problems of the first stage of psychosocial development according to E. Erikson in a blind child

ABSTRACT: Joanna Gładyszewska-Cylulko, *Problems of the first stage of psychosocial development according to E. Erikson in a blind child*, Interdisciplinary Contexts of Special Pedagogy, No. 22, Poznań 2018. Pp. 133–146. Adam Mickiewicz University Press. ISSN 2300-391X. DOI: <https://doi.org/10.14746/ikps.2018.22.08>

Erik H. Erikson, the author of the theory of psychosocial development, claimed that every human being experiences eight developmental crises from birth to death. Every time, at each stage there are two poles, two opposite values. To overcome these crises it is necessary to find an optimal balance between them. The way of resolving the crises will affect the integration, as well as the relations with others and oneself. In the article, the author would like to concentrate on the first developmental stage, considered by many researchers to be the most important one. Its two poles are basic trust and basic mistrust, while the basic virtue is hope. Unfortunately, due to the lack of appropriate experiences, improper attitude of other people and various other factors, blind children already at this stage often fail to properly resolve the developmental crisis. In the further part of the article the author will discuss the causes of the problem and will suggest the possibilities of preventing the disturbances at the first stage of development.

KEY WORDS: developmental crisis, basic trust, blind children

Introduction

Erik H. Erikson, the author of the theory of psychosocial development, claimed that every human being experiences eight developmental crises during their life from birth to death. Every time, at each stage, there are two poles, two opposite values. To overcome the crises it is necessary to find an optimal balance between them. The way of resolving the crises will affect the integration, as well as the relations with others and oneself. In the article, the author would like to concentrate on the first developmental stage, considered by many researchers to be the most important one. Its two poles are basic trust and basic mistrust, while the basic virtue is hope. Unfortunately, due to the lack of appropriate experiences, improper attitude of other people or various other factors, blind children already at this stage often fail to properly resolve the developmental crisis. In the further part of the article the author will discuss the causes of the problem and will suggest the possibilities of preventing the disturbances at the first stage of development.

The importance of psychosocial aspects of development

Human beings are influenced by two environments, a social and biological one. The course of their development is influenced by both the maturation process (which initiates readiness to undertake a task) and the process of socialization and education (which stimulates people through requirements adapted for their age, as well as tasks and standards for their execution). If these processes continue in the appropriate way, human development proceeds correctly.¹ Although at the beginning of his path human beings are primarily dependent on the environment, with age, using the competences

¹ A. Brzezińska, *Jak przebiega rozwój człowieka?*, [in:] *Psychologiczne portrety dziecka*, ed. A. Brzezińska, Wydawnictwo GWP, Gdańsk 2005, pp. 26–28.

gained earlier, they become able to influence it more effectively, modifying it according to their own needs.²

The importance of psychosocial aspects of development was noticed by E.H. Erikson. Moreover, he showed that not only the past, but also the way of constructing the future can affect the personality of a human being.³ The first significant changes in the field of identity formation happen as early as in the first months of life. Hence, this time is the basis for the formation of basic trust in relation to oneself and the world built on trust in the world and a feeling of certainty in relation to oneself. It concerns "a specific, pre-reflective "setting" in the environment, symbiosis with possible threats that do not paralyse (...) is an irreducible to self-knowledge existential condition that allows expecting and anticipating a minimum comfort of interaction with the closest environment".⁴ E.H. Erikson writes: "Developing children have to draw an animating sense of reality from the consciousness that their individual way of experience management (synthesis of their ego) is a successful variant of group identity and is consistent with its spatiotemporal and life plan"⁵. As he continues, children who, for example, have learnt to walk develop this skill with enthusiasm, not only because it gives them pleasure, but they probably become aware of the new status of "the one who is walking" or even "the one who will walk far away". Thanks to this compliance with social identification, they gain self-esteem and the conviction that their "ego effectively approaches a tangible collective future, that it develops into a clearly defined ego placed within the framework of social reality"⁶. This conviction is called by Erikson "the ego identity".

² A. Brzezińska, *Jak przebiega rozwój człowieka?*, [in:] *Psychologiczne portrety dziecka*, ed. A. Brzezińska, Wydawnictwo GWP, Gdańsk 2005, pp. 21–24.

³ L.A. Pervin, *Psychologia osobowości*, translated by M. Orski, GWP, Gdańsk 2005, pp. 178–180.

⁴ L. Witkowski, *Rozwój i tożsamość w cyklu życia. Studium koncepcji Erika H. Eriksona*, Wyższa Szkoła Edukacji Zdrowotnej w Łodzi, Łódź 2009, p. 113.

⁵ E.H. Erikson, *Tożsamość a cykl życia*, translated by M. Żywicki, Wydawnictwo Zysk i S-ka, Poznań 2004, p. 19.

⁶ *Ibidem*, pp. 20.

Newborns, according to Erikson, “experience and love with their mouth”⁷, while the mother with her breast. At the beginning, they accept mother food, fill with it, but quickly pass to the incorporation stage, in which they are able to “accept” or receive what appears in their field of vision, hearing, touch. Their senses can help him to “track” an object and follow it, they learn to take and keep objects. At this time, the first crisis takes place, caused by firstly “an increasing drive to incorporation, closer and more active observation”⁸, secondly, an increase in awareness of their own separateness, and thirdly, less focus of the mother on the child and her “return” to marital relationship, greater involvement in other home duties.⁹ During this period, it happens that the mother stops breastfeeding, or bitten by the child while giving food takes the breast away from them. All this can cause uncertainty, anxiety or even childhood depression in the child. And, in order to prevent such unfavourable phenomena, basic trust is formed.¹⁰

A positive solution to the crisis at this age results in the virtue, which is hope. It is the belief that the world is orderly and meaningful and favourable to people. It favours coping in difficult situations, when the cognitive and emotional order is disturbed, it is also helpful in predicting the course of events, generates a positive attitude to the situation and stimulates a human being to acquire new experiences. J. Trzebiński and M. Zięba propose to define it using the term of “basic hope”.¹¹ At the stage of infancy, the child’s conviction of the order and sense of the world is based on the regularity of certain events, while the sense of favour of the world is created on the basis of experience that their needs are satisfied and understood. Thanks to this hope, a human being has the impression that the world is full of good events and does not have any problems to

⁷ Ibidem, p. 53.

⁸ Ibidem, p. 56.

⁹ Ibidem, p. 56.

¹⁰ Ibidem, p. 53.

¹¹ J. Trzebiński, M. Zięba, *Nadzieja, strata i rozwój*, „Psychologia Jakości Życia” 2003, vol. 2, no. 1, pp. 5-6.

face them. He also predicts that in case of problems he will encounter other people's help. This hope is justified. It is built at the same time from trust and mistrust, with mistrust concerning more individual events, and trust manifesting itself in the belief that even when something unpleasant happens, everything can change for the better. Such an approach provides a human being with strength to fight, and hope becomes a component of the cognitive schema of the world. According to Erikson, hope favours coping both when a human being experiences personal failures in the context of an existing order and when this order is disturbed. The first situation is clear, a human being who hopes, takes action to get out of the impasse, to pay back. The second situation is more complex. It may include, for example, the destruction of the current order (e.g. through accident, impairment of physical function), new life situations may arise, and finally, the possibility of entering into a new situation (not as a necessity, but an alternative) may appear.¹² A blind person can be in the first situation if they lose their way while moving in a new place. This is their personal failure, but their order is not disturbed. When in their cognitive schema of the world hope occupies a prominent position, they take action to deal with failures (ask someone for directions, look for a landmark, etc.). In the second situation, for example, they may experience a worsening of their eyesight (or even loss of a sense of light), they may find themselves in a new situation of becoming a parent and taking on a new role with all its consequences, they may also, for example, get a job offer and decide whether accept it or not. In each of these situations, the existing order is disturbed and the way of managing the situation depends on the hope built on the feeling of meaningfulness and friendliness of the world.

According to J. Koziellecki, hope consists of several components, but its main cognitive component is the conviction with a certain probability that in the future one will achieve the desired goal or the desired good. Another component is the emotional component,

¹² Ibidem, pp. 8-10.

because this belief is filled with emotions, feelings that stimulate a human being to achieve the desired goal. There is also a temporal component, because hope refers primarily to the future, although it is impossible to omit past experiences, nor to mention the importance of the present. Koziellecki also mentions an affiliative component, as the social environment can also help or weaken hope, as well as the causative component, since hope undoubtedly has a positive effect on human activity and, consequently, on the quality of life.¹³ The stimulation of the blind children activity, their motivation to act favours their self-rehabilitation. Although we cannot talk about it in relation to early childhood, its foundations are formed precisely when the identity, trust in oneself and in the world are formed.¹⁴ Koziellecki draws attention to the importance of the physical intimacy of mother and child for the development of hope, and also emphasizes the need of the child to recognize the environment, as well as highlights the role of modelling. It also draws attention to the correlation between hope and an authority-based style.¹⁵

Based on the concept of psychosocial crises of Erikson, B.M. Newman and Ph. M. Newman developed the main areas of changes. As the developmental tasks of the infancy phase, they listed social attachment, sensorimotor intelligence and primitive causality, maturation of sensory and motor functions, constancy of the object and emotional development. Threats to development at this age are genetic factors, psychosocial influences and the role of parents.¹⁶ In the further part of the article the author will try to analyse the situation of blind babies in this aspect.

¹³ J. Koziellecki, *Psychologia nadziei*, Wydawnictwo Akademickie Żak, Warszawa 2006, pp. 42-46.

¹⁴ J. Konarska, *Zdolność do autorehabilitacji jako konsekwencja wcześniejszych zabiegów wychowawczo-rehabilitacyjnych*, "Annales Universitatis Mariae Curie-Skłodowska" 2014, Vol. 27, No. 1, pp. 38-39.

¹⁵ J. Koziellecki, *Psychologia nadziei*, Wydawnictwo Akademickie Żak, Warszawa 2006, pp. 138-143.

¹⁶ A. Brzezińska, *Wczesne dzieciństwo – pierwszy rok życia: szanse i zagrożenia rozwoju*, „Remedium” 2003, no. 4(122), pp. 4-5.

Blindness and emotional and social development

Literature is dominated by the opinion that the lack of eyesight adversely affects various spheres of child development, not only motor (it is difficult, among others, because the eyesight provides important feedback to the vestibular and proprioceptive systems)¹⁷, or cognitive, but also emotional and social development. This is not conditioned by biological abnormalities, but rather by the improper influence of the social environment, because “a blind child comes into the world with the same developmental possibilities as a sighted person and through the appropriate orientation of activity by their social environment, they can fully shape their personality as a subject”.¹⁸

Characteristic disturbances in emotional and social development of blind children include, among others, the domination of negative emotions over positive ones, acoustic and spatio-motor fears, fear of independent movement¹⁹, disturbances of sleep and wakefulness, which can result, among others, in mood disorders.²⁰ As I already mentioned, the basic task of the infancy period is the acquisition of trust in oneself and in the world. The result of this process depends on the quality of the relationship between the child and the closest social environment, especially the mother. This quality of contact is affected by a number of factors such as the maturity of the mother and father, their willingness to become parents, but also family and cultural support at the early stage of motherhood.²¹ In early child-

¹⁷ H.F. Prehtl et al., *Blindness and Early Motor Development*, “Developmental Medicine & Child Neurology” 2001, no. 43, pp. 198–201.

¹⁸ K. Czerwińska, *Niepełnosprawność wzrokowa a samowychowanie – wybrane aspekty psychospołeczne*, “Annales Universitatis Mariae Curie-Skłodowska”, 2014, vol. XXVII, p. 78.

¹⁹ T. Majewski, *Tyflopsychologia rozwojowa (Psychologia dzieci niewidomych i słabowidzących)*, „Zeszyty Tyflogiczne” 2002, no. 20, pp. 240–242.

²⁰ M. Skalski, *Melatonina w zaburzeniach snu i zaburzeniach rytmu okołodobowego*, „Farmakoterapia w psychiatrii i neurologii” 1998, no. 1, pp. 103–111.

²¹ H.S. Shlesinger, *A Developmental Model Applied to Problems of Deafness*, “Journal of Deaf Studies and Deaf Education” 2000, no. 5(4), p. 350.

hood, the child and parents mainly get to know each other, learn how to recognize each other's needs and the different ways of fulfilling them. The successful execution of these activities will influence, among others, the sense of influence on the environment, the sense of achievement etc.²² It would seem that blindness does not affect the disturbances of contact between mother and child. Unfortunately, this is a mistaken impression. It cannot be forgotten that often blind children are subjected to medical procedures or surgeries shortly after their birth (e.g. due to congenital cataract). Separation from the mother, experiencing pain, can cause a strong stress that has a negative impact on their development. It is impossible not to mention that parents also experience at the same time a strong stress caused by the existence of a child's disability. Although most often in the later months or years they accept the fact that their child will not see, in the initial period they may develop a sense of injustice and helplessness, which contributes to inadequate satisfaction of the child's mental needs in the first period of their life. Parenting stress is treated as a predictor of the perception of mothers of visually impaired children,²³ it can influence the attitude to the child, and hinder satisfaction of their needs. The first diagnosis and the way of its communication is very important. Parents may then experience fear of the future²⁴, feeling of guilt or shame for more or less imagined misconduct from the past that might have affected the child's current condition²⁵, which may

²² A. Brzezińska, *Wczesne dzieciństwo – pierwszy rok życia: szanse i zagrożenia rozwoju*, „Remedium” 2003, no. 4 (122), pp. 4–5.

²³ A.H. Graungaard, L. Skov, *Why do we need a diagnosis? A qualitative study of parents' experiences, coping and needs, when the newborn child is severely disabled*, „Child Care Health and development” 2006, no. 33, pp. 296–307.

²⁴ J. Gładyszewska-Cylulko, *Relacja rodzic-specjalista w kontekście psychologicznych następstw błędów popełnianych podczas informowania rodziców o wykryciu zaburzeń rozwoju dziecka*, „Psychiatria i Psychologia Kliniczna” 2016, no. 16(4), pp. 256–261.

²⁵ J. Juvonen, M. Leskinen, *The function of onset and offset responsibility perceptions in fathers' and mothers' adjustment to their child's developmental disability*, „Journal of Social Behavior & Personality” 1994, no. 9(5), pp. 350–362.

make mutual contacts difficult. Referring to the concept of Erikson, a mother who is insecure in her role, full of conflicting feelings, focused on her own fear or sadness, has difficulty with "giving", which can disturb the child to experience the process of friendly otherness.

A serious limitation of learning opportunities through imitation also has a negative impact on the development of a blind child. In the modelling process, a small child focuses on their mother's behaviour, then memorizes it and tests in their own activity. In this way, they not only learn to reproduce useful behaviours, but also create a kind of base of such behaviours, which they can then modify in different ways in their own actions. J. Koziellecki writes that modelling (he does not mean the mechanical imitation of model action, but imitating behaviours with the inclusion of own innovations) teaches not only different behaviours, but also life in hope.²⁶

Lack of visual perception also negatively affects social interactions by hindering the acquisition of the ability to conduct a dialogue.²⁷ Threats to social and emotional development of blind infants are caused, among others, by difficulties in creating a mutual interactive communication system in the mother-child dyad. The infant has difficulty in receiving non-verbal information from their mother, they are deprived of the opportunity to perceive countless smiles addressed to them, but they cannot also transmit non-verbal feedback understandable to her on their own.²⁸ This does not mean that blind children do not gesticulate²⁹, but their gestures are not based on imitation. Although they use a wide range of facial expres-

²⁶ J. Koziellecki, *Psychologia nadziei*, Wydawnictwo Akademickie Żak, Warsaw 2006.

²⁷ H. Tröster, M. Brambring, *Early social-emotional development in blind infants*, "Child Care Health and development" 1992, no. 18(4), pp. 209-225.

²⁸ S.J. Rogers, C.B. Puchalski, *Social Characteristics of Visually Impaired Infants' Play*, "Topics in Early Childhood Special Education" 1984, no. 3(4), pp. 52-53.

²⁹ J. Iverson, S. Goldin-Meadow, *What's Communication Got to Do With It? Gesture in Children Blind From Birth*, "Developmental Psychology" 1997, no. 33(3), pp. 453-467.

sions, body movements and vocalizations, firstly they are specific to them, or they do not have to be properly read by adults, and secondly, in comparison with sighted infants, this range is limited.³⁰ When the mother is unable to read the signals sent by the child, she cannot give the right answer, and thus will not satisfy these needs, which are important to them at that moment. Referring to the concept of Erikson, a child who has learned to read and send non-verbal messages improves this ability also because they can probably become aware of the status of "the one that affects the environment". However, if this skill is lacking, this may give rise to a sense of lack of achievement.

In comparison with sighted children, the social smile also appears later. The first emotions of a child emerge after their birth and are dependent on satisfying their needs, they feel simple primary positive emotions such as, for example, satisfaction, as well as negative ones, above all, anger and fear. With time, under the influence of experience acquired during contacts with the environment, they develop secondary emotions, they react positively or negatively to the contact with certain objects, phenomena. While there are no significant differences between blind and sighted children as far as primary emotions are concerned, they can still be noticed in terms of secondary emotions. First smiles of the sighted child in response to the mother's smile appear as early as at the age of 2-3 months. The blind child does not notice this smile.³¹ It is problematic insofar as this smile is interpreted by the mother as a signal that the child is satisfied and that she caused such a state of satisfaction (or, meaning, she is a good mother). When the smile does not appear or appears rarely, the mother may begin to doubt her maternal competence. The difference between sighted and blind children as far as smiling is concerned is that blind children do not respond with a smile to other people's questions, but rather to their behaviour. It

³⁰ L. Dorn, *The mother/blind infant relationship: a research programme*, "The British Journal of Visual Impairment" 1993, no. 11-1, p. 14.

³¹ T. Majewski, *Tyflopsychologia rozwojowa (Psychologia dzieci niewidomych i słabowidzących)*, „Zeszyty Tyflogiczne” 2002, no. 20, pp. 240-242.

is worth noting that the smile of a blind infant appears irregularly in response to the mother's voice, but regularly, in response to tactile contact.³²

The study conducted by S.J. Rogers and C.B. Puchalski aimed to check to what extent an infant with visual impairment and their mother can improve mutual contacts while playing. Participants included children with visual disability aged from 4 to 25 months and their mothers. Based on the analysis, it has been found that visual disability seems to diminish the pleasure of playing and hinders them from transmitting positive feedback received from each other. The researchers were surprised that there was no difference between blind and visually impaired infants in this regard. Perhaps the visually impaired infants could not yet use their visual abilities. Importantly, infants were not only deprived of visual information but also of affective information from their mothers. Mothers, on the other hand, did not have a clear feedback on whether their actions are pleasant for children, or give them satisfaction. Help in achieving positive mutual interactions during play or feeding can help the development of children.³³

Summary

In conclusion, the author would like to try to answer the question of how to enable blind infants to overcome the crisis of the first stage described by E. H. Erikson. The author thinks that first of all it is necessary to be aware of the dangers that the blind child has to face already at this stage and concentrate activities around building a support system for the child and their family. This should be done starting from the appropriate way of providing the mother with information about the child's disability, considering her emotional

³² L. Dorn, *The mother/blind infant relationship: a research programme*, "The British Journal of Visual Impairment" 1993, no. 11-1, pp. 13-14.

³³ S.J. Rogers, C.B. Puchalski, *Social Characteristics of Visually Impaired Infants' Play*, "Topics in Early Childhood Special Education" 1984, no. 3 (4), pp. 53-55.

and perceptual condition, through psychological help directed to the family, covering the child with the program of early development support as early as possible, basic typhlopedagogical training for mothers and fathers, the possibility of being in a constant contact with a typhloeducator or tyflopsychologist. A constant care provided by one particular person from the first moments of life, as well as the correct interpretation of signals sent by the child is necessary in order to develop appropriate behaviour patterns, to create a sense of security conditioning all activity and to develop attachment.³⁴ The organization of the child's activity so that it can acquire new skills in the field of manipulation, locomotion, communication, and thus experience its own autonomy, independence, sense of achievement, sense of control, and above all, build at least the basic picture of the world in which they could act, or gain experience seems not less important. Though, unfortunately, it may happen that those children will not pass positively the first stage crisis according to Erikson and will not penetrate smoothly into more advanced stages.³⁵

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³⁴ M. Czub, *Wiek niemowlęcy. Jak rozpoznać potencjał dziecka?*, [in:] *Psychologiczne portrety dziecka*, ed. A. Brzezińska, Wydawnictwo GWP, Gdańsk 2005, p. 49.

³⁵ S.Z. Sacks, *The Social Development of Visually Impaired Children: A Theoretical Perspective*, [in:] *Development of Social Skills by Blind and Visually Impaired Students: Exploratory Studies and Strategies*, ed. S.Z. Sacks, L.S. Kekelis, L.J. Gaylord-Ross, AFB Press, New York 1997, p. 8.

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Typhlo music therapy interventions supporting the motor development of a child with visual disability

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The article presents the possibilities of using music therapy to facilitate the motor development of children with visual impairments. The cognitive functioning of blind children causes certain psychophysiological, emotional and social problems, including a substantial delay in the motor development in comparison to sighted peers. The integration of music and various forms of movement and the sonic and musical interaction between a music therapist and a child reduce a psychomotor delay and improve orientation and locomotion in small and large spaces.

The author, musician, teacher and music therapist, shares his observations and experiences gained during almost thirty years of work with children at the Maria Grzegorzewska Lower Silesian Special Educational Centre No. 13 for the Blind and the Visually Impaired in Wrocław.

KEY WORDS: visually impaired child, music therapy, rehabilitation, motor development, typhlo music therapy

Introduction

People with visual disability constitute a complex and diverse population in terms of eyesight deficiency¹. Nevertheless, two basic groups of children can be distinguished: the blind and visually impaired. The former acquire information, orientate themselves in the physical and social space, move, communicate, learn and rest in a non-visual manner using mainly touch and hearing, followed by the sense of smell and taste. On the other hand, under the same circumstances, visually impaired children primarily use the preserved visual abilities, and to a lesser extent the remaining senses. This way of cognitive functioning causes specific psychophysiological, emotional and social problems². These include the largely delayed motor development compared able-bodied peers³.

Various specialists claim that each child from the first moment of life shows great interest in music, and that musicality is innate⁴. For the child with visual disability, this type of art becomes even more important. Thanks to the sound nature, music is the closest, the most accessible and communicative type of art. The perception of music is direct, i.e. without the involvement of the sense of sight, touch, smell or taste. A blind or partially sighted child does not suffer any difficulties or limitations when listening, reproducing

¹ Z. Palak, *Uczniowie niewidomi słabowidzący w szkołach ogólnodostępnych*, Wydawnictwo UMCS, Lublin 2000, pp. 10–11.

² A.I. Miedziak, T. Perski, P.P. Andrews, L.A. Donoso, *Stargardt's macular dystrophy – a patient's perspective*, "Optometry" 2000, No. 71(3), pp. 165–176; G.M. Preisler, *A descriptive study of blind children in nurseries with sighted children*, „Child: care, health and development” 1993, No. 19(5), pp. 295–315; H. Tröster, M. Brambring, *Early motor development in blind infants*, "Journal of applied developmental psychology" 1993, No. 14(1), pp. 83–106.

³ O. Levtzion-Korach, A. Tennenbaum, R. Schnitzer, A. Ornoy, *Early motor development of blind children*, "Journal of paediatrics and child health" 2000, No. 36(3), pp. 226–229.

⁴ S.N. Malloch, *Mothers and infants and communicative musicality*, "Musicae scientiae" 1993, No. 1_suppl, pp. 29–57.

or creating music. Thus, the child can equally compete with able-bodied peers and sometimes achieve even better results in this field⁵.

The prevailing belief in the modern society is that 1) each blind has above-average musical abilities, absolute pitch, a special sense of rhythm and outstanding musical memory; 2) musical abilities compensate for "disability" and go hand in hand with "frailty"; 3) each child will be an outstanding musician and will make an artistic career in the future⁶. At the very beginning of work, this attitude pigeonholes the child by wrongly ascribing extraordinary musical skills. On the one hand, the child can feel pressure from a specialist, peer group or family, on the other hand, it can feel bitterness when unable to meet musical challenges. If such a false belief maintains, educational, rehabilitation and therapeutic interactions using the musical art will not produce anticipated results. In order to avoid such dangerous traps, we ought to remember about the compensatory role of the child's auditory analyser, better development in various acoustic situations and the fact that the sight defect may be accompanied by hearing damage, which largely determines not only the musical activity, but also the functioning of the child in other areas of life⁷.

⁵ M. Antović, A. Bennett, M. Turner, *Running in circles or moving along lines: Conceptualization of musical elements in sighted and blind children*, "Musicae scientiae" 2013, No. 17(2), pp. 229–245; A.A. Darrow, J. Novak, *The effect of vision and hearing loss on listeners' perception of referential meaning in music*, "Journal of Music Therapy" 2007, No. 44, pp. 57–73; Z. Eitan, E. Ornoy, R.Y. Granot, *Listening in the dark: Congenital and early blindness and cross-domain mappings in music*, "Psychomusicology" 2012, No. 22(1), p. 33; P.J. Flowers, C.H. Wang, *Matching verbal description to music excerpt: The use of language by blind and sighted children*, "Journal of Research in Music Education" 2002, No. 50(3), pp. 202–214.

⁶ X. Pfammatter, *Music as a Leisure-Time Occupation for the Blind*. "Review of the European Blind" 1988, No. 2(60), p. 28.

⁷ A. Okupińska, *Zagadnienia rehabilitacji i edukacji osób głuchoniewidomych*, [in:] *Dajmy szansę niewidomym i słabowidzącym. Poradnik metodyczny dla nauczycieli*, ed. T. Żółkowska, „Pedagogium” Wydawnictwo OR TWP in Szczecin, Szczecin 2010, p. 58.

Characteristics of motor development in the child with visual disability

A child with visual disability has the same need for movement as its sighted peers. However, this need is not always satisfactorily and sufficiently fulfilled because of slower mastering of new motor skills and more difficulty in performing self-service and household activities. It is also remarkable that a blind child is prone to being inactive, which contributes to further passivity and reduced mobility⁸. Because of the less developed musculoskeletal apparatus, the child often has spinal deformities described as body posture defects that also affect his or her mobility⁹. This may also include traumatic experiences of independent movement, physical exercises, fitness games, overcoming obstacles and moving around in space¹⁰. As a result of mechanical injuries, the child may develop anxiety, indirectly affecting also the motor sphere. The lack of the appropriate amount and intensity of movement also restricts the time-space-motion imagination leading to a secondary weakening of general mobility, the loss of faith in one's own abilities. The most frequently disturbed components of the child's motor skills include: strength, speed of movements, static coordination, dynamic coordination of the whole body, aesthetics, harmony and fluidity of movements¹¹.

⁸ E. Dziedzic-Szeszuła, *Wprowadzenie*, [in:] *Taniec Towarzyski w rehabilitacji osób niewidomych*, Waclaw Wróblewski, AWF, Poznań 2005, pp. 10–11.

⁹ R. Wypart, *Praca nauczyciela wychowania fizycznego z uczniem z dysfunkcją wzroku*, [in:] *Dajmy szansę niewidomym i słabowidzącym. Poradnik metodyczny dla nauczycieli*, ed. Żółkowska Teresa, „Pedagogium” Wydawnictwo OR TWP in Szczecin, Szczecin 2010, p. 171.

¹⁰ P.S. Haibach, M.O. Wagner, L.J. Lieberman, *Determinants of gross motor skill performance in children with visual impairments*, „Research in developmental disabilities” 2014, No. 35(10), pp. 2577–2584.

¹¹ M. Brambring, *Divergent development of gross motor skills in children who are blind or sighted*, “Journal of Visual Impairment & Blindness” 2006, No. 100(10), pp. 620–634; F.M. Murphy, M. O’Driscoll, *Observations on the Motor Development of Visually Impaired Children Interpretations from Video Recordings*, “Physiotherapy” 1989, No. 75(9), pp. 505–508.

Because of the large or very large delay in the motor development of the visually impaired child, some authors claim that this process is specific as it is characterized by abnormalities in the functioning of the motor apparatus, delays in manipulation and locomotion, greater functional asymmetry (i.e. lateralization) of the hands and the formation of abnormal movement habits called blindisms. Given the above it seems reasonable to undertake rehabilitation and therapeutic interventions aimed at improving the motor development of the child with visual disability.

The specificity of music therapy in children with visual disabilities

The specialist literature contains a relatively small number of works on the use of music therapy in children with visual disabilities, and the available studies combine music education, rehabilitation and music therapy. Generally speaking, authors make attempts to present music therapy as a method integrating musical, educational and therapeutic structures and strategies in order to eliminate abnormal verbal, motor and social behaviours and to stimulate the development of the child, thus increasing its quality of life¹². In the early 1990s this type of approach led to the emergence of a new subdiscipline of music therapy referred to as typhlo music therapy. Although for more than twenty years along with, for instance, occupational therapy, kinesitherapy, hippotherapy, sensory integration therapy, the method has been one of the forms of revalidation applied in facilities for the blind and visually impaired children, it is still treated as a non-standard improvement corrective solution¹³.

¹² R.C. Lam, C. Wang, *Integrating Blind and Sighted through Music*, "Music Educators Journal" 1982, No. 68(8), pp. 44–45; A.L. Steele, C. Crawford, *Music Therapy for the Visually Impaired*, "Education of the Visually Handicapped" 1982, No. 14(2), pp. 56–62; F.M. Wolf, *Music Therapy with the Blind*, "British Journal of Music Therapy" 1978, No. 9(3), p. 29.

¹³ J. Kędzierska, *Planowanie pracy rewalidacyjnej z dziećmi niewidomymi i słabowidzącymi w szkołach ogólnodostępnych*, [in:] *Dajmy szansę niewidomym i słabowidzącym*.

Typhlo music therapy is an interaction that uses music and other non-musical acoustic phenomena to improve, correct and compensate for the impaired functions in people with visual disabilities and to optimally adapt patients to the active participation in various areas of life, especially social. It is carried out in accordance with the paradigm of the humanistic-subjective disability concept maintaining a balance between theoretical knowledge and practical experience. This type of therapy is based on the means of interaction (acoustic material, therapeutic methods and techniques, props, laboratory equipment, classroom scenarios and therapeutic program) adapted to the non-visual way of acquiring experiences and participating in therapeutic sessions. As a result, there is mainly the sound-musical interaction between the therapist and the child (group of participants) based on touch-kinaesthetic, auditory, olfactory, taste and visual sensations (in visually impaired children). The resultant relationship between the therapist and the child has a dynamic, friendly and emotional character¹⁴. This, in turn, allows the child to experience the feeling of security, intimacy, togetherness and interpersonal relationship¹⁵. Thus, it can be concluded that typhlo music therapy fundamentally differs from other contemporary therapeutic models and approaches.

Movement integrated with music in typhlo music therapy interactions

Movement is one of the most important means of child's expression. Some authors claim that it is a condition sine qua non for chil-

Poradnik metodyczny dla nauczycieli, ed. T. Żółkowska, „Pedagogium” Wydawnictwo OR TWP in Szczecin, Szczecin 2010, pp. 104–105.

¹⁴ M. Pavlicevic, *Dynamic interplay in clinical improvisation*, “The Journal of British Music Therapy” 1990, volume 4, No. 2, pp. 5–9.

¹⁵ K. Sobey, *Out of sight – out of mind?*, *Reflections on a blind young woman's use of music therapy*, “The Journal of British Music Therapy” 1999, volume 7, No. 2, p. 8; H.H. Decker-Voigt, *Musiktherapeutische Hilfen für die Begleitung von Blinder und Schbenhinderten*, „Musiktherapeutische Umschau” 1994, volume 15, No. 2, pp. 140–141.

dren's rehabilitation and independence¹⁶. We can hazard a guess that it is impossible to rehabilitate and treat a disabled child without perfecting its motor activity, because it largely determines autonomy, and thus the sense of subjectivity and self-determination¹⁷. Movement cannot be replaced by anything, neither literature, art, film, or even music. It is a phenomenon more difficult to approach by a child with a damaged visual analyzer than music, but it is necessary for the proper growth¹⁸. Most often, it develops spontaneously, from the need to express emotions, feelings, thoughts, associations resulting from the interaction with musical art. On the one hand, movement is stimulated by music, and on the other hand, it is integrated with music and its selected elements constituting the centre of influence in music therapy of children.

Through the structural elements, such as: rhythm, metre, tempo and dynamics music stimulates imagination of the child, implies the intensity and fluidity of movements and helps to remember the sequence of movement activities¹⁹. In this way, it has an orderly and harmonizing effect on the child's motility, encouraging it to move freely in space and to perform everyday life activities, such as toilet treatments, preparing and eating meals, bedding, washing, ironing, folding clothes, dressing and undressing²⁰.

¹⁶ R. Emery, *Blind role models in rehabilitation*, "Journal of Visual Impairment and Blindness" 1986, No. 80(9), p. 934.

¹⁷ M. Metell, "A great moment. because of the music": *An exploratory study on music therapy and early interaction with children with visual impairment and their sighted caregivers*, "British Journal of Visual Impairment" 2015, No. 33(2), pp. 111-125.

¹⁸ J. Stadnicka, *Rewalidacja dzieci niewidomych przez rytmikę*, „Szkoła Specjalna” 1990, No. 2-3, p. 76.

¹⁹ A. Pielecki, E. Skrzetuska, *Nauczanie niedowidzących w klasach 4-8*, WSiP, Warsaw 1991, p. 130.

²⁰ M.D. Bertolami, L.A. Martino, *Music Therapy in a Private School for Visually Impaired and Multiply Handicapped Children*, "In Voices: A World Forum for Music Therapy" 2002, volume 2, No. 1, <https://voices.no/index.php/voices/article/view/69/59> [access: 24.06.2018]; P. Kern, M. Wolery, *Participation of a preschooler with visual impairments on the playground: Effects of musical adaptations and staff development*, "Journal of Music therapy" 2001, No. 38(2), pp. 149-164.

The production of acoustic sounds by the child using simple motor activities is called music making with gesture sounds or natural music making. The unconventional sources of sounds in a child are, for example: clapping hands, stomping feet, snapping fingers. In this way, the child learns self-orientation and masters self-service and locomotion activities. Moreover, this type of music making is also a form of body massage.

A small blind child is interested in various objects in the immediate surroundings, making them a source of various acoustic phenomena, such as: squealing, ringing, buzzing, rumbling, roaring, creaking, tapping and rattle. In this way, it makes music using everyday objects (mugs, bottles, combs, cellophane, squeaking mascots, blocks, drawers, radiators, etc.). This activates the child and improves its manual and auditory skills.

In the work with a disabled child we most often use simple percussion musical instruments commonly known as school instruments (rattles, drums, harpsichords, tambourines, clappers, harness bells, etc.)²¹. The ways of stimulating the instruments to produce sounds and vibrations include: hitting the instrument with the palm, fingers or fist, shaking the instrument held in one hand, hitting the instrument with the hand, elbow, knee, hitting one part of the instrument against the other, rubbing the hand over the instrument surface, snapping the fingers against an instrument. In this was the child not only develops musicality, but also improves small motor skills, mainly manual dexterity (e.g. touching, gripping, moving, reaching out, squeezing, reaching out hands), positively influencing speed, dynamics, coordination and accuracy of movements.

During music therapy activities children can move in small and large spaces: walking, marching, running, bouncing, sliding, swaying while shifting the weight of the body from foot to foot. During these activities children adapt their movements to the pace, dynamics, character, mood and duration of the musical piece. In

²¹ W. Olszewska, *Ewolucja w muzykoterapii ze szczególnym uwzględnieniem metody Karla Orffa*, „Postępy Rehabilitacji” 1992, No. 3, p. 63.

this way, they develop hearing and movement coordination, correct body posture and spatial orientation. Thanks to the integration with sounds, exercises practicing natural forms of locomotion have a relaxing effect on the child, reduce fear of space, obstacles, injuries and physical effort, thereby strengthening the sense of security²².

Musical-movement games inspire the child to perform various activities accordingly to changes in music i.e. tempo, dynamics, metre and articulation. These games generally use simple ways of moving in space and imitation of everyday activities. The activities improve fluidity, precision and strength of movements. They can also be used to eliminate motor anxiety and suppress movement obsessions. Thanks to the atmosphere of cooperation and competition even passive children are activated to play.

The aim of musical and movement improvisation is to improve the child's imagination (especially time-motion-space), spontaneity of movements, and the ability to express emotional states. As part of this technique, they can spontaneously make single movements and their combination, create the ways of moving, performing everyday activities and dance to the music. Through improvised movements the child explores own body, learns to accept and consciously uses it.

Music, and especially its constituents, such as timbre and dynamics can be used in blind children in teaching and correcting the expression of emotions through countenance²³. For this purpose, we apply exercises which transfer and process the means of musical expression into facial expression. Mood and character of pieces of music imply movements of the facial muscles to be adopted by the child.

Mainly ballroom dancing is used in music therapy in blind and visually impaired children²⁴. The elements (steps, turns, bows, hand

²² W. Sapp, *Somebody's jumping on the floor: incorporating music into orientation and mobility for preschoolers with visual impairments*, „Journal of Visual Impairment & Blindness” 2011, No. 105(10), p. 715.

²³ H. Zamęcka, *Metody działania muzykoterapeuty w pracy z dziećmi z uszkodzonym wzrokiem*, „Szkola Specjalna” 1985, No. 3, p.196

²⁴ A valuable help in teaching children the steps of ballroom dance is the method of Waclaw Wróblewski using spatial visual tables based on a six-point Braille

movements, head positions, ways to hold a partner, etc.), which are complicated in terms of performance and expenditure of physical effort, are modified and simplified according to the specificity of child's functioning. Children can also, without any rules, improvise the elements of dance by gesture, movement or musical instruments to the original or arranged dance music. Dance (or its elements) improves coordination of movements with the sound and music material, their elegance, precision, creates a correct posture, perfects self-orientation, and reduces automatic movements called blindisms²⁵.

Summary

A child with visual disability can fully experience music and benefit from its various pro-health advantages. Thanks to the therapeutic potential this kind of art inspires the child to spontaneous tasks, musical and play activities. It triggers, organizes and modifies movements and thus stimulates time-motion-space imagination. As a result, the child's behaviour becomes more free, and thus more predictable, easier to be shaped and corrected. In this way, psychomotor inhibition is reduced and orientation and locomotion are improved in small and large spaces in the blind and visually impaired child. In addition, movements are often accompanied by the joy of meeting the natural need of movement, relieving psycho-physical and emotional tension and sublimation of aggression.

Typhlo music therapy is an effective and safe space for children with visual disabilities. This space creates an area to reduce a delay in motor skills development and improve its individual components. We can hazard a guess that movement alongside music is the

script at 60 times magnification. W. Wróblewski, *Taniec Towarzyski w rehabilitacji osób niewidomych*, AWF, Poznań 2005.

²⁵ J. Kuczyńska-Kwapisz, *Spostrzeżenia dotyczące prowadzenia zajęć z młodzieżą niewidomą w kole tanecznym*, „Szkola Specjalna” 1979, No. 4, p. 288; A. Mazurkiewicz, *Zainteresowania muzyczno-taneczne niewidomych*, „Kultura Fizyczna” 1968, Yearbook XXI, No. 3, p. 122.

most important means of influence to be used in this type of interaction. Multiple positive experiences acquired by the child and linked to the physical activity are transposed from the area of therapeutic interactions into the non-visual functioning, thus contributing to the improvement of the quality of life. Therefore, it can be concluded that typhlo music therapy interventions may be used to support the motor development of a child with visual disability with the simultaneous involvement of the preserved senses and creative potentials.

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Evaluation of Art of Visually Impaired People by Children and Adults

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The aim of the study was to determine whether the age of the audience of an exhibition influences the aesthetic preferences for artistic products created by visually impaired people. The research was conducted with the aim of finding an answer whether there are any differences in the preferences of different categories of artworks created by artists who are blind or visually impaired. The research consisted in the evaluation of raised-line drawings, photographs, sculptures and a tactile picture book. These artistic products were presented in an art gallery. The evaluations were made on a 5-point scale, where the respondents indicated how much they liked the artworks that they saw. 118 people participated in the study, including 80 children and 38 adults. It turned out that age and type of art exerted interactive impact on the aesthetic evaluation. Age differences in aesthetic preferences were found in reference to drawings and the picture book. Visual art created by people with sight impairment was evaluated very positively.

KEY WORDS: visual impairment, visual art, art evaluation, aesthetic preference

Introduction

The attitude to people with disabilities has been changing throughout the years. On the one hand, it turns out that on the international scale, the society's stance towards such persons is becoming more friendly and accepting¹. On the other, domestic studies show that positive stances towards people with disabilities are not frequent among Poles². Studies conducted by Orłowska³ indicate that persons with disabilities are perceived positively and negatively in an equal degree. On the other hand, according to data collected by Instytut Badania i Rozwoju Aktywności Społecznej (Institute for Research and Development of Social Activity)⁴ persons with disabilities see themselves as unfavourably perceived by the society. Larkowa's studies may offer an explanation for diverging impressions of people with disabilities as compared to the society's declarations about them⁵. Larkowa draws attention to the fact that declared stances of people which are most often positive, are different than the non-verbalised ones, which are, in turn, negative. The most frequent cause of reluctance towards people with disabilities are stereotypes, which are manifested in a negative emotional attitude, erroneous impressions and lack of knowledge about the needs of such persons. Knowledge pertaining to independent functioning and potential of people with visual impairment is quite limited in the society. This is probably why visual impairment is considered

¹ G. Berkson, *Intellectual and physical disabilities in prehistory and early civilization*. "Mental Retardation" 2004, No. 42(3), pp. 195–208.

² M. Zaorska, E. Andrulonis, *Postawy społeczne wobec osób niepełnosprawnych*. „Wychowanie na co dzień” 2006, No. 7–8 (154–155), pp. 20–23.

³ M. Orłowska, *Postawy Polaków wobec osób niepełnosprawnych*, „Szkoła Specjalna” 2001, No. 4, pp. 208–212.

⁴ Instytut Badania i Rozwoju Aktywności Społecznej, *Wspólnie na rzecz integracji. Diagnoza preferencji, oczekiwań i potrzeb niepełnosprawnych mieszkańców Poznania*, 2010. Downloaded from: <http://www.poznan.pl/mim/hc/diagnoza-preferencji-oczekiwan-i-potrzeb-niepelnosprawnych-mieszkancow-poznania,p,22190,22194,22474.html>

⁵ H. Larkowa, *Postawy społeczne wobec osób z odchyleniami od normy*, [in:] *Pedagogika rewalidacyjna*, ed. A. Hulek, Wydawnictwo PWN, Warszawa 1980, pp. 478–491.

one of the most threatening disabilities, related to dependence on others and feeling of insecurity⁶. These conclusions are supported by Czerwińska's studies⁷ conducted among school youth. In a text with unfinished sentences, young people entered negative opinions pertaining to blind people in the majority of fields. This study showed slight knowledge about visually impaired people and negative consequences of insufficient school education with respect to disabilities.

The natural need of children is to establish relations with peers. However, children with disabilities experience difficulties in establishing and maintaining friendship. Children's stances towards blind peers are often a reflection of stances presented by parents and the society in general⁸. Marzec⁹, on the basis of her studies, pinpoints the fact that if models of relations with peers are formed during childhood, then it is possible to use it for future interactions with people with disabilities. It is known that pre-school children would not be willing to have a visually impaired child as a play companion¹⁰. Palak was studying the sociometric position of visually impaired students in general schools¹¹. Based on her studies, it may be indicated that only 20% of visually impaired children are

⁶ R. Reina, V. Lopez, M. Jiménez, T. García-Calvo, Y. Hutzler, *Effects of awareness interventions on children's attitudes toward peers with a visual impairment*, "International Journal of Rehabilitation Research" 2011, No. 34(3), pp. 243–248.

⁷ K. Czerwińska, *Obraz osób niewidomych w opiniach dzieci w wieku wczesnoszkolnym – komunikat z badań*, „Niepełnosprawność i Rehabilitacja” 2011, No. 1, pp. 46–54.

⁸ E. Skoczylas, *Dziecko z dysfunkcją wzroku w integracyjnym systemie kształcenia*, [in:] *Uczeń ze specjalnymi potrzebami edukacyjnymi w środowisku rówieśniczym*, ed. E. Domagała-Zyśk, Wydawnictwo KUL, Lublin 2012, pp. 93–110.

⁹ E. Marzec, *Modyfikacja postaw wobec osób z dysfunkcją wzroku*, [in:] *Postawy wobec niepełnosprawności*, ed. L. Frąckiewicz, Wydawnictwo Uczelniane AE, Katowice 2002, pp. 63–78.

¹⁰ S.-Y. Hong, K.-A. Kwon, H.-J. Jeon, *Children's Attitudes Towards Peers with Disabilities: Associations with Personal and Parental Factors*, "Infant and Child Development" 2014, No. 23(2), pp. 170–193.

¹¹ Z. Palak, *Uczniowie niewidomi i słabowidzący w szkołach ogólnodostępnych*, Wydawnictwo UMCS, Lublin 2000, p. 155.

accepted by peer groups. Majority of blind children (63.3%) are in a socially disadvantageous situation. 33.3% of blind and visually impaired students covered by the study were isolated by fully-able peers and 30% of them experienced rejection. On the other hand, Zielińska's studies¹² conducted among high school students on the one hand show frequent (68.2%) declarations of positive attitude to peers with disabilities and on the other rare (22%) declarations of readiness to befriend a student with disabilities. Comparative studies on stances of students from the Netherlands and Poland¹³ show that Poles are less tolerant with respect to people with disabilities, which results from negative experiences in interactions with people with disabilities or lack of such experiences. Summing up, the aforementioned studies show that in spite of the fact that the attitude towards people with disabilities is changing and becoming more positive, yet stereotypes caused by lack of knowledge still create a situation in which both children and adults are not willing to maintain contacts with people with disabilities. Meanwhile, a change in the attitude may be triggered by information and awareness-raising activities. Pielecki examined changes in attitudes among middle school students¹⁴. In his studies, the most efficient modes of expanding knowledge and change of attitudes were film screenings; the greatest increase of knowledge after an awareness-raising action was recorded with respect to sensory disabilities (sight, hearing).

Visually impaired and blind people may independently move around the city, set up a family, be successful in professional life, and also be fulfilled creatively. It is interesting to note that the areas

¹² M. Zielińska, *Postawy młodzieży licealnej wobec niepełnosprawnych rówieśników*, Wyższa Szkoła Pedagogiczna im. T. Kotarbińskiego w Zielonej Górze. Unpublished master's thesis, Zielona Góra 2000.

¹³ B. Papuda-Dolińska, *Postawy wobec osób z niepełnosprawnością: na podstawie opinii polskich i holenderskich studentów*, „Przegląd Naukowo-Metodyczny. Edukacja dla Bezpieczeństwa” 2012, No. 4, pp. 129-143.

¹⁴ A. Pielecki, *Zmiany postaw młodzieży wobec osób niepełnosprawnych*, Wydawnictwo Uniwersytetu Marii Curie-Skłodowskiej, Lublin 2013.

of their creativity are often the so-called visual arts¹⁵, and the selected artistic media are, for example, raised-line drawings (the first promoters of the view that even blind people can draw were John Kennedy¹⁶ on the international arena and Wanda Szuman in Poland)¹⁷, sculptures¹⁸ or photos¹⁹.

According to studies, reception of fine art works of visually impaired artists is excessively positive - as if the viewers did not believe in the authors' potential and accepted them not account of the fact that they liked them, but due to the fact that they were created without the use of eyes, which may be considered reception through the stereotype of the author's disability²⁰. Such stereotypical reception is revealed already at the stage of looking at the artwork, which was shown in eye-tracking studies: the power of correlation of the time of eye fixation in the same regions of interest in respondents convinced about the disability of the author of the photograph was higher than in people who were not told about the photographer's disability²¹. In popular studies pertaining to the aesthetic perception via the stereotype of the author's disability, neither Niestorowicz²² nor Szubielska with her team²³ presented the

¹⁵ M. Szubielska, E. Niestorowicz, *Sztuki wizualne oczami niewidomych*, "Fragile" 2017, No. 1(35), pp. 36–40.

¹⁶ J.M. Kennedy, *Drawing and the blind: Pictures to touch*, CT, Yale University Press, New Haven 1993, pp. 95–126.

¹⁷ W. Szuman, *O dostępności rysunku dla dzieci niewidomych*, Państwowe Zakłady Wydawnictw Szkolnych, Warszawa 1967, pp. 5–139.

¹⁸ E. Niestorowicz, *Świat w umyśle i rzeźbie osób głuchoniewidomych*, Wydawnictwo Uniwersytetu Marii Curie-Skłodowskiej, Lublin 2007, pp. 38–40.

¹⁹ J. Rothenstein, *The Blind Photographer: 150 Extraordinary Photographs from Around the World*, Princeton Architectural Press, London 2016.

²⁰ E. Niestorowicz, *Świat w umyśle i rzeźbie osób głuchoniewidomych*, Wydawnictwo Uniwersytetu Marii Curie-Skłodowskiej, Lublin 2007, pp. 231–235.

²¹ M. Szubielska, B. Bałaj, A. Fudali-Czyż, *Estetyczny odbiór fotografii poprzez stereotyp umysłowej niepełnosprawności twórcy*, „Psychologia Społeczna” 2012, No. 23(4), pp. 372–378 - in the studies, the authors did not examine the stereotype of a visually impaired person, but an intellectually impaired person.

²² E. Niestorowicz, *Świat w umyśle i rzeźbie osób głuchoniewidomych*, Wydawnictwo Uniwersytetu Marii Curie-Skłodowskiej, Lublin 2007, pp. 231–235.

respondents with original artworks, but only their reproductions in the form of photographs. The author of this study was interested in the perception of art created by blind and visually impaired people presented in an actual gallery. In such a situation, the viewers have a chance to contemplate properly exhibited originals of artistic products which, on account of being located in an exhibition space, receive the status of artworks.

The purpose of the study which was conducted at an exhibition of works of blind and visually impaired people was to provide an answer to the following questions: does the age of the exhibition recipients influence the evaluation of aesthetic preference for works created by blind and visually impaired persons? And also: are there any differences in preferences for various categories of artistic products created by visually impaired persons?

Study Method

118 persons took part in the study, including 80 children (from 5 to 7 years of age) from Lublin schools and kindergartens and 38 adults (between 18 and 22 years of age) - psychology students. Detailed information pertaining to the age, sex and numbers of individual age groups is contained in Table 1. Participation in the study was voluntary. Parents of all children expressed written approval for the participation of their children in the study.

The subject matter of evaluation was an exhibition entitled "Miasto, którego nie widać" ("An Invisible City") presented in the Labirynt Gallery in Lublin between 19 December 2017 and 28 February 2018 (cf. Fig. 1). The authors of works were visually impaired persons, students of the Special School and Education Centre for Disabled Children and Youth of Professor Zofia Sękowska in Lublin.

²³ M. Szubielska, B. Bałaj, A. Fudali-Czyż, *Estetyczny odbiór fotografii poprzez stereotyp umysłowej niepełnosprawności twórcy*, „Psychologia Społeczna” 2012, No. 23(4), pp. 372–378 – in the studies, the authors did not examine the stereotype of a visually impaired person, but an intellectually impaired person.

Table 1. Characteristics of respondents

	5 year-old children	6 year-old children	7 year-old children	Adults
Number	22	33	25	38
Number of women	7	16	13	33
Number of men	15	17	12	5
Age: arithmetic average	5.20	6.09	7.04	19.71
Age: standard deviation	0.25	0.20	0.14	0.73



Fig. 1. View of exhibition “An Invisible City” (photograph by Wojciech Pacewicz, courtesy of the “Labirynt” Gallery in Lublin)

The following artworks were presented at the exhibition: twelve raised-line drawings on film (titles of works: “The NN Theatre”, “Pekin Skyscraper”, “A Walk”, “Louis Braille and Selena Gomez. A Pair in the City”, “Kunicki Central Station”, “Try Not to Fall Over”, “School”, “Kraków Gate”, “Rest”, “Bus”, „Wyścigowa”,

“Multi-Functional Building”), a series of twelve black and white photographs made with the analogue Kiev camera (under a joint title “An Invisible City”), eight small uncoated ceramic sculptures (titles of works: “Fountain”, “Beijing”, “A Couple on a Walk”, “A Doll”, “Just a Tower”, “Resting on a Bench”, “Newest iPhone”, „Bus”) and a tactile picture book “An Invisible City” containing stories about life in the city (written on a Braille machine) and collage illustrations. All works were created in 2017.

The respondents viewed the exhibition in small groups, without reading the curatorial information, as well as without any guidelines on the part of educators working in the gallery or persons taking care of the exhibition (in case of questions, they were informed that answers would be provided after viewing the entire exhibition and its evaluation). Before viewing the artworks, the respondents were only told that the title of the exhibition was “An Invisible City” and that its authors were blind and visually impaired people (it was additionally explained to children that these are people who cannot see at all or who see very badly). After the visit, the artworks presented in the gallery were evaluated by every child on the response sheet. The sheet contained an image-based preference scale, consisting of five emoticons, arranged in a sequence from a clearly happy one (on the left) to the clearly unhappy one (on the right). The respondents’ task was to mark the emoticon that was the best illustration of the degree in which they liked the drawings, sculptures, photographs and the picture book presented at the exhibition. The respondents were given the following instructions: “Mark the degree in which you liked the presented drawings”, “Mark the degree in which you liked the presented photographs”, “Mark the degree in which you liked the presented sculptures”, “Mark the degree in which you liked the presented book.” Every child independently (or with slight assistance of the person conducting the study) marked the selected emoticon as a response to every question.

Independent variables in the study included: (1) Age (5 year-old, 6 year-old and 7 year-old children, adults) and (2) Type of artwork (drawings, photographs, sculptures, picture book). As a dependent variable, evaluation of the exhibition in the dimension of aesthetic

preference was examined; its index, expressed by a selected emotion, constituted a degree in which the artworks presented at the exhibition were liked by the respondents.

Study Results

Analysis of data was made with the use of the SPSS programme. The respondents' responses were coded in a numerical form, by assigning values from 1 to 5 to the scale of drawings (1 - a clearly unhappy face, 5 - a clearly happy face). Descriptive statistics of grades of individual categories of works made by the viewers in various ages are contained in Table 2.

Table 2. Evaluation of drawings, photographs, sculptures and a picture book by children in various ages and adults - descriptive statistics

Type of artwork	Age group	Grade: arithmetic average	Grade: standard deviation
Drawings	5 year-olds	4.68	0.57
	6 year-olds	4.39	1.06
	7 year-olds	4.28	0.89
	Adults	3.95	0.93
Photographs	5 year-olds	4.27	1.20
	6 year-olds	4.12	1.19
	7 year-olds	4.00	1.04
	Adults	4.13	1.04
Sculptures	5 year-olds	4.64	0.73
	6 year-olds	4.30	1.05
	7 year-olds	4.56	0.82
	Adults	4.34	0.91
Picture book	5 year-olds	4.00	1.54
	6 year-olds	3.88	1.52
	7 year-olds	3.48	1.48
	Adults	4.45	0.83

For the dependent variable of aesthetic preference, a mixed variance analysis was performed with intra-object factor Type of Artistic Product and inter-object factor Age. Statistically significant main effect of the Type of Artistic Product factor was ascertained, $F(2.64, 301.10) = 5.90$, $p = 0.001$, $\eta^2 = 0.05$ and significant interaction of factors Type of Artistic Product and Age, $F(7.92, 301.10) = 2.48$, $p = 0.013$, $\eta^2 = 0.06$. The main effect of the Age factor was not statistically significant $F(3, 14) = 0.92$, $p = 0.434$. In relation to the received interaction, simple effects were calculated by analysing differences in the evaluation of individual artworks by viewers in the same age (four one-factor variance analyses with repeated measures, conducted in the group of 5 year-old, 6 year-old and 7 year-old children and adults), as well as by analysing age differences in the evaluation of artworks belonging to a given category (four one-factor variance analyses conducted for the evaluation of: drawings, photographs, sculptures and the picture book).

In variance analyses with repeated measures, no effect of main factor Type of Artistic Product was ascertained in the group of 5 year-old viewers $F(2.11, 44.24) = 2.53$, $p = 0.089$, nor in 6 year-old viewers, $F(3, 96) = 1.37$, $p = 0.256$. Statistically significant main effect of factor Type of Artistic Product was ascertained in the group of 7-year old recipients, $F(3, 72) = 5.31$, $p = 0.004$, $\eta^2 = 0.17$, as well as adults, $F(3, 111) = 3.09$, $p = 0.030$, $\eta^2 = 0.08$. Based on the results of Bonferroni post-hoc tests, it was determined that 7-year old children liked sculptures more than the picture book (significance of post-hoc test: $p = 0.020$, cf. Table 2); other comparisons in pairs in this group of respondents were not statistically significant. On the other hand, adult viewers liked drawings significantly less than sculptures (post-hoc test significance $p = 0.032$, cf. Table 2) and picture book (post-hoc test significance: $p = 0.025$, cf. Table 2); other comparisons in pairs in this group of respondents were not statistically significant.

In single-factor variance analyses, no main effect of the Age factor was ascertained in the evaluation of photographs $F(3, 114) = 0.23$, $p = 0.873$, or sculptures, $F(3.114) = 0.90$, $p = 0.446$. On the other

hand, Age significantly diversified both the evaluation of drawings, $F(3, 114) = 3.32, p = 0.022, \eta^2 = 0.08$, as well as the evaluation of the picture book $F(3, 114) = 2.81, p = 0.043, \eta^2 = 0.07$. Based on Bonferoni post-hoc test results, the following significant differences in the evaluation of works were ascertained: drawings were preferred more by 5 year-old children than by adults ($p = 0.018$, cf. Table 2), and adults liked the picture book more than 7 year-old children ($p = 0.033$, cf. Table 2).

In order to determine whether the evaluation of works seen at the exhibition significantly differs from the average evaluation on the scale of answers (i.e. neither positive nor negative) in individual groups of recipients, 16 t tests were conducted for one sample with

Table 3. Results of the t test for one sample of evaluation for drawings, photographs, sculptures and the picture book by children in various ages and adults (statistically significant differences are marked with “*”)

Type of artwork	Age group	Test result
Drawings	5 year-old children	$t(21) = 13.89, p < 0.001^*$
	6 year-old children	$t(32) = 7.56, p < 0.001^*$
	7 year-old children	$t(24) = 7.19, p < 0.001^*$
	Adults	$t(37) = 6.29, p < 0.001^*$
Photographs	5 year-old children	$t(21) = 4.97, p < 0.001^*$
	6 year-old children	$t(32) = 5.40, p < 0.001^*$
	7 year-old children	$t(24) = 4.80, p < 0.001^*$
	Adults	$t(37) = 6.68, p < 0.001^*$
Sculptures	5 year-old children	$t(21) = 10.56, p < 0.001^*$
	6 year-old children	$t(32) = 7.16, p < 0.001^*$
	7 year-old children	$t(24) = 9.51, p < 0.001^*$
	Adults	$t(37) = 9.10, p < 0.001^*$
Picture book	5 year-old children	$t(21) = 3.04, p < 0.001^*$
	6 year-old children	$t(32) = 3.33, p = 0.002^*$
	7 year-old children	$t(24) = 1.63, p < 0.117^*$
	Adults	$t(37) = 10.77, p < 0.001^*$

a test value equal to 3. Results of all tests are presented in Table 3. Only in the case of evaluation of the picture book by 7 year-old children no statistically significant difference was ascertained between the evaluation received in the study and the average evaluation of the applied measurement scale (which may be determined as neutral). In the case of other grades, they were significantly higher than the neutral grade (cf. Table 2).

Study: Discussion of Results

The purpose of the study was to find an answer to two questions: (1) Does aesthetic evaluation of art created by visually impaired persons change together with the viewers' age (children aged 5-7 and young adults were examined); (2) Does aesthetic evaluation depend on the category of artistic products seen (raised-line drawings made on special film, black and white photography, uncoated ceramic sculptures and a picture book containing text and tactile collages were taken into account)?

It was ascertained that the evaluation of visual works made by blind and visually impaired people to a significant degree depends on the interaction of factors such as age and type of artistic product. In other words, the fact of whether and in what manner the aesthetic preferences change with age depends on whether the object of evaluation are drawings, photographs, sculptures or a picture book, which were produced by visually impaired people.

Aesthetic evaluation by 5 year-old and 6 year-old children did not depend on the type of evaluated artistic product. This may testify to the fact that children aged 5 and 6 received all the works presented at the exhibition with equal enthusiasm – possibly on account of the fact that the visit in an art gallery was a great experience for them. Meanwhile, preference for artworks of both 7 year-old children and adults depended on the category of artistic product that was subject to evaluation. 7 year-old children liked the sculptures significantly more than the picture book. On the other

hand, adults liked drawings significantly more than sculptures and the picture book. Furthermore, it was determined that both the evaluation of photographs and sculptures did not significantly change with the age of respondents. Age differences in aesthetic preference were ascertained in reference to the drawings and the picture book. Five year-old children liked drawings significantly more than adults. On account of delay in drawing development of blind people as compared to fully-able people²⁴ drawings of blind authors in a formal aspect resemble drawings of small children which are, in turn, similar to the so-called geometric abstractions created by modern and contemporary artists. In an experiment devoted to reception of abstract art with the participation of children²⁵ it was found out that they liked works made by their peers than works created by professional artists more. Similarity of works made by blind people and children's sketches may explain higher preference for drawings made by blind people in the group of youngest children as compared to the preferences of adult viewers. On the other hand, adults liked the picture book more than 7 year-old children. This may be caused by the fact that in their reception of the picture book, the adult viewers were more focused on the content of texts than on collages illustrating them, whereas children paid attention to illustration (most of them could not read). Stories contained in the book referred primarily to problems of life in the city from the perspective of a person who cannot see, about spatial disorientation or losing way and fears related to it. Collages presented in the book may be predominantly described as "childish" – they were similar to the illustrations which could be encountered in the majority of books for small children. It is probable that adult

²⁴ M. Szubielska, E. Niestorowicz, B. Marek, *Jak rysują osoby, które nigdy nie widziały? Badania niewidomych uczniów / Drawing without eyesight. Evidence from congenitally blind learners*, „Roczniki Psychologiczne// Annals of Psychology” 2016, No. 19(4), pp. 659–700.

²⁵ J. Nissel, A. Hawley-Dolan, E. Winner, *Can young children distinguish abstract expressionist art from superficially similar works by preschoolers and animals?*, “Journal of Cognition and Development” 2016, No. 17(1), pp. 18–29.

recipients appreciated stories of visually impaired people, whereas the oldest group of respondent children did not like the illustrations as they were too infantile.

It is worth emphasising the fact that almost all evaluations of artworks of visually impaired persons by young and adult viewers may be considered positive. The exception is the evaluation of the picture book made by 7 year-old children, which may be determined as neutral (neither positive or negative). It would be interesting to find out whether such high grades result from a stereotypical approach to the creativeness of visually impaired people. A recipient may be convinced that artists who cannot see find it more difficult to be creative in the area of visual arts and if they produce something, they are evaluated excessively positively with a "correction" for their disability. It may also happen that high grades for artistic products resulted from the fact that they were presented in a real art gallery, where works of accomplished visual artists are presented on a daily basis. It is known that the context of the exhibition space increases the evaluation of art²⁶, because placing works in a gallery or a museum ennobles a work. Hypotheses pertaining to the fact whether reception of art of blind and visually impaired people is more influenced by concentration on the author's disability or location of artworks in an art gallery are worth verification in subsequent experiments on the reception of art of people with disabilities.

Recapitulation

Both children and adults positively evaluated almost all artworks presented at the exhibition, whose authors were blind and visually impaired persons (however, differences were also observed in preferences with respect to age and the type of artwork: some

²⁶ D. Brieber, M. Nadal, H. Leder, *In the White Cube: Museum Context Enhances the Valuation and Memory of Art*, "Acta Psychologica" 2014, No. 154, pp. 36-42.

works were evaluated in individual groups of children recipients and adults well whereas other very well). This result may be treated as an argument in favour of organising subsequent exhibitions of this type - thanks to similar initiatives fully able people will have an opportunity of learning what the creative potential of visually impaired artists amateurs is and, due to this, they may change their attitude towards those who have to live without the sense of sight. Such projects may exert impact on the recipients in the form of an awareness-raising intervention²⁷, expanding - beyond the area of school education (which turned out to be efficient in Polish conditions²⁸) - the possibility of educating the society about disabilities.

It is interesting to note that differences in preference for individual categories of artworks, namely drawings, sculptures, photographs and books, were revealed only in 7 year-old children, thence children who attend school, whereas younger children liked works created in various techniques in an equal degree. It is difficult to conclude whether the received results are related to cognitive and aesthetic development of a child or to fine art education offered in junior classes of primary schools. This issue is worth exploring in subsequent empirical studies pertaining to aesthetic perception of art by children.

It is also significant that activities in the area of visual arts may stimulate cognitive, social and emotional development of blind people²⁹. It seems that creativity in the area of visual arts may make an artist who does not see more sensitive to the visual and spatial aspects of surroundings in which the artist stays or which he/ she

²⁷ R. Reina, V. Lopez, M. Jiménez, T. García-Calvo, Y. Hutzler, *Effects of awareness interventions on children's attitudes toward peers with a visual impairment*, "International Journal of Rehabilitation Research" 2011, No. 34(3), pp. 243-248.

²⁸ A. Pielecki, *Zmiany postaw młodzieży wobec osób niepełnosprawnych*, Wydawnictwo Uniwersytetu Marii Curie-Skłodowskiej, Lublin 2013.

²⁹ M. Szubielska, E. Niestorowicz, *Twórczość plastyczna jako forma wspierania rozwoju osób niewidomych i głuchoniewidomych*, [in:] *Rozwój i jego wspieranie w perspektywie rehabilitacji i resocjalizacji*, ed. D. Müller, A. Sobczak, Wydawnictwo Uniwersytetu Łódzkiego, Łódź 2013, pp. 89-104.

intends to visualise and is thus conducive to development of spatial imagination. In practice, this may translate to better spatial orientation and ease in independent movement. Paradoxically, activity in the area which may seem completely inadequate for a blind person may contribute to improvement of such person's quality of life.

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Self-stigma in the visually impaired

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The blind and visually impaired are one of the groups prone to stigma. Stigma imposed by social environment may lead to self-stigma, that is expressing negative opinions about oneself as a result of the carried sigma. Self-stigma usually develops in three stages: first the stigmatised person realizes that they have been stereotyped, then they accept the stereotype and finally apply it to themselves. Thus, to develop self-stigma, the person has to be aware that they are perceived by the society in a stereotypical way (a blind person is usually perceived as passive, dependent and reliant on other people's help), accept it and acknowledge themselves that this is their real image. Not every visually impaired person will develop self-stigma. The article presents selected factors and preventive measures that may reduce the risk of self-stigma.

KEY WORDS: self-stigma, the blind, the visually impaired, stigma

Typhlopsychologists and typhloeducators agree that one of the most important tasks of education and rehabilitation of people with visual impairment is to prepare them for life among sighted people. This can be done by providing them with help in acquiring skills and abilities allowing them to behave according to the role that is determined by their age and position in the social environment. However, it should be noted here that social adaptation does not depend only on the person with disability, but also on the environ-

ment in which they live, including the environment of sighted people.¹ Unfortunately, it often happens that the environment is dominated by the tendency to perceive blind and visually impaired people from the angle of differences (mostly unfavourable) between them and the sighted. In this situation, a change in the social mentality, including first of all the recognition of advantages in people with disability and helping them to use their strong points and talents would be desired.² Social stigma can not only hinder the rehabilitation process of people with visual impairment, but also cause the occurrence of the self-stigma with all its negative consequences. And, the analysis of the author will cover this latter phenomenon. In the first part, the author will try to explain psychological mechanisms underlying social stigma, as well as to present the most common beliefs of the society about the functioning of people with visual impairment. In the next part, the author will focus on the phenomenon of self-stigma, discussing the stages of its development, specifying the conditions which favour its strengthening, as well as characterising some behaviours of blind and visually impaired people that indicate its existence. The analysis of the author will end with reflections on the prevention of this negative phenomenon.

At the beginning of the analyses on the phenomenon of self-stigma in people with visual impairment, the author would like to address the concepts of social stigma and stigma (mark of shame) that underlies it. "Social stigma is a response to the individual (or characteristic for a wider group or social category) stigma. In turn, stigma (mark of shame) is a feature that, after being noticed, reveals existing, though not expressed, expectations regarding appearance, behaviour, and ways of fulfilling social roles".³ Stigma is a cognitive

¹ T. Majewski, *Psychologia niewidomych i niedowidzących*, PWN, Warsaw 1983, pp. 139-140.

² R. Ossowski, *Teoretyczne i praktyczne podstawy rehabilitacji*, Wydawnictwo Uczelniane WSP, Bydgoszcz 1999, p. 235.

³ I. Kudlińska, *Stygmatyzacja społeczna jako perspektywa teoretyczno-badawcza (na przykładzie badań nad stygmatyzacją ludzi biednych)*, "Acta Universitatis Lodziensis Folia Sociologica" 2011, no. 38, p. 52.

construction, appearing as a result of a dissonance arisen in the consciousness between the expected identity and the actual identity of a person possessing a negative feature or attribute. This difference discredits the person.⁴

Although there could be numerous reasons for stigma (physical deformities, character defects, race, nationality and religion), in all "stigma variations (...) the same sociological properties can be found".⁵ When a person who could easily interact with others is stigmatised, they are observed with suspicion or other negative emotions, not only when they presents characteristics that testify to their weakness, but also characteristics that could otherwise make a positive impression. Stigma modifies the anticipations in relation to them, and results in the attribution of features that they do not necessarily have, but which are consistent with one's view.⁶ The perception of a human being based on only one attribute, which stands out on the first plan, results in a simplified, only one-dimensional image, without noticing other real features.

Stigma in people with visual impairment is caused by various psychological mechanisms⁷, such as e.g. cognitive dissonance. It can result from misunderstanding of some blind people's behaviours, such as not turning their heads towards the interlocutor. Such behaviour causes discomfort in a sighted person who does not know specific needs of the blind. It can be eliminated, for example, by trying to justify the situation by assuming that the blind is ashamed, shy, or unwilling to interact. Another psychological mechanism may be a sense of belonging to social groups and identification with

⁴ I. Kudlińska, *Stygmatyzacja społeczna jako perspektywa teoretyczno-badawcza (na przykładzie badań nad stygmatyzacją ludzi biednych)*, "Acta Universitatis Lodzianis Folia Sociologica" 2011, no. 38, pp. 52-53.

⁵ E. Goffman, *Piętno. Rozważania o zranionej tożsamości*, translated by A. Dzierżyńska, J. Tokarska-Bakir, GWP, Gdańsk 2005, p. 35.

⁶ *Ibidem*, pp. 34-36.

⁷ E. Jackowska, *Stygmatyzacja i wykluczenie społeczne osób chorujących na schizofrenię - przegląd badań i mechanizmy psychologiczne*, "Psychiatria Polska" 2009, no. 6, pp. 664-666.

“own” group, or those who can see. Then, the group of blind people becomes an unfamiliar group, which is assessed on the basis of simplified schemes and unproven opinions. Yet another mechanism that is applicable to this case is the phenomenon of generalization of behaviour. When it is perceived that a blind person cannot for example read the information on the board about a departing train, it is assumed that they cannot travel independently. Yet another mechanism is the phenomenon of a self-fulfilling prophecy. Because of a stereotypical image of the blind, only these their features which confirm this opinion will be noticed. For example, the belief that blind people are unable to deal with their daily lives independently will result in noticing such phenomena as the fact that they move with the help of a guide in a new area, or that in a new situation they require a description of a room in which they are located instead of paying attention to the fact that in many known situations they will not need this kind of help.

When a person has an attribute that shows their disability, people are inclined to see in them not only other defects, but also other attributes that are not entirely negative, but somewhat embarrassing. Mentioning this, Erving Goffman gives an example of blind people who are often treated as having other disabilities. People, for example, speak loudly to them, as if they suffered from hearing impairment, or support them as if they were lame. Sometimes, they are also treated as possessing the sixth sense, a supernatural way of learning about reality in the situation of being deprived of the main teleanalyzer.⁸

E. Goffman claims that in order to form stigma, the mark has to be not only visible but also intense.⁹ In case of blind people, some of them have clearly visible traits in their appearance which testify to their difference. They include, visible nystagmus, eyeballs inserted into the eye sockets, blindisms manifested by shaking the head, swaying, impoverishment of facial expression. Although there are

⁸ Ibidem, p. 36.

⁹ Ibidem, p. 85.

people whose stigma is invisible even after a closer look, they are also identified as blind on the basis of attributes such as a white cane, dark glasses or a guide dog. It is worth stopping for a moment at this point to confirm that knowledge about people with visual impairment, even as superficial as the one regarding their attributes, is updated on the basis of stereotypical views that are not always reflected in reality, where, for example, relatively few blind people have a guide dog. Although stigma of the blind is usually visible, it does not have to be intense, that is, it does not have to interfere with social interactions. When a blind person walks along the pavement and moves smoothly, can go in the direction they has chosen and does not disturb the path of movement of other people, their stigma is visible, but it does not attract enough attention to assess it as significant. However, during a conversation with a blind person when they have a problem with keeping their eye on the interlocutor, and they look in a different direction than he does, then the interlocutor may feel uncomfortable in this situation and consider their stigma intense.

On the basis of the author's study of the image of people with visual impairment in the eyes of the able-bodied society¹⁰ it can be stated, among others, that although the society has a rather positive view of blind people, it is stereotypical. The respondents attributed to people with visual disability such features as timidity, excessive sensitivity, low self-confidence, patience, seriousness. In the answers of the respondents also typical stereotypes concerning blind people, such as the belief about their passivity, were revealed. One of the reasons for this may be occasional contacts between the respondents and blind people, usually limited to situations when they really need help from sighted members of a society (e.g. at a tram stop when they cannot read the number of the approaching tram). This may favour the division of roles into sighted people, helping

¹⁰ J. Gładyszewska-Cylulko, *Obraz osoby niepełnosprawnej wzrokowo w oczach pełnosprawnego społeczeństwa w kontekście przemian kulturowo-społecznych*, „Wychowanie na co Dzień” 2013, no. 12, pp. 9-13.

(stronger, active, resourceful) and blind people, in need of help (weaker, passive, helpless). What is worth noting, similar results were obtained in countries as culturally and socially different, as Poland and Australia.¹¹

Stigmatization "can be manifested in four forms, as lack of help, avoidance, applying coercion and institutional segregation".¹² Stigmatizing people say, for example, that blind people should learn in special schools, and work in supported employment enterprises. In addition, they are convinced that the blind feel better in their own company and do not need contacts with sighted people. According to Elżbieta Czykwin, being a stigmatized person reduces the sense of control, which affects self-confidence and trust in the world, and also has an impact on undertaking actions aimed at influencing reality, including the social one.¹³ Stigma affects the self-image because "the stigmatizing attitude is a kind of negative social interaction, and according to the fundamental knowledge of clinical psychology, the sense of Self of a human being at different stages of development and adulthood shows a high correlation coefficient with the quality of interpersonal relations. This dependence is causal and bilateral, meaning that low self-esteem (critical self-esteem) increases the likelihood of social rejection and isolation".¹⁴ Danger can arise when stigmatized people start considering the category associated with stigma to be the central Self category. Then, it constitutes "a binder connecting various other elements of the self-image into a coherent whole. The essence of this coherence is the negative emotional stigma and internalization of certain socially

¹¹ J. Gładyszewska-Cylulko, *Postrzeganie możliwości i potrzeb osób niewidomych w Polsce i Australii*, „Niepełnosprawność. Dyskursy pedagogiki specjalnej” 2017, no. 26, pp. 29–43.

¹² P. Corrigan, A. Watson, *Understanding the impact of stigma on people with mental illness*, "World Psychiatry" 2002, no. 1(1), p. 18.

¹³ E. Czykwin, *Stygmat społeczny*, PWN, Warsaw 2007, p. 224.

¹⁴ E. Jackowska, *Stygmatyzacja i wykluczenie społeczne osób chorujących na schizofrenię – przegląd badań i mechanizmy psychologiczne*, „Psychiatria Polska” 2009, no. 6, p. 657.

stereotypic contents".¹⁵ This leads to a sense of vulnerability, worthlessness, reduced control and, consequently, to destruction. E. Czykwin proposes to apply here the term of "mistletoe stigma syndrome", using the analogy to the tree and the mistletoe growing on it. This small plant can lead to the destruction of the tree, being its parasite and taking away its water and mineral salts. And just as the mistletoe hinders the intake of life-giving food by the tree, the stigma placed in the centre of the self-image may cause self-isolation effects, which means that the interactions (also those previously established) become shallower or disappear.¹⁶ In a stigmatized person, a continuous cognitive and affective conflict between the cognitive need for coherence and the emotional need for self-evaluation takes place, because a human being constantly strives for self-verification (or the coherence of observations on oneself) and self-estimation (or the coherence of these observations with information from outside). Nevertheless, the need for self-verification seems to be stronger.¹⁷ Stigmatized people take different ways of dealing with life. The first of these may be the acceptance of the "new self" taking place in different manners. Another one can be the mastery of various areas of activity that at first glance seem to be impossible to learn. They can also use stigma as an explanation for all kinds of life failures. Moreover, they can perceive it as a kind of blessing, enabling a better understanding of the world and people.¹⁸

One of the consequences of stigmatization may be self-stigma. It usually takes place in three stages: first, people marked with stigma become conscious of the stereotype, then they agree with it and finally apply it to their own self. Thus, in order to create self-stigma in a given person, they must be aware of the stereotypical way in which the society perceives them (a blind person in the eyes of the society is generally passive, dependent, needs help from others) and

¹⁵ E. Czykwin, *Stygmat społeczny*, PWN, Warsaw 2007, p. 212.

¹⁶ *Ibidem*, p. 224.

¹⁷ L.A. Pervin, *Psychologia osobowości*, translated by M. Orski, GWP, Gdańsk 2005.

¹⁸ E. Goffman, *Piętno. Rozważania o zranionej tożsamości*, translated by A. Dzierżyńska, J. Tokarska-Bakir, GWP, Gdańsk 2005, pp. 39–44.

agree with it (“Yes, visual impairment actually causes that a person has a tendency to passivity, is rather dependent and needs help from other people”). However, these two stages are not enough for self-stigma to occur, additionally a human being must accept that he has such features. When a person with visual impairment enters an environment, they expect acceptance, which in their opinion belongs to them either by assumption or because of having various attributes (e.g. empathy, creativity, willingness to cooperate). In contrast, they do not arouse any interest, they can face indifference or even ostracism. In this situation, a cognitive dissonance appears between the way they perceive themselves in the environment and the way they are perceived by the environment. One of the methods to deal with this kind of dissonance is to find one’s characteristics that justify the negative behaviour of the environment in relation to oneself. Characteristics that indicate low social attractiveness may become dominating in self-perception, while features that were strong points in confrontation with others may become less significant in the self-evaluation. Sight loss, or limitation of its performance, can become a superior feature, according to which a person with visual impairment determines their social identity, but can also be treated not only as one of features, but an embarrassing attribute that should be hidden from the world. For example, visually impaired people can hide from others that they cannot see well (they pretend to copy from the board, although they are unable to see what was written on it, they do not use optical aids, etc.). They can also try to eliminate from the self-image the fact of “being a person with visual impairment”. For example, they refuse to learn Braille, although the vision disorder progresses, they are reluctant to participate in vision rehabilitation claiming that they do not need it. It also happens that they do the opposite, which means that they take all possible actions to improve their visual performance, or attempt to learn skills that seem to be inaccessible due to their vision disorders, e.g., skiing, playing football. Unfortunately, even if they manage to make progress in this area, they will not become free from their handicap for sighted people.

As it was mentioned above, not all people with visual impairment will develop the phenomenon of self-stigma. Some researchers believe that stigmatizing does not affect the self-esteem of a stigmatized person, or this influence is small. This is because "it is not stigma that affects self-esteem, but rather self-esteem shapes perception and reactions to the experience of stigmatization. Considering this alternative view, all doubts concern the existence of a relationship between stigma and self-esteem, as well as an explanation of this relationship.¹⁹ Worth mentioning here are the results of research conducted by Zofia Palak. They concerned issues focused on the problem of the self-image and the level of self-acceptance in blind youth. They demonstrate that the self-image of blind people did not differ from the image of their sighted peers. Moreover, there were also no major differences between the blind and the sighted in the field of the level of self-acceptance. It should be noted, however, that among blind youth 91.7% were people with congenital vision disorders, or those who experienced anomalies before 5 years of age, so it can be assumed that the factors significantly facilitating self-acceptance in this group were: early start of rehabilitation activities, and acknowledging the level of physical condition as a constant value.²⁰ Acceptance of own disability was also the most important determinant of minimizing the sense of otherness in blind people and people with residual vision in the research conducted by M. Zaorska. This factor was even more important than acceptance from the closest social environment. In these studies, it was also discovered that people who are or were educated within mainstream or integrated education system experience a stronger sense of otherness.²¹ At this point the research conducted by Bruce Link

¹⁹ B. Link et al., *The Consequences of Stigma for the Self-Esteem of People With Mental Illnesses*, "Psychiatric Services" 2001, no. 52(12), p. 1622.

²⁰ Z. Palak, *Obraz własnej osoby młodzieży niewidomej*, UMCS, Lublin 1988, pp. 58-155.

²¹ M. Zaorska, *Poczucie „Inności” u osób niewidomych i osób z resztkami wzroku w sferze funkcjonowania psychicznego, fizycznego i emocjonalnego*, „Interdyscyplinarne konteksty pedagogiki specjalnej” 2013, no. 1, pp. 37-59.

and his team should be mentioned. They concerned the impact of stigma on the self-esteem of mentally ill people. Their results have contributed to understanding the role that stigma plays in the lives of mentally ill people in many aspects. Contrary to the claim that stigma is relatively irrelevant, the obtained results suggest that stigma has a significant impact on the self-esteem of mentally ill people. The researchers based on the social psychology theory, explaining the mechanism by which stigmas affect people. However, as stigma can affect people in numerous ways, they postulate that future research should aim to determine exactly what these mechanisms are, in order to enable the development of effective interventions.²²

As it can be perceived, people deal with stigma situation differently. Some stigmatized people feel anger, being justified in this situation, concerning the way how they are treated and start to fight against the harmful stereotypes, while others do not care about opinions from outside. Currently, researchers are attempting to find the reason for differences between stigmatized people. Attempts have been made to explain these differences by emphasizing that self-esteem is usually formed in early childhood, therefore, children with positive self-esteem, facing stigma, for example at the time of starting school education, is not very important (while in those whose self-esteem based on early childhood experiences was low, experiences related to the stigmatizing attitude of the environment may cause self-stigma). There are also concepts that self-stigma does not arise, because the attitude of the environment is rather ambivalent than uniformly negative. Feelings of disgust, hostility and avoidance coexist with a sense of compassion, and are often suppressed and not shown. Unfortunately, it is inconsistent with the evidence that the society presents behaviours that demonstrate lack of acceptance, even if they are not accompanied by a certain attitude. This is particularly the case when expressing prejudices is not

²² B. Link et al., *The Consequences of Stigma for the Self-Esteem of People With Mental Illnesses*, "Psychiatric Services" 2001, no. 52(12), pp. 1621–1626.

socially undesirable or when people are unable to control their behaviour.²³ J. Crocker and B. Major suggest that stigmatized people may use a mechanism of behaviour consisting not so much in comparing themselves to stigmatizing people as to other stigmatized ones similar to themselves. This allows them to focus on features and qualities other than those that are stigmatized.²⁴ Clinical experience shows that in the case of blind children and youth, being surrounded by young people who are similar to them (e.g. in school and education centres) can be a factor protecting against self-stigma. The inclination to self-stigma will also depend on how quickly the person will experience the manifestations of stigmatization in their life (it may be different in the case of people born blind, and in people who became blind at a mature age). However, at the same time, researchers emphasize that more important than the age, when the process of stigmatization began, is the time that has elapsed since the stigma was acquired. The longer this time is, the more likely a person has already acquired certain strategies to deal with stigma.²⁵

Self-stigma is a more complex phenomenon than initially assumed. Along with the deepening of the insight into the related issues, new doubts, new side scenarios requiring explanation, and new theories that need development appear. Researchers have no doubt that this is an important problem for issues related to the quality of life, emancipation or autonomy of people with disabilities. As a result of the internalization of stigma, they begin to accept discriminatory social attitudes, "which further reduces their self-esteem, leading to the avoidance of any social challenges (e.g. applying for a job)".²⁶ It is proposed that the theories developed so

²³ J. Crocker, B. Major, *Social Stigma and Self-Esteem: The Self-Protective Properties of Stigma*, "Psychological Review" 1989, no. 96(4), pp. 611-612.

²⁴ *Ibidem*, pp. 614-615.

²⁵ *Ibidem*, p. 619.

²⁶ M. Podogrodzka-Niell, M. Tyszkowska, *Stygmatyzacja na drodze zdrowienia w chorobach psychicznych – czynniki związane z funkcjonowaniem społecznym*, „Psychiatr. Pol.” 2014, no. 48(6), p. 1204.

far as well as models for preventing and eliminating this phenomenon should be tested on various subpopulations. Researchers should investigate, for example, whether changes resulting from anti-stigma interventions are maintained over time.²⁷

Because of gaps in knowledge concerning self-stigma, it is difficult to present any universal advice on preventing its negative effects. However, it is possible to try the application of certain methods of prevention, provided that each time they should be selected according to individual cases. According to E. Czykwin, such methods may include, for example, not hiding a stigma, because it may trigger the fear of being unmasked, which in turn may cause isolation from other people, or formation of detached or seemingly close relationships. Instead, she proposes to reveal stigma while interacting with other people, which gives its carrier the opportunity to choose the way of sharing information about stigma and its scope. Another recommended method may be to reduce anxiety between representatives of minorities and the majority resulting from lack of knowledge or lack of contacts between them, for example through the use of humour, presenting attitudes of acceptance and respect.²⁸

Researchers dealing with the problem of auto-stigma in the mentally ill also believe that the attitude towards oneself as a disabled person can be presented on the continuum, with self-stigma at its one end, and the the sense of subjectivity at the other end. Therefore, at the first extremity of the continuum there are people who are unable to overcome negative expectations and stereotypes about mental illness. They have low self-esteem and little confidence in their future success. At the other end there are those who, despite this disability, have positive self-esteem and are not significantly burdened with public stigma. Instead, they seem to be aroused by stigma to achieve empowerment. Identification with a stigmatized group seems to be an important factor in this respect. Although on

²⁷ P. Corrigan, A. Watson, *Understanding the impact of stigma on people with mental illness*, "World Psychiatry" 2002, no. 1(1), pp. 16-20.

²⁸ E. Czykwin, *Stygmat społeczny*, PWN, Warsaw 2007, pp. 268-275.

one hand, stigmatized people, when entering into close relationships with similar people, may internalize negative expectations addressed to each other, on the other hand positive experiences in a group of similar people may positively affect their attitude towards themselves, as well as their self-efficacy. Thus, identification with a group of people with the same type of disability may be a protective factor that reduces the probability that a given person will accept public stigma and apply it to oneself. Preventing self-stigma will involve taking such actions that will result in the lack of occurrence of at least one of the three conditions for the existence of self-stigma, which were presented in the initial part of the article. Apart from the development of positive contacts with representatives of one's group, cognitive work on beliefs (not concerning oneself, but rather the essence of beliefs), knowledge about the mechanism of stigmatization, etc. also seem important.²⁹

P. Corrigan and A. Watson believe that the fight against an unfair stereotypical approach to stigmatized people may involve the use of three strategies. The first of these is a protest sent by the environments of stigmatized people wherever a false image of stigmatized people is presented. The second one is education consisting in carrying out campaigns showing the true image of people so far perceived stereotypically, and the third one is contact with these people.³⁰ In the case of people with visual impairment, examples of such strategies can be social campaigns such as „Czy naprawdę jesteśmy inni?” [“Are we really different?”] presented by the Friends of Integration Association, or “Support Scent” organized by the Guide Dogs Australia, or “Invisible exhibition” – a place where sighted people can perceive the world from the point of view of a blind person.

At the beginning of the present paper, the author quoted the words of Tadeusz Majewski that one of the main tasks of education

²⁹ A. Watson i wsp., *Self-Stigma in People With Mental Illness*, “Schizophr Bull.” 2007, no. 33(6), pp. 1312-1318.

³⁰ P. Corrigan, A. Watson, *Understanding the impact of stigma on people with mental illness*, “World Psychiatry” 2002, no. 1(1), pp. 16-20.

and rehabilitation of the blind and visually impaired is to prepare them for life among sighted people through help in acquiring these skills and abilities that are consistent with the role determined by their age and position in the social environment. The author thinks that in this aspect the greatest danger of the self-stigma in people with visual impairment is that by adopting a stigma, they begin to behave in accordance with wrong expectations of the society. The imposed label unites with them, is assimilated, and treated as a true, obvious, and incontestable one. Self-stigma can become the main obstacle in fulfilling social roles and functioning both in the environment of sighted people as well as outside it. It can negatively affect self-attitude, hinder undertaking actions aimed to improve one's situation, blocks the desire to achieve new goals and pursue plans and dreams. To put it even broader – it may hinder undertaken actions related to education and rehabilitation, as well as negatively affect the processes of autonomy or emancipation. That is why the author thinks that the phenomenon of stigma is worth a closer approach and more thorough understanding, especially in the aspect of finding the preventing factors. Although it is undoubtedly difficult to eliminate existing stereotypes from the social space, and it is difficult to change the self-image of a person who underwent self-stigma, it is, however, possible to intensify actions aimed to strengthen a positive self-image in blind and visually impaired people, improve their social contacts (both with the environment of able-bodied and visually impaired people), increase their sense of subjectivity, as well as develop their autonomy and improve their quality of life in various spheres.

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Communication Skills of Children with Down Syndrome¹

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The purpose of this article is to present the results of a study devoted to the setting of functional cooperation with the interlocutor in children with Down syndrome in a peer group. Analysis of results indicates the relationship between methods of therapy and development of children with Down syndrome. The methods of Alternative and Augmentative Communication (AAC) are important in achieving success in building relationships for children with problems with verbal communication. Secondly, peer group is important to increase social skills. This study shows that children with Down syndrome need similar friends. The above leads to the conclusion that a group with homogeneous disability is the proper area of development.

KEY WORDS: communication skills, peer group, Down syndrome, alternative and augmentative communication (AAC)

The approach to people with disabilities has changed throughout the last century. De-institutionalisation, integration and normalisation have resulted in the fact that more people with disabilities

¹ The text presents selected results of studies from a PhD dissertation, published in a monograph entitled „Wspomaganie rozwoju społecznego dziecka z zespołem Downa w przedszkolnej grupie rówieśniczej”, Oficyna Wydawnicza Atut – Wrocławskie Wydawnictwa Oświatowe, Wrocław 2017.

were able to change their social position. Helplessness and isolation gave way to hope, empowerment, activity, fulfilment and sense of life.

Changes in the attitude towards people with difficulties in development has set a new direction for support which I would like to present using the example of studies conducted among children with Down Syndrome (in a further part of the text, the DS abbreviation will be used). Małgorzata Skórczyńska notes that in the recent times, more emphasis has been placed on supporting the development of children with this syndrome by encouraging them to take part in activities in which they can make use of their skills and talents². Nevertheless, certain specific features accompanying their development will always determine the accomplished successes or experienced failures. In relation to this, the educational needs of such children, understood as learning needs, are fulfilled by taking the individual potential into account, including hindrances and blockades in development which determine the mode and the conditions of meeting such needs. However, this does not form a basis to separate, among all needs of a child, special educational needs. In children with DS, these needs are the same as in their fully able peers. Satisfaction and fulfilment of such needs sometimes requires adjustment of the mode of pedagogical activities to the varied levels of the child's development. Wincenty Okoń emphasises that the purpose of such procedure is to ensure a maximum possibility of development for children with varied capacities³.

Specific features that influence the capacity of children with DS to participate in contacts with other people, as well as learning, have varying intensity in different individuals. They include hypotonia, i.e. weak muscular pressure, which impacts manual and motor skills. Here, as a consequence of the above, it is possible to perceive a more limited participation in games involving movement,

² M. Skórczyńska, *Wspomaganie rozwoju dziecka z zespołem Downa w wieku przed-szkolnym*, [in:] *Wczesna interwencja i wspomaganie rozwoju małego dziecka*, ed. B. Cytowska, B. Winczura, Oficyna Wydawnicza „Impuls”, Kraków 2008, p. 345.

³ W. Okoń, *Nowy słownik pedagogiczny*, Żak Wydawnictwo Akademickie, Warsaw 1998, p. 134.

which constitute one of the basic activities of children. Other features which may affect the functioning of children among peers may include: lower efficiency of speech apparatus, problems with speech and language, slower rate of expressive vocabulary development and lexical and syntactic deficits. Monika Niklasińska examined the manner in which healthy children perceive their disabled peers from kindergarten. She proved that for fully able children from kindergarten, readiness to play, clarity of communications and mode of showing emotions were more important than intellectual skills and external appearance. On account of the inborn desire to establish contact, children with DS excited the desire to offer assistance and care in other children⁴. To confirm this, it is worth comparing results on the functioning of children with autism spectrum disorder, whose unpredictable and unclear behaviour is often the cause of reluctance and rejection by peers. The ability to co-exist in a group is combined with the development of the mind theory, i.e. the ability to read somebody's thoughts and emotions. Children with DS have a high level of empathy, which positively affects the building of contacts in a group. At the same time, it is necessary to be aware of the fact that even though the age of social maturity is moving forward, children with DS will never accomplish full emotional maturity (expressing, recognizing and controlling emotions). It may be concluded that children with DS will better function in simple social situations. Circumstances that are incomprehensible may trigger off difficult behaviour in them⁵. An example of such behaviour that may be observed in the work with kindergarten groups is de-concentration, abandoning play in a circle, talking, provoking other children, fussing with pieces of cloth-

⁴ B. Bartosik, L. Sadowska, A.M. Choińska, *Dojrzałość społeczna dzieci z zespołem Downa rehabilitowanych zgodnie z zasadami Wrocławskiego Modelu Usprawniania w środowisku rodzinnym*, [in:] *Zespół Downa – postępy w leczeniu, rehabilitacji i edukacji*, ed. J. Patkiewicz, Polskie Towarzystwo Walki z Kalectwem, Wrocław 2008, pp. 106–107.

⁵ B. Bartosik, L. Sadowska, A.M. Choińska, *Dojrzałość społeczna dzieci z zespołem Downa rehabilitowanych zgodnie z zasadami Wrocławskiego Modelu Usprawniania w środowisku rodzinnym*, [in:] *Zespół Downa – postępy w leczeniu, rehabilitacji i edukacji*, ed. J. Patkiewicz, Polskie Towarzystwo Walki z Kalectwem, Wrocław 2008, p. 108.

ing, vocalisation, boredom. The teacher's awareness that such behaviour is not a manifestation of the child's bad intentions, but a limited potential in the cognitive realm is crucial for the process of education and therapy. The child's difficult behaviour is not meant to undermine the teacher's position, but it is a cry for the adjustment of methods, forms and means of work to the child's needs.

These children, apart from motor difficulties and difficulties in the area of verbal communication, also suffer from sensory deficits (visual and auditory). Yet first and foremost, psychological processes are less developed; there are difficulties in short-term auditory memory, shorter attention span, cognitive delays, difficulties with generalising, connecting knowledge with previously acquired knowledge and its storage and understanding.

In relation to the above, Alina Smyczek⁶, an expert in the area of alternative and augmentative communication, suggests that situations of multi-sensory cognition should be arranged. Multi-modality of the message consists in the fact that verbal communication (dominant in the instruction-based method of education) is intensified by a non-verbal communication (a look, a gesture indicating places or persons, an item, a manual or a graphic sign). It is necessary to engage various systems of perception, which:

- improves understanding (receptive communication): word + visual stimulus + movement (gesture) increase the chances of understanding the situation and the communication addressed to the child; exhibiting an item/ a graphic sign and/ or a manual sign + uttering a word teaches the child the modes of representing (marking) elements of reality;
- creates conditions for expression (expressive communication): a new code for communication is built - spatial and tactile signs, manual and graphic signs are easier to use for the child; the adult models the potential communication behaviour of

⁶ A. Smyczek, *Zastosowanie wspomagających i alternatywnych metod komunikacji (AAC approach) w terapii małych dzieci zagrożonych poważnymi zaburzeniami w porozumiewaniu się*, [in:] *Alternatywne i wspomagające metody komunikacji*, ed. J.J. Bleszyński, Oficyna Wydawnicza „Impuls”, Kraków 2006, p. 79.

the child; the repertoire, efficiency and speed of transmitting communications by the child in safe conditions increases - there is no threat of being misunderstood by persons from the immediate surroundings.

Children with DS acquire new skills by learning based on the use of the visual channel and ability to learn with the use of gestures and visual signs, e.g. pictures⁷. This leads to the conclusion that supporting the development of such children is possible by applying adequate methods of work (adjusted to the specific development and individual potential, and not applied, for example, on account of the commonly approved efficiency).

An adequate method gives the child an opportunity to develop the modes of communication that are available to him/ her. This is important on account of the second constitutive condition of development of children with DS in the group, i.e. dialogue (even without words) based on ties among children and significant others. Significant others may include peers with DS, fully able peers and teachers or therapists. Being in a communication and in a relation results in the fact that a person feels accepted, important, respected by others and also needed by others. "Rejection, separation and exclusion are painful, because we are no longer in a circle where we are obliged to take care of each other, offer help to each other and where we are liable for each other. This entails being in a depopulated area, in a place of carelessness"⁸.

Study Methodology

As a special education teacher in a kindergarten integration group, I observed children with DS from the point of view of their

⁷ A. Żyta, *Życie z zespołem Downa. Narracja biograficzne rodziców, rodzeństwa i dorosłych osób z zespołem Downa*, Oficyna Wydawnicza „Impuls”, Kraków 2011, p. 38.

⁸ J. Mizińska, *Troska o Innego – potrzeba bycia potrzebnym*, [in:] *Troska o Innego. Szkice humanistyczne*, ed. J. Sośnicka, J. Dobrołowicz, Kieleckie Towarzystwo Naukowe, Instytut Pedagogiki i Psychologii Uniwersytetu Jana Kochanowskiego, Kielce 2011, p. 13.

disrupted development and difficulties in meeting the expectations addressed to them; on the other hand, I saw children among other children who were aiming for establishing relations and who built them in a specific manner. Thus, it was important to perceive social mechanisms and tendencies that transpire in the functioning of such children by means of studies (observation, analysis of behaviour) and to find a way to support psycho-social development of children with DS.

The diagnosis of psycho-social development of children took place on the basis of analysis of documentation, i.e.:

- decision of a psychological and pedagogical clinic about the necessity of special education;
- individual educational and therapeutic programme prepared for every child from year 2010/2011, preceding the year of the experiment;
- daily log of revalidation and didactic classes conducted by a teacher;
- observation book of behaviour of children with DS prepared in the form of socio-grams in the situations of free play, instructed play and organised classes from year 2010/2011;
- talks conducted with children, teachers and educators taking care of the child.

The tools for diagnosis of psycho-social development were P-PAC and P-PAC-1 of H.C. Gunzburg (PAC: Progress Assessment Chart⁹).

Additionally, the "Communication Efficiency Profile" of Magdalena Grycman was determined for every child prior to the implementation of the experimental project of didactic and therapeutic impact¹⁰. The author of the tool suggested that the evaluation of the children's communication efficiency consisted of the ability to communicate information, to build utterances, functional interac-

⁹ T. Witkowski, *Metody PAC i PAS w społecznej rewalidacji upośledzonych umysłowo*, Centralny Ośrodek Metodyczny Poradnictwa Wychowawczo-Zawodowego Ministerstwa Edukacji Narodowej, Warsaw 1988, p. 3.

¹⁰ M. Grycman, *Sprawdź, jak się porozumiewam*, Stowarzyszenie Rehabilitacyjne Centrum Rozwoju Porozumiewania, Kraków 2009, p. 6.

tion with the interlocutor (conversation-based interaction), general attitude and motivation to communication. Based on such tools, I evaluated the communication skills (communication is the sphere least developed and disrupting the functioning of children in the group). Subsequently, I created a programme of tasks and interactive plays developing communication skills. The programme of didactic and therapeutic measures entitled "I Can Speak" was prepared for five children with DS and diversified with respect to the needs and the potential of every child.

When diagnosing the functional interaction with an interlocutor, I used the levels proposed by M. Grycman¹¹:

Level 0: complete lack of interaction during communication: passivity in contacts with the interlocutor, potentially difficult behaviour, e.g. biting and auto-stimulating behaviour, e.g. swinging, hitting the wall.

Level 1: almost complete lack of interaction during communication, one type of communication behaviour from the group or negating or requesting types of behaviour;

Level 2: brief moments of interaction. The other person maintains the conversation, the respondent requires assistance to maintain contact, e.g. the interlocutor says: "I do not understand what you are saying. I will be asking other questions to find it out. Did you mean water?" If the respondent is unable to communicate his/her thoughts, it is possible to observe withdrawing behaviour, e.g. averting eyes from the communication partner, change in mood.

Level 3: clear absence of balance between the role of the speaker and the listener. In the conversation with the child, there are irritating breaks, which result from misunderstandings. There is no balance between the roles of the speaker and the listener. The active person in the dialogue is the speaker. Such person initiates the conversation and keeps it going. During the conversation, the respondent does not withdraw from conversation, he/ she is

¹¹ M. Grycman, *Sprawdź, jak się porozumiewam*, Stowarzyszenie Rehabilitacyjne Centrum Rozwoju Porozumiewania, Kraków 2009, p. 16.

capable of active cooperation in search of proper understanding of the communication that he/ she wishes to impart. He/ she prompts words that may lead the listener in the right direction of the conversation.

Level 4: quite good interaction, yet there are difficulties with maintaining it. No effort is observed in relation to the purpose and direction of the selected form of conversation. It refers to a single subject matter. There may be lack of clarity with respect to the structure related to communication, e.g. a clear commencement, elaboration and end, e.g. the respondent expresses a wish at the beginning: "I want to play with you" when the social standard is to say "hello" to a person whom we see for the first day on a given day.

Level 5: good functional interaction. The respondent has a good feeling of balance between the role of the speaker and the listener. The message is unequivocal, compliant with the subject matter.

In my study, I decided to apply the method of a quasi-experiment. The model of this experiment does not fulfil the randomisation requirement, thence the quasi-experiment (qE). The sampling of groups in my studies was purposive. As a researcher, I did not have the possibility of creating an experimental and control group by random assignment from a common sample (I worked as a teacher in a group of children with DS, assigned to me by the headmasters of the facility). I found an existing control group *in situ*, which seemed similar to the experimental group (in methodology known as a non-equivalent control group)¹². The advantages of the quasi-experimental plan included the possibility of conducting studies in natural and real conditions. In such quasi-experimental plan, the following drawbacks may be indicated: lack of proper control over alternative explanations as to what affects difficulties when formulating unequivocal conclusions. The second weakness of the plan was the researcher's inability to manipulate

¹² E. Babbie, *Podstawy badań społecznych*, translated by W. Betkiewicz, M. Bucholc, P. Gadomski et al., PWN, Warsaw 2013, p. 400.

the independent variable; due to this, it was necessary to determine the direction of cause and effect relation only by logical or theoretical concluding.

Organisation and Area of Study

Out of over 100 public kindergartens and approx. 30 non-public kindergartens in Wrocław, I chose integration facilities in the purposive sampling for the study. Among such kindergartens in purposive sampling, I selected these facilities which have been implementing the premises of inclusive education for groups with uniform disability since 2009 and I looked for children with DS in such kindergartens. The sampling was conditioned by the child's participation in the integration group in which there are 1-4 peers with the same disorder.

Subsequently, I divided the group of 15 children with DS into a control and experimental group. The division was purposive due to the fact that as a researcher, I also acted as the special education teacher, implementing the didactic and therapeutic programme in the experimental group.

In the summer semester of 2010/2011, I prepared an observation book for nine children with DS (in the form of socio-grams), picturing the psycho-social functioning of children in the peer group (five children from the experimental group and four from the control group). The observations were carried out in situations of free play, instructed play and classes organised with respect to interaction with peers.

At the stage of pilot study, it has turned out that communication on the part of fully able children in the direction of observed children with DS is exceptionally rare and non-spontaneous. Lack of mutual understanding resulted in the fact that they were not attractive partners for play and companions in joint tasks. Furthermore, it was clear that children had difficulties with understanding requirements and situations arranged by teachers in the kindergarten,

as well as could not physically handle them on account of weaker, as compared to their peers, motor development. The observation of emotions experienced by children suggested a comparison to emotions that accompany a person who just “missed” a bus (in spite of exercising maximum effort, a person running to the bus stop to which a bus has just arrived, is limited by his/ her capacity; he/ she cannot move faster or stop the driver; emotions experienced by such person when the bus is leaving include anger, regret, frustration, despondence, withdrawal). Such emotions accompanied every child several times a day (e.g. when a peer was quicker to get a ball and played with it; when a peer built a higher tower; when a peer was able to get dressed quickly and without difficulties, and was later praised by the teacher).

The experimental procedure (and thus therapeutic work, conducted individually and in groups) lasted from October 2011 to June 2012. The therapy encompassed stimulation of all spheres of development with special attention given to communication. Verbal communication was accompanied by elements of alternative and augmentative communication: primarily natural gestures and signs derived from the GuK system: Gebarden unterstutze Kommunikation – “gesture-supported communication”¹³), items, item-related tactile symbols, photos, selected PCS symbols, pictograms.

After nine months of therapy, final measurement of the level of psycho-social development of every child was made with the use of PPAC/PAC-1 tool and the profile for evaluation of communication skills by M. Grycman (as in the initial measurement). Individual descriptions of children’s functioning were prepared. What is more, the pre-test and post-test of results accomplished in individual areas were juxtaposed in the form of a table: self-service skills, communication, socialisation, participation in classes.

Such procedure allowed for examining the role of alternative and augmentative communication in the functional development of

¹³ Method from the scope of Alternative and Augmentative Communication, based on gestures and pictures, created by Professor Etta Wilken, who initially worked with children hard of hearing and later with children with Down Syndrome.

interaction with the interlocutor (on account of a very broad scope of studies, I will only present a part of the results that pertain to the subject matter of this text). I was looking for an answer to the question whether and in which degree a child with DS could be taught the communication skills (receiving and sending) with the application of individual therapeutic programmes built on alternative and augmentative communication methods.

Analysis and Interpretation of Study Results

Aleksandra Maciarz¹⁴ emphasised that mastering various types of social skills is conditioned by the formation of motor, physical, emotional, motivation and intellectual disposition in children. In relation to the fact that all children with DS are accompanied by deficits or delays in the above-listed disposition, it was essential to support these areas in a mode that makes their functioning in a peer group easier.

Participant observation and performance of studies in a group where apart from fully able children (15), there were also children with a uniform disorder (in this case, five children with DS) showed that this may be a key solution for supporting social development of children with development difficulties. The group of children with DS started to function within a group that presented models of correct social behaviour. Daily observation of interactions among children with DS led to the conclusion that apart from social development, children stood a chance for a happy personal development.

The observations have shown that the source of the feeling of happiness, safety, joy and satisfaction from contacts among children with DS is the conviction about mutual similarity. Children with DS noticed that they were similar in a number of dimensions: they looked similar, they saw similar behaviour (e.g. stubbornness, hug-

¹⁴ A. Maciarz, *Rewalidacja społeczna dzieci*, Wyższa Szkoła Pedagogiczna, Zielona Góra 1981, p. 23.

ging) and they copied such behaviour, often uncritically. The cause for the feeling of communion were also experiences resulting from the same or similar treatment by teachers and experts (during games and classes, they were usually assigned to one group; they often expected it; the same/ similar requirements were set for them). Children with DS also performed categorisation. A majority of observed children during free play chose children with the same disability as partners. During organised activities, at tables or on the carpet, they chose places close to one another (even when they were assigned places at a distance, they changed them after a moment).

This indicates a close and important bond between the children. Bonds are the foundations for friendship. Having a friend results in the fact that a child has a better opinion about himself/ herself, feels liked and appreciated, has better access to play, which is the basic form of the child's activity. In studies performed by Judy Dunn, four year-old friends also turned out to be similar with respect to the level of understanding the thoughts and feelings of other people, in their verbal capacity and with respect to overall intelligence¹⁵.

Alternative and augmentative communication (AAC) made it easier for children to communicate with their immediate environment. However, the immediate environment is not to be understood as proxemically close, but close on account of bonds and trust which the children had in selected persons. Development of communication skills took place in interactions among children with DS and between children and adults (teacher and other therapists).

Alternative and augmentative communication accompanied children in natural situations; it was a means to an end, and not an end in itself. Mastering of familiarity with gestures and pictures also took place in the office in the form of games and not instruction-based learning. At the moment of commencement of therapy, children communicated with the use of all means available to them, thus the selection of the system of signs took into account their communication skills.

¹⁵ J. Dunn, *Przyjaźnie dzieci*, Wyd. Uniwersytetu Jagiellońskiego, Kraków 2008, p. 53.

By means of the proposed impact, the basic direction of social development has been set. Children, thanks to the use of gestures, pictures and vocalisation became more and more independent, self-confident, composed and ready to undertake tasks. The outcomes included new (socially accepted) forms of behaviour, new interests, extension of the circle of friends, ability to enter into social interactions conditioned by readiness for verbal and non-verbal communication.

A social individual not only co-exists with others, but also cooperates with them. The studies led to the conclusion that children with DS are able to adjust to daily life in various degrees. This is primarily determined by the degree of development disorder. The second factor is the environment which should look for a place of meeting, a dialogue beyond such disorder. In children who were offered assistance in the form of AAC, it was possible to see progress in the area of communication skills. The range of improvement of this area after a year of work was different in the case of every child.

Paulina¹⁶ at the beginning of the study primarily used vocalisation and communicated clear "yes" / "no". After nine months, the girl's dominant forms of communication were gestures; she showed a number of daily-use items and activities: doll, fish, bread, yoghurt, cat, dog, banana, apple, car, train, eat, sleep, drink, dress, play on the computer (with an intention that she needed this item or activity); she used simple words - mum, dad, Mata - Marta (sister), Basia (babysitter), Aga (teacher).

Mateusz mainly communicated via mimicry and single words and treated gestures as a play and did not transfer their functions to daily life. He usually copied them after other children without any intention. It seemed that he wanted to get close to them through such activity. In line with his parents' decision, after the end of the school year he continued education in a special school.

¹⁶ Children's names were changed.

Kuba advanced from vocalisation and gestures to communication with the use of simple sentences, consisting of 3–4 words, e.g. “Karol goes to the swimming pool”, “Aga, don’t go home”.

Adrian, after a year of systematic exercises, communicated with the use of gestures and did it so fast that it was often difficult to keep up with the course of “recounted” events. He told entire stories, which testifies to his smartness and development of cause-and-effect thinking; he re-enacted scenes from fairy-tales, e.g. he used gestures to re-enact Zig-Zag McQueen that moves fast, suddenly stops because he drove into a nail; Adaś took out a jack, lifted the car, changed the type, wiped dirty hands on his trousers, then wiped his forehead, got into the car, waved goodbye and drove off.

Wiktoria: she vocalised and gestured a lot; words in the form of elision started to appear: mum, dad, Róża (sister), “Aa” (Aga – teacher), “Aś” (Adaś), “Ol” (Karol). She expected, similarly to Adaś, that her language would be commented on.

In a situation when I incorrectly interpreted a gesture or vocalisation, children said “no” or shook their heads/ fingers and repeated the gesture slower and more precisely. Here, it is possible to draw an analogy to a situation when a foreigner arrives in a country whose language he/ she does not know and has to ask for directions. Even though the native explains and repeats the words slowly and loud, maintaining eye contact, this does not result in understanding of the message, as it is still in an unknown language. Meanwhile, it is sufficient to change the verbal code for a gesture or a map drawn on a piece of paper to understand each other.

The observations of children (for subsequent four years, I was a special education teacher in a facility attended by children who took part in the experimental procedure) led to the conclusion that manual signs positively influence learning of speech. All children started to use verbal communication in a smaller or greater degree.

Learning of manual, graphic, spatial and tactile signs very often starts too late. The main reason may be fears that teaching a child alternative communication may hinder the development of speech. Meanwhile, speech and alternative forms of communication do not exclude each other.

Efficient communication is a great personal accomplishment for a child, which results in causal joy and the necessity of improving contacts with significant others.

The characteristic features of behaviour of children who had the possibility of compensating verbal communication with the use of gestures or pictures were harmony and peace. Children were more willing to undertake renewed attempts at communicating when they were misunderstood, and they looked for other ways because they were aware that the environment wanted to understand them. Such behaviour of clemency, high spirits, fearless acceptance of challenges transferred to social behaviour. The frequency of biting and shoving among children with DS (this was often the line of self-defence, when a fully-able peer was physically and verbally stronger in a conflict for a toy) was reduced. Children with DS could approach a teacher and show who harmed them or even re-enact the scene in which they were wronged.

Thanks to thematic boards, it was possible to maintain a dialogue with children in which they decided about its course.

Children did not communicate with everybody with the use of gestures and pictures. They consciously chose a person with whom they wanted to talk. Most frequently, these were peers with DS, fully able peers with mild and caring nature or adults. Children knew who wanted and was capable of interacting and communicating with them. These persons were often included in games organised by children with DS. It may be said that a certain culture of play has developed among these children. It was dominated by simple and clear rules, which could be explained with the use of gestures. Here, it was possible to see the greatest application of gestures which the children learnt via augmentative communication. The rules of a play could be understood also from the prepared aids, e.g. a thematic play "birthday": the children prepared a table, settings, draw a birthday cake on a card, pretended that they played "Happy Birthday" on guitar (the teacher, when one of the members of the group had birthday, usually played "Happy Birthday" on guitar – and children carefully re-enacted this scene in their play).

Another form were theatre scenes where they re-enacted situations that they saw in the past (from fairy-tales, films, other theatre plays) or used puppets to do it. In spite of the fact that there were no verbal parts here, children tried to communicate the content of the play most faithfully with the use of mimicry, gestures and proxemics. They engaged a lot of emotions and were able to re-enact emotions of characters of the play (through this, they learnt to express them). They also set up the audience, welcomed the viewers to watch the performance by gestures and subsequently encouraged them to applaud.

In task-based situations, thanks to gestures and pictures, it was possible to maintain the children's attention for longer periods of time. This was the result of the fact that they understood the tasks better. Even though they were frequently unable to finish a task independently, yet with maintenance of attention and thanks to visual instruction, it was easier for them. Furthermore, it is important to give the child more time to understand the information that was heard and to prepare an answer, which results from delayed time of reaction, characteristic for children with DS.

Recapitulation and Conclusions

Summing up, the specific nature of neurological development of children with DS affects their learning. However, knowledge about such development among teachers and parents makes us liable for searching for methods thanks to which the child will more efficiently internalise specific materials and skills. Determination of specific features of development, i.e. an individual profile of the child's weak and strong sides sets the direction of work.

Children with DS, just as all other children, in a mode more or less clear for the environment, aim for contacts with other people, in particular their peers. They try to establish contacts due to various reasons, e.g. social ones, guided by the desire to communicate what

they think and feel in a given moment, to receive information that is important for them, to communicate a desire or to procure assistance for others. The necessity of establishing such contacts is often released by the situation conducive to communication, e.g. via play. The ability to communicate and to receive linguistic and verbal, correctly constructed communications which are one of the significant features for man, is sometimes hardly available for persons with DS. However, in reality they handle this problem well. In a communication situation, they use the means that are available to them and that assist their communication with the environment, i.e. various types of gestures, mimicry, important proxemic signs for the recipient. Communicating information not only takes place verbally, but also non-verbally (non-verbal communication). Non-verbal signals may be communicated and received via the oral and auditory channel, oral, auditory and kinesic channel or kinetic, optical and emotional channel, which facilities – in particular for children with DS – establishment of contacts with the environment¹⁷.

Summing up, the fundamental task for the organisers of kindergarten education is to build such conditions where children with disabilities will have peers that are similar to them (in various respects). Conviction about mutual similarity brings them closer and protects them from loneliness. Groups with a homogeneous disorder are undoubtedly a good solution in this respect. This results from the fact that they offer a possibility of identifying with somebody who has a similar potential and limitations, which, in effect, builds a feeling of safety. Such safety is a foundation for establishment of bonds conditioning a person's development in all areas. Establishment of bonds also via multi-modal communication with the child affects his/ her happier functioning in the environment.

¹⁷ E.M. Minczakiewicz, J.J. Bleszyński, *Niepełnosprawność intelektualna jako zaburzenie współwystępujące*, [in:] *Diagnoza i terapia logopedyczna osób z niepełnosprawnością intelektualną*, ed. J.J. Bleszyński, K. Kaczorowska-Bray, Wydawnictwo Harmonia, Gdańsk 2012, p. 79–80.

A person who wishes to contact the child (a teacher, a peer) searches for paths of understanding and makes the child fully accepted the way she/ he is.

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Coding of word formation structures by children/adolescents with deeper intellectual disability (on the example of the category of the tool names)

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Word formation plays an important role in the child's linguistic and cognitive development, because the ability to interpret word formation structures and active use of the knowledge of derivation rules are the most important manifestations of linguistic competence at the lexical level. The aim of the article is a linguistic interpretation of selected names of tools obtained from children and adolescents aged 6–19 with diagnosed moderate and severe intellectual disability.. In the article, the author would like to draw attention first of all to the existence of word-formation structures in the linguistic awareness of children / adolescents and to the fact whether newly formed words are created in accordance with word-formation patterns existing in the Polish language or they diverge from these patterns.

KEY WORDS: word formation, tool names, word formation skills, moderate and severe intellectual disability

Introduction

Word formation plays an important role in the child's linguistic and cognitive development¹. Words very early begin to mediate in the child's perception of the surrounding world and exert a decisive influence on the development of their cognitive processes. From the earliest moments of life, children strive to understand the world: they ask questions, want to know, and search for adequate names. Nomination is very important, because children really get to know people, things, objects only at the time when they distinguish them using a separate name. Until a referent has a name in the child's personal language, it remains an unidentified part of paralinguistic reality². As stated by Amelia Dziurda-Multan: "In a personal language, children refer to reality, denominate it and reveal their attitude towards it. They name every object, person, thing, phenomenon using an appropriate name"³. Ida Kurcz, on the other hand, ascertains that the human cognitive system categorizes the world, allows distinguishing in it sets of real objects and phenomena, and creating categories. A special group are ontological categories that serve to systematize and interpret the image of the world, e.g. categories of things, movement, place, activity, event, state, quantity, manner, property, time, cause, God and human person. The categorization process is a process of creating a system of concepts in the mind of a small child⁴.

¹ E. Muzyka-Furtak, *Kwestionariusz słowotwórczy w ocenie kompetencji językowej dzieci z zaburzeniem słuchu*, [in:] *Metody i narzędzia diagnostyczne w logopedii*, ed. M. Kurowska, E. Wolańska, Dom Wydawniczy Elipsa, Warsaw 2015, p. 251.

² A. Dziurda-Multan, *Dziecięce sposoby tworzenia nazw*, Wydawnictwo Katolickiego Uniwersytetu Lubelskiego, Lublin 2008, p. 19, 155.

³ A. Dziurda-Multan, *Dziecięce sposoby tworzenia nazw*, Wydawnictwo Katolickiego Uniwersytetu Lubelskiego, Lublin 2008, p. 7.

⁴ I. Kurcz, *Język a psychologia*, WSiP, Warsaw 1992, pp. 223–225; I. Kurcz, *Psychologia języka i komunikacji*, Wydawnictwo Naukowe „Scholar” Warsaw 2000, pp. 160–161, 167.

As confirmed by the most important word-formation theories, e.g. the theory of apperception of Jan Rozwadowski⁵, the logical-syntactic theory of Witold Doroszewski⁶, the theory of Miłosz Dokulił⁷ or the cognitive theory⁸, the language builds the image of the world in human minds, and constituting a system of social categories, unifies cognition⁹. Therefore, a relationship between cognitive and linguistic processes is clearly visible on the word-formation level of language.

Perception and naming the world and its elements by children/adolescents with intellectual disability

The acquisition of linguistic competence by children is not an easy process, especially in field of the Polish language, characterized by the richness of word forms and the complexity of principles for word and sentence construction.

Intensive development of vocabulary as well as grammatical structures connected with the development of children's cognitive processes: memory, observation and attention, is observed in children with typical development at pre-school age¹⁰, when children

⁵ J. Rozwadowski, *O zjawiskach i rozwoju języka*. 9. *O dwuczłonowości wyrazów*, „Język Polski” 1921, vol. 6, p. 129-139.

⁶ W. Doroszewski, *Kategorie słowotwórcze*, „Sprawozdania z posiedzeń Towarzystwa Naukowego Warszawskiego”, Wyd. I, 1946, vol. XXXIX, pp. 18-39.

⁷ M. Dokulił, *Teoria derywacji*, translated by A. Bluszcz, J. Stachanowski, Ossolineum, Wrocław 1979.

⁸ R. Grzegorzczkowska, B. Szymanek, *Kategorie słowotwórcze w perspektywie kognitywnej*, [in:] *Współczesny język polski*, ed. J. Bartmiński, Wydawnictwo Uniwersytetu Marii Curie-Skłodowskiej, Lublin 2001, pp. 469-484.

⁹ S. Grabias, *Język, poznanie, interakcja*, [in:] *Język. Interakcja. Zaburzenia mowy. Metodologia badań*, ed. T. Woźniak, A. Domagała, Wydawnictwo Uniwersytetu Marii Curie-Skłodowskiej, Lublin 2007, p. 376.

¹⁰ In the literature on the subject, it is stated that a child in the second year of life discovers that every thing has its own name (cf. Aitchison 2002, p. 128; Stawinoga 2007, p. 65).

assimilate a language system, i.e. a specific lexical resource and basics of grammar from its environment¹¹.

The explosion of naming, the desire to denominate everything around consists in labelling what is within the field of vision and leads to children becoming aware of the fact that words are symbols that refer to things. Next, the label is extended to other elements of the same type¹². The perceived objects first as a whole (or a set of features) are attributed to a particular conceptual class and in this way new phenomena are assigned to the general class of concepts known earlier, and then, based on a distinctive feature, they are distinguished from other similar elements of this class¹³.

Word formation development cannot be considered in isolation from the formation of the dictionary. When considering word-formation phenomena from this perspective, first, the following question should be asked: what do children have to do to learn the words of a given language?

First of all, as emphasized by Ewa Muzyka, they must learn to isolate words in the speech stream, extract parts of words and identify topics, inflectional endings and affixes. Secondly, they must learn to recognize potential meanings of individual elements, reaching to various ontological categories established to represent and organize the surrounding world, the category of objects, activities,

¹¹ H. Borowiec, *Kategorie interpretowania rzeczywistości w języku dzieci*, [in:] *Język – interakcja – zaburzenia mowy. Metodologia badań*, ed. T. Woźniak, A. Domagała, Wydawnictwo Uniwersytetu Marii Curie-Skłodowskiej, Lublin 2007, p. 107; see also M. Zarębina, *Kształtowanie się systemu językowego dziecka*, Ossolineum, Wrocław 1965; M. Zarębina, *Język polski w rozwoju jednostki. Analiza tekstów dzieci do wieku szkolnego. Rozwój semantyczny języka dziecka*, Wydawnictwo Naukowe WSP, Kraków 1980; L. Kaczmarek, *Nasze dziecko uczy się mowy*, Wydawnictwo Lubelskie, Lublin 1966; M. Chmura-Klekotowa, *Neologizmy słowotwórcze w mowie dzieci*, „Prace Filologiczne” 1971, no. 21, pp. 99–235; M. Mnich, *Sprawność językowa dzieci w wieku wczesnoszkolnym*, Impuls, Kraków 2002.

¹² R. Stawinoga, *Twórczość językowa dziecka w teorii i praktyce edukacyjnej*, Wydawnictwo Uniwersytetu Marii Curie-Skłodowskiej, Lublin 2007, p. 65.

¹³ E. Muzyka-Furtak, *Twórczość wyrazowa dzieci 7-letnich*, „Logopedia” 2011, vol. 39/40, p. 57.

relations, and properties. Thirdly, they must learn to represent potential meanings with the identified word forms¹⁴.

In order to be able to correctly recognize, determine or create a morphemic structure of words, children should have a modelled image of their categorical significance, be able to see differences expressed by the affix and differentiate lexically (fruit, fruity, **fruitful**), understand derivation with a phonetic exchange (**róg-rożek** [horn, small horn]), recognize grammatical categories of words and their integration in the complete meaning¹⁵.

Gradually, individual thematic ranges are extended with new words that expand the network of semantic connections¹⁶.

According to the author, the general directions for acquisition of vocabulary by children can be summarized as follows:

- first understanding, then production,
- first the content words, then the functional ones,
- first concrete, then abstract,
- first related to the situation, then detached,
- first nouns, then verbs, pronouns, adjectives, adverbs, and finally prepositions and conjunctions,
- first the concepts from the basic level, then from the inferior and superior level,
- first unclear meanings (extended/narrowed), then definite ones,
- first words without inflection, then grammatically marked ones¹⁷.

The development of vocabulary is intertwined with the development of grammar skills, the foundations of which are learnt very early by Polish-speaking children¹⁸.

¹⁴ E. Muzyka, *Sposoby interpretowania konstrukcji słowotwórczych przez dzieci niesłyszące*, „Logopedia” 2007, vol. 36, p. 98.

¹⁵ A. Giermakowska, *Ocena kompetencji słowotwórczej uczniów z trudnościami w czytaniu i pisaniu na poziomie edukacji wczesnoszkolnej*, „Szkoła Specjalna” 2012, vol. 5, p. 357.

¹⁶ A. Wątopek, *Kompetencja językowa uczniów z lekką niepełnosprawnością intelektualną*, Nomos, Kraków 2014, p. 17.

¹⁷ A. Wątopek, *Kompetencja językowa uczniów z lekką niepełnosprawnością intelektualną*, Nomos, Kraków 2014, pp. 16–17.

¹⁸ E. Łuczyński, *Fleksja języka polskiego z punktu widzenia ontogenezy mowy*, „Biuletyn Polskiego Towarzystwa Językoznawczego” 2002, vol. 58, p. 158.

There is evidence, as reported by Wątopek, that even small children analyse the internal structure of words, separating them into morphemes. One of the proofs is the ability of three-, four-year-old children to generate their own words, or so-called children's neologisms. Following a pattern of familiar words, through numerous analogies, children create new names needed for communication at a given moment¹⁹.

In cognitive terms, the ability to discriminate is essential for the development of linguistic communication. Speck emphasizes that children should learn to perform four forms of discrimination, there they must:

1. Understand that the symbol (word) refers to a specific object or that it represents, for example, an object or activity.
2. Distinguish between different conditions in a given environment, which differ from one another and which are identified and categorized through own language system, that is, distinguish between things and processes.
3. Distinguish between various language symbols; the point is to properly distinguish between similarly sounding symbols, e.g. *stift* "pencil" and *schiff* "ship", as well as see fundamental differences, for example between a *cow* and *scissors*.
4. Make distinctions between different order of symbols, that is, different word order in a sentence. It matters if we say "the door is closed" or "is the door closed" or: "Mark leads Ann" or "Ann leads Mark"²⁰.

The above comments apply to children with typical development. The perception and naming the world and its elements look slightly different in children with intellectual disability.

In the literature on the subject, attention is drawn to the fact that intellectual disability is not only a "delay of development, but

¹⁹ A. Wątopek, *Kompetencja językowa uczniów z lekką niepełnosprawnością intelektualną*, Nomos, Kraków 2014, p. 17.

²⁰ K. Kaczorowska-Bray, *Kompetencja i sprawność językowa dzieci z niepełnosprawnością intelektualną w stopniu znacznym, umiarkowanym i lekkim*, Wydawnictwo Uniwersytetu Gdańskiego, Gdańsk 2017, p. 104.

a different quality of development"²¹, to the inharmoniousness of this development, a completely different life experience of children with this dysfunction²², to the fact that "activities of the highest organization or those which were formed at the end in phylogenesis and ontogenesis, which are above all thinking and speech²³, are developmentally retarded and delayed to the greatest extent", finally, that the dictionary used by these children is poor, agrammatisms persist for a long time, different types of speech disorders are reported²⁴.

Disturbances in the subjective (individual), and therefore cognitive, motivational and emotional determinants of the acquisition and use of language, are, as reported by Kaczorowska-Bray, inscribed in the definition of mental disability²⁵.

In literature, on the one hand, it is emphasized that in children with moderate intellectual disability, the ability to understand reality and formulate conclusions about it is significantly reduced²⁶, and

²¹ H. Nartowska, *Opóźnienia i dysharmonie rozwoju dziecka*, WSiP, Warsaw 1980, p. 106.

²² J. Kostrzewski, *Różnice profilu inteligencji, niektórych uzdolnień oraz w cechach motoryczności dzieci umysłowo upośledzonych i normalnych*, [in:] J. Kostrzewski (ed.), *Z zagadnień psychologii dziecka umysłowo upośledzonego. Materiały pomocnicze do psychologii upośledzonych umysłowo*, vol. 1, Wydawnictwo WSPS im. M. Grzegorzewskiej, Warsaw 1978; J. Kostrzewski, *Podstawy współczesnej diagnostyki psychologiczno-klinicznej niedorozwoju umysłowego u dzieci*, J. Kostrzewski (ed.), *Z zagadnień psychologii dziecka umysłowo upośledzonego. Materiały pomocnicze do psychologii upośledzonych umysłowo*, vol. 1, Wydawnictwo WSPS im. M. Grzegorzewskiej, Warsaw 1978.

²³ H. Nartowska, *Opóźnienia i dysharmonie rozwoju dziecka*, WSiP, Warsaw 1980, p. 102.

²⁴ M. Bogdanowicz, *Psychologia kliniczna dziecka w wieku przedszkolnym*, WSiP, Warsaw 1985, pp. 88–89.

²⁵ K. Kaczorowska-Bray, *Zaburzenia komunikacji językowej w grupie osób z niepełnosprawnością intelektualną*, [in:] J.J. Bleszyński, K. Kaczorowska-Bray (ed.), *Diagnoza i terapia logopedyczna osób z niepełnosprawnością intelektualną*, Harmonia Universalis, Gdańsk 2012, p. 42.

²⁶ J. Kostrzewski, *Charakterystyka osób upośledzonych umysłowo*, [in:] K. Kirejczyk (ed.), *Upośledzenie umysłowe – Pedagogika*, PWN, Warsaw 1981; M. Bogdanowicz, *Psychologia kliniczna dziecka w wieku przedszkolnym*, WSiP, Warsaw 1985; R. Kościelak,

on the other hand, that they are able to give meaning to objects, have the ability to detach their thinking from the data of the current perception, they begin to consider various aspects (e.g. length, height, colour), as well as mutual relations between the features of objects, although the ability to extract important details, characteristics of phenomena and objects is significantly reduced²⁷. The beginnings of understanding the relation of the part to the whole, the relation occurring between the superior and inferior concepts can also be observed in these children²⁸. Children with moderate intellectual disability also have serious problems in remembering, storing, recognizing and reproducing information²⁹.

Children with severe intellectual disability are, as reported by Lidia Cierpiałkowska³⁰, a group similar to moderate intellectual disability in terms of both the clinical picture, as well as the genesis, pathomechanism and the co-occurring neurological and psychological disorders. However, the capacity level of all intellectual functions is lower. Conceptual and verbal thinking is deeply impaired³¹.

Psychologiczne podstawy rewalidacji upośledzonych umysłowo, PWN, Warsaw 1989; L. Cierpiałkowska, *Psychopatologia*, Wydawnictwo Naukowe Scholar, Warsaw 2007.

²⁷ J. Głódkowska, *Pomóżmy dziecku z upośledzeniem umysłowym doświadczać przestrzeni. Orientacja przestrzenna w teorii, diagnozie i rozwoju dziecka*, WSPS, Warsaw 2000, s. 66; L. Cierpiałkowska, *Psychopatologia*, Wydawnictwo Naukowe Scholar, Warsaw 2007.

²⁸ As in: E. Kudłacik, *Poziom funkcjonowania dzieci głębiej upośledzonych umysłowo w wieku przedszkolnym w zakresie porozumiewania się oraz umiejętności słuchowo językowych i wzrokowoprzestrzennych*, [in:] E. Minczakiewicz (ed.), *Komunikacja – mowa – język w diagnozie i terapii zaburzeń rozwoju u dzieci i młodzieży niepełnosprawnej*, Wydawnictwo Naukowe AP, Kraków 2002, pp. 40–69.

²⁹ J. Kostrzewski, *Charakterystyka osób upośledzonych umysłowo*, [in:] K. Kirejczyk (ed.), *Upośledzenie umysłowe – Pedagogika*, PWN, Warsaw 1981; M. Bogdanowicz, *Psychologia kliniczna dziecka w wieku przedszkolnym*, WSiP, Warsaw 1985; R. Kościelak, *Psychologiczne podstawy rewalidacji upośledzonych umysłowo*, PWN, Warsaw 1989; L. Cierpiałkowska, *Psychopatologia*, Wydawnictwo Naukowe Scholar, Warsaw 2007.

³⁰ L. Cierpiałkowska, *Psychopatologia*, Wydawnictwo Naukowe Scholar, Warsaw 2007, p. 178.

³¹ E. Kudłacik, *Poziom funkcjonowania dzieci głębiej upośledzonych umysłowo w wieku przedszkolnym w zakresie porozumiewania się oraz umiejętności słuchowo językowych*

Incorrect course of speech development and incorrectly formed mechanisms of its functioning cause that it does not properly fulfil its role "as a factor supporting the reception of denominated phenomena and as a factor of generalization (of a concept) that drives all adjustments of (new) received information to the former ones present in the memory "deposit", arranged in models defined by words"³².

Disturbances of linguistic communication, visible on every level of the language description (phonology, morphology, syntax, semantics and pragmatics), deplete the process of expressing meanings, recognizing thoughts and reaching reality (culture)³³.

Children with intellectual disability are usually described as those preferring concrete vocabulary in their vocabulary resources³⁴.

Researchers agree that assimilation of concrete vocabulary and semantic relationships occurs in children with intellectual disability and in normal children in the same way, although in the first group at a definitely slower pace. The advantage of vocabulary with a concrete meaning increases with the profoundness of disability³⁵.

Research conducted by Tadeusz Gałkowski³⁶, allowed assessing the state of development of passive and active vocabulary within

i wzrokowoprzeznaczonych, [in:] E. Minczakiewicz (ed.), *Komunikacja – mowa – język w diagnozie i terapii zaburzeń rozwoju u dzieci i młodzieży niepełnosprawnej*, Wydawnictwo Naukowe AP, Kraków 2002, p. 41.

³² Z. Tarkowski, *Mowa osób upośledzonych umysłowo i jej zaburzenia*, [in:] T. Gałkowski, E. Szelaż, G. Jastrzębowska (ed.), *Podstawy neurologopedii. Podręcznik akademicki*, Uniwersytet Opolski, Opole 2005, p. 588.

³³ M. Michalik, *Kompetencja składniowa w normie i zaburzeniach. Ujęcie integrujące*, Wydawnictwo Naukowe Uniwersytetu Pedagogicznego, Kraków 2011, p. 178.

³⁴ M.R. Griffer, *Language and children with intellectual disorders*, [in:] V.A. Reed (ed.), *An introduction to children with language disorders*, M.A. Pearson, 4th ed., Boston 2012; J.J. Bleszyński, *Niepełnosprawność intelektualna. Mowa – język – komunikacja. Czy iloraz inteligencji wyjaśnia wszystko?*, Harmonia Universalis, Gdańsk 2013.

³⁵ M. R. Griffer, *Language and children with intellectual disorders*, [in:] V.A. Reed (ed.), *An introduction to children with language disorders*, M.A. Pearson, 4th ed., Boston 2012, pp. 250–251.

³⁶ T. Gałkowski, *Dzieci specjalnej troski. Psychologiczne podstawy rehabilitacji dzieci opóźnionych umysłowo*, Wiedza Powszechna, Warsaw 1979, pp. 194–195.

eleven categories (everyday objects, body parts, animals and birds, toys, vegetables and fruits, vehicles, parts of clothing, people, sizes, shapes, colours) in the group of children with severe disability. The obtained results confirmed that in both vocabularies concrete vocabulary, useful for children in numerous life situations, was dominant. Everyday objects, body parts, names for animals and birds, toys obtained the highest ranks.

The vocabulary used by children with moderate and severe disability has often a different meaning than the dictionary one: a small number of words present in their lexical resource must serve the child in many situations, hence the presence of specific "keywords". It is true that the use of a word in a broader than dictionary meaning occurs in all children, but in the case of children with intellectual disability, it concerns a significant part of the vocabulary resource³⁷.

Coding of word formation by children/adolescents with deeper intellectual disability, methodological issues

A. Aim of the paper

The aim of the paper is the linguistic interpretation of selected names of tools obtained as a result of pilot studies in one of the rehabilitation, education and remedial centres in the Łódź Voivodeship. The aim of the pilot studies is to answer the question whether to include children/adolescents with deeper intellectual disabilities in the research concerning the acquisition of word formation rules.

In the article, the author would like to draw attention: a) to the way of existence of word formation structures in the linguistic awareness of the subjects; b) to the fact whether the newly created words are formed in accordance with the word formation patterns existing in the Polish language, or whether they diverge from these patterns.

³⁷ K. Kaczorowska-Bray, *Kompetencja i sprawność językowa dzieci z niepełnosprawnością intelektualną w stopniu znacznym, umiarkowanym i lekkim*, Wydawnictwo Uniwersytetu Gdańskiego, Gdańsk 2017, p. 137.

B. Study group

The study group consists of children and adolescents aged from six to nineteen with diagnosed moderate and severe intellectual disability with multiple disability. These people cannot fulfil their schooling obligation in public schools. Out of 39 children attending the centre, originating from similar backgrounds, only eight (six with moderate disability and two with a severe one) fulfil the condition of research, or communicate verbally with the environment. At the stage of pilot studies, data on the sex of the respondents were treated as insignificant. Furthermore, such a large age range was assumed intentionally, the criterion was the fulfilment of schooling obligation.

C. Research procedure

In the studies concerning assimilation of word formation rules in the process of language acquisition, should concentrate on, above others, the assessment of understanding (reception, decoding, interpreting) and creating (expression, coding) of word formation structures.

The ability to understand and create word formation structures is treated as follows, according to Ewa Muzyka-Furtak:

- understanding is a formal and semantic analysis of constructions, decoding meanings of constituent elements of formations, is the interpretation of word formation constructions, consistent with social arrangements and own experience;
- creating is a formal and semantic synthesis of features constituting the meaning of constructions, is the encoding of meanings into a word formation construction, is the production consisting in recalling specific units formally and semantically connected with a specified set of semantic features, from own lexical resource³⁸.

³⁸ E. Muzyka-Furtak, *Konstrukcje słowotwórcze w świadomości językowej dzieci niesłyszących*, Wydawnictwo Uniwersytetu Marii Curie-Skłodowskiej, Lublin 2010, p. 80.

The source of the gathered information about word formation competences in children are in this case experimental tests, consisting in asking, under conditions, which are favourable for children, of properly formulated questions in order to extract a specific word form.

In terms of the scope of research, exploration and analysis covered two types of skills that assess the level of acquisition of word formation rules, or skills of understanding (decoding, interpreting, reception) and creating (coding, expressing) derivative words.

The article is limited to the discussion of coding skills for names belonging to one selected word formation category, or the category of tool names, according to the classification of Renaty Grzegorzycykowa³⁹. The questionnaire contains twenty five questions concerning names of the tools. Regarding the rule of selection of the study material, mainly the distribution criterion was applied.

In terms of coding, the questionnaire checked the ability to create a name based on a word formation paraphrase or, in the case of difficulties, the ability to create on the basis of a set of semantic features expounded from the structural importance of the formation⁴⁰. As a support, a pictorial questionnaire was also used.

The questionnaire was completed individually with each child. Each child was instructed how the test would look like and what was expected from the child. Furthermore, exemplary answers were presented to each child.

Coding of word formation by children/adolescents with deeper intellectual disability, conclusion from the study

Language expresses feelings, observations and thoughts of a small human being connected with reality⁴¹. As emphasized by Stefan

³⁹ R. Grzegorzycykowa, *Zarys słowotwórstwa polskiego. Słowotwórstwo opisowe*, PWN, Warsaw 1982.

⁴⁰ E. Muzyka-Furtak, *Konstrukcje słowotwórcze w świadomości językowej dzieci niesłyszących*, Wydawnictwo Uniwersytetu Marii Curie-Skłodowskiej, Lublin 2010, p. 81.

⁴¹ A. Dziurda-Multan, *Dziecięce sposoby tworzenia nazw*, Wydawnictwo Katolickiego Uniwersytetu Lubelskiego, Lublin 2008, p. 89.

Szuman, thoughts of children are processes in which they not only denominate an object with an appropriate name, but processes in which the small human being claims something about the features of the object, the relationships it can enter with other objects, the activities the object performs, the functions it fulfils. If thoughts of children did not have a nominative basis, that is, if they could not adequately name the objects they perceive, they could not include them in their vocabulary⁴². Amelia Dziurda-Multan adds that "children first distinguish features necessary for the performance of practical activities in objects and then their concepts of everyday objects are created"⁴³.

Conclusions regarding the ability to create word formation constructions by study children/adolescents with moderate intellectual disability:

Children/adolescents are good at coding (creating, expressing) certain tool names, cf. *budzik* [alarm clock] (6,1; 15,6; 17,11; 19,1; 19,6)⁴⁴, *drukarka* [printer] (17,11; 19,1; 19,6), *dźwig* [crane] (8,11; 15,6; 19,1), *grzejnik* [radiator] (8,11; 17,11; 19,1; 19,6), *gwizdek* [whistle] (15,6; 17,11; 19,1), *koparka* [excavator] (6,1; 19,1; 19,6), *lejek* [funnel] (15,6; 17,11; 19,6), *lokówka* [curler] (15,6; 17,11; 19,1; 19,6), *odkurzacz* [vacuum cleaner] (6,1; 8,11; 15,6; 17,11; 19,6), *skakanka* [skipping rope] (6,1; 8,11; 15,6; 17,11; 19,1; 19,6), *spinacz* (do bielizny) [clothes peg (for undergarment)] (8,11; 15,6; 17,11), *spinacz* (biurowy) [paper clip (used in office)] (15,6), *zapałka* [match] (15,6; 17,11; 19,1), a bit worse at the names *gaśnica* [fire extinguisher] (17,11; 19,6), *suszarka* [dryer] (6,1; 19,1) *wycieraczka* (do butów) [wiper (for shoes)] (17,11; 19,6), *zapalniczka* [lighter] (15,6; 17,11) and *krajalnica* [slicer] (19,6), *pokrywka* [lid] (19,1), *śrubokręt* [screwdriver] (17,11) or *trzepaczka* [beater] (17,11).

This shows that the majority of children more often used in the answers the principle of clarity of meaning, using known formants,

⁴² S. Szuman, *Rozwój treści słownika dzieci. Zagadnienie i niektóre wyniki badań*, [in:] *O rozwoju języka i myślenia dziecka*, ed. S. Szuman, PWN, Warsaw 1968, pp. 10–11.

⁴³ A. Dziurda-Multan, *Dziecięce sposoby tworzenia nazw*, Wydawnictwo Katolickiego Uniwersytetu Lubelskiego, Lublin 2008, p. 19.

⁴⁴ Age of the subject/subjects in years and months is specified in brackets.

what is more, selecting one of the most productive formants in the category of tool names, or. *-acz, -ak, -aczka, -arka, -nik*.

In addition, the subjects with regard to the above names of tools either did not name the referent at all, see no name for: *drukarka* [printer] (8,11), *dźwig* [crane] (19,6), *gaśnica* [fire extinguisher] (8,11), *gwizdek* [whistle] (19,6), *krajalnica* [slicer] (6,1; 8,11), *lokówka* [curler] (8,11), *pokrywka* [lid] (8,11), *spinacz* [clothes peg] (19,6), *śrubokręt* [screw-driver] (19,1), *trzepaczka* [beater] (6,1; 19,1; 19,6), *wycieraczka* (do szyb) [wiper (for windscreen)] (8,11), *zapałka* [match] (8,11) or they specified incorrectly created formations, creating, among others, word formation neologisms. The latter, according to some researchers, gives evidence of the creativity of the child, and according to others, the immaturity of his speech. "Perhaps, as stated by Agnieszka Wątopek, neologisms appear where someone's knowledge and related vocabulary end, to give vent to the need of verbalisation of thoughts that is stronger than fear of making a language mistake"⁴⁵. The incorrectly created forms included: a) constructions created with incorrect formants, which are however typical of the discussed word formation category, see *gwizdak* 'gwizdek [whistler]' (6,1), *lejak* 'lejek [funnel]' (19,1), *odkurzak* (19,1); b) constructions created with incorrect formants, unusual for this category, see. *gaśninka* 'gaśnica [fire extinguisher]' (19,1), *grzejka* 'grzejnik [radiator]' (6,1), *kopara* (17,11), *krajniczka*, *krojonka* 'krajalnica [slicer]' (17,11), *krajanka* 'krajalnica [slicer]' (19,1), *pokrywa*⁴⁶ 'przykrywka [lid]' (19,6), *spinka* 'spinacz (do bielizny) [clothes peg (for undergarment)]' (6,1; 19,1; 19,6), *spinka* 'spinacz (biurowy) [paper clip (used in office)]' (6,1; 8,11; 19,1), *suszar* 'suszarka [dryer]' (8,11), *wycieranka* 'wycieraczka (do butów) [wiper (for shoes)]' (19,1), *zapała* 'zapałka [match]' (6,1), *zapałkarka* 'zapałka [match]' (19,6).

The use of the formants *-ka, -anka, -niczka, -ara* etc., which are not typical for the category of tool names by children/adolescents, may

⁴⁵ A. Wątopek, *Kompetencja językowa uczniów z lekką niepełnosprawnością intelektualną*, Nomos, Kraków 2014, p. 109.

⁴⁶ The dictionaries of the Polish language allow the name „*pokrywka*” apart from the more common name „*przykrywka*” for the lid.

mean that these children know formants, know the rules of their use, but they do not know their meaning.

Very often, instead of the name of the tool, the subjects with moderate intellectual disability gave names of activities performed with the help of these tools/by these tools/devices, see *drukuje* [*prints*] 'drukarka [printer]' (15,6), *grzeje* [*radiates*] 'grzejnik [radiator]' (15,6), *kopie* [*excavates*] 'koparka [excavator]' (15,6), *kroi chlebek* [*slices bread*] 'krajalnica [slicer]' (8,11), *suszy* [*dries*] 'suszarka [dryer]' (15,6), *śrubki wkręca* [*drives screws*] 'śrubokręt [screwdriver]' (15,6), *trzepie się* [*beats*] 'trzepaczka [beater]' (15,6), *wyciera się* [*wipes*] 'wycieraczka (do butów) [mat for shoes]' (15,6), *wyciera* [*wipes*] 'wycieraczka (do butów, do szyb) wiper [for shoes, for windscreen]' (6,1), *wycieramy buty* [*we wipe shoes*] (15,6), sporadically, the names of the products of the activity, see *druki* [*prints*] 'drukarka [printer]' (6,1), *loczki* [*curls*] 'lokówka [curler]' (6,1). In the case of one child, the verbal answers were of an echolalic nature, see *kopie* [*excavates*] 'koparka [excavator]' (8,11), *leje* [*fuelling*] 'lejek [funnel]' (8,11), *trzepie* [*beats*] 'trzepaczka [beater]' (8,11).

In addition to the above-mentioned tool names, children/adolescents created derivatives: a) based on other word formation rules, see *podnośnik* [*lift*] 'dźwig [crane]' (17,11); b) based on the basis with word initial position cut, see *szarka* 'suszarka [dryer]' (17,11).

The answers created by children/adolescents on the way of associations and combinations appeared several times, see *dywan* [*carpet*] 'wycieraczka (do butów) [wiper [for shoes]' (8,11), *ogień* [*fire*] 'gaśnica [fire extinguisher]' (6,1), *patelnia* [*frying pan*] 'przykrywka [lid]' (15,6), *do patelni* [*for a frying pan*] 'przykrywka [lid]' (6,1), *szpilka* [*pin*] 'spinacz (biurowy) paper clip [used in office]' (17,11), *szyba* [*glass*] 'wycieraczka (do szyb) wiper [for windscreen]' (19,6), *śrubka* [*screw*] 'śrubokręt [screwdriver]' (6,1), *śrubek* [*of screw*] 'śrubokręt [screwdriver]' (8,11; 19,6), *zegar cyk, cyk* [*clock tick tock*] 'budzik [alarm clock]' (8,11), *od włosa* [*for hair*] 'suszarka [dryer]' (19,6).

Sometimes the associations were very distant, see *gas* 'gaśnica [fire extinguisher]' (15,6) (however, here a zero formant might have been used), *lew* [*lyon*] 'lejek [funnel]' (6,1) (here it might have been

derived from *wlew* [infusion], *wlewać* [pour]), *pokrętka* [tap wrench] 'przykrywka [lid]' (17,11).

Slightly bigger problems appeared with the names of such referents as: *cedzak* [colander], *otwieracz* [opener] or *trzepaczka* [beater] 'a tool, usually made of wire, used in the household to whip egg white'. The study children/adolescents usually know these objects, they know what they serve for (during the study they showed the activities which are performed with their use), but they cannot denominate them, see no name for: *cedzak* [colander] (6,1; 19,6), *otwieracz* [opener] (8,11) or they use incorrectly built formations, i.e. a) choosing inappropriate formants, which are however typical for the discussed word formation category, see *cedzarka* 'cedzak' [colander] (17,11); b) choosing inappropriate formants, unusual for this category, see *cedzanka* 'cedzak' [colander] (19,1), *otwieranie* [opening] 'otwieracz [opener]' (17,11), *otwórka* 'otwieracz [opener]' (19,1) or based on other word formation stems and using unusual formants, see *ubijanka* 'trzepaczka (do jaj) [beater (for eggs)]' (19,1).

Also for these names some of the subjects wrote the names of activities performed with the use of these tools/by these tools/devices, see *otwiera* [opens] 'otwieracz [opener]' (6,1; 19,6).

One of the children created a name derived from a wrong word formation stem, but used a formant typical of tool names, see *odkrywacz* 'otwieracz [opener]' (15,6).

On the way of associations and combinations, a form of *obiad* [dinner] 'cedzak [colander]' (15,6) was created.

Conclusions regarding the ability to create word formation constructions by study children/adolescents with severe intellectual disability:

The subjects with severe intellectual disability significantly differ from those with moderate disability. They did not know and did not write numerous names, see no answer for: *budzik* [alarm clock] (9,6), *cedzak* [colander] (9,6), *dźwig* [crane] (9,6), *gaśnica* [fire extinguisher] (9,6), *grzejnik* [radiator] (9,6), *gwizdek* [whistler] (9,6), *lejek* [funnel] (9,6; 15,2), *lokówka* [curler] (9,6), *otwieracz* [opener] (15,2), *przykrywka* [lid] (15,2), *skakanka* [skipping rope] (9,6), *spinacz* [clothes peg] (9,6; 15,2), *suszarka*

[dryer] (9,6), *śrubokręt* [screwdriver] (15,2), *trzepaczka* [beater] (9,6; 15,2), *wycieraczka* [wiper] (9,6), *zapalka* [match] (9,6; 15,2).

In addition to correctly created derivatives, see *drukarka* [printer] (15,2), *odkurzacz* [vacuum cleaner] (9,6) people with severe intellectual disability wrote: a) formations based on correct word formation stems, but with incorrect formants, which are however typical of the category of the tool names category, see *gwizdak* 'gwizdek [whistler]' (9,6), *suszacz* 'suszarka [dryer]' (15,2); b) formations based on correct word formation stems, but with incorrect formants that are not typical of the tool names category, see *kopara* 'koparka [excavator]' (15,2), *krajanie* [slicing] 'krajalnica [slicer]' (15,2), *odkurzan* 'odkurzacz [vacuum cleaner]' (15,2), *skakanie* [skipping] 'skakanka [skipping rope]' (15,2), *spina*, -y (plural) 'spinacz [clothes peg] (for undergarment)' (15,2), *suszawka* 'suszarka [dryer]' (9,6).

Similarly, as in the case of people with moderate disability, it happened also here that one of the subjects reported no names of tools, but names of activities performed with the use of these tools/by these tools/devices, see *gasi* [extinguishes] 'gaśnica [fire extinguisher]' (15,2), *gwizda* [whistles] 'gwizdek [whistler]' (15,2), *wyciera* [wipes] 'wycieraczka (do szyb) wiper [for windscreen]' (15,2).

Several names given by the subjects occurred as a result of associations and combinations, both direct, see *auto* [car] 'dźwig [crane]' (15,2), *dzwonek* [bell] 'budzik [alarm clock]' (15,2), *garnek* [pot] 'przykrywka [lid]' (9,6), *misa* [bowl] 'cedzak [colander]' (15,2) and indirect, see *kredka* [crayon] 'drukarka [printer]' (9,6) (perhaps by association with printouts of colouring pages), *szuflada* [drawer] 'śrubokręt [screwdriver]' (9,6) (sometimes screwdrivers are kept in this place), maybe also *rękaw* [sleeve] 'budzik [alarm clock]' (9,6) (hands of some watches for children have the shape of sleeves/hands of a clown).

Conclusions

It is difficult to draw any specific conclusions with such small study groups. The formulation of detailed conclusions can only take place when representative and rich material is gathered to illustrate

the processes of acquisition of word formation rules. However, it is possible to propose a few general remarks:

1. Children/adolescents with moderate intellectual disability are relatively good at coding word formations, which are tool names, while people with severe intellectual disability are significantly worse at the study of the expression of tool names.
2. The conclusions from the above-mentioned study can verify postulates known from the literature on the subject that people with deeper intellectual disability, especially those with a severe one, know and use only a minimal resource of words.
3. The results of the study may also indicate the fact that the acquisition of language depends not only on the overall development of children, but also on the conditions provided to them by their family and the closest environment⁴⁷. Factors determining the development of linguistic competence in children with intellectual disability include, among others, situations and events/life experience⁴⁸. This can be evidenced by examples of the type of *drukarka* [printer], *odkurzacz* [vacuum cleaner], and even *gwizdak*, *kopara*, *krajanie* [slicing], *odkurzan*, *suszacz*, *suszawka* etc. recorded in people with severe intellectual disability.

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⁴⁷ J. Porayski-Pomsta, *O rozwoju mowy dziecka. Dwa studia*, Ed. Dom Wydawniczy „Elipsa”, Warsaw 2015, p. 48.

⁴⁸ Z. Dołęga, *Promowanie rozwoju mowy w okresie dzieciństwa – prawidłowości rozwoju, prognozowanie i profilaktyka*, Wydawnictwo Uniwersytetu Śląskiego, Katowice 2003, p. 30.

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Resistance as an interdisciplinary phenomenon – inspiration for special education

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The article concerns the issue of resistance, with a particular focus on the philosophical, sociological, psychological and educational adumbration. The interdisciplinary notion of the resistance phoneme constitutes a contribution to its introduction to the special education area, to the world of persons with disabilities. Moreover, attention was drawn to the learning environment as a place triggering the students' resistance to the school system and authority. The undertaken considerations have been located in the critical theory, defining the stance on authoritarianism, injustice, emancipation or liberation, and especially on stigmatization, marginalization and exclusion.

KEY WORDS: resistance, critical pedagogy, special education, disability

Introduction

In the relevant literature resistance is described as a category of opposing external influences and impacts, which is related with relations of power, dominance, order and conflicts¹. Considerations

¹ H.A. Giroux, *Reproduction. Resistance and Accommodation (Reprodukcja. Opór i akomodacja)*, [in:] *"Absent Discourses" („Nieobecne dyskursy")*, part I., ed. Z. Kwieciń-

included herein have been situated in the critical theory paradigm, which specifies, among others, the vision of a human being and society, as well as the existing and preferred world, subjects to observation and analysis educational processes occurring in the society as well as the processes influencing it (especially situations of conflicts regarding education). T. Szkudlarek notices that critical pedagogy is an extremely interesting, theoretically dense, analytically reliable, politically important and pedagogically responsible theory². Therefore, this conception provides crucial explanations concerning the situation, relation, scope and interpretation of discussed phenomenon occurring e.g. as students' resistance against school³, teachers' resistance against students manifesting itself e.g. in the area of perceiving, thinking, behaviour towards students, adopted methods of teaching, bringing up, therapy, communication etc.⁴. The critical pedagogy originating from Frankfurt School of philosophy and postmodern thought aims to disclose another layers

ski, Wydawnictwo Naukowe Uniwersytetu im. Mikołaja Kopernika, Toruń 1991; H. A. Giroux, L. Witkowski, ed. *Education and Public Sphere. Ideas and Experiments in Radical Pedagogy (Edukacja i sfera publiczna. Idee i doświadczenia pedagogiki radykalnej)*, Oficyna Wydawnicza „Impuls”, Krakow 2010; T. Szkudlarek, *Knowledge and Freedom in American Postmodern Pedagogy (Wiedza i wolność w pedagogice amerykańskiego postmodernizmu)*, Oficyna Wydawnicza „Impuls”, Krakow 1993.

² T. Szkudlarek, *What Do We Need Critical Pedagogy for Today (Po co nam dziś pedagogika krytyczna)*, [in:] *Education and Public Sphere. Ideas and Experiments in Radical Pedagogy (Edukacja i sfera publiczna. Idee i doświadczenia pedagogiki radykalnej)*, ed. H.A. Giroux, L. Witkowski, Oficyna Wydawnicza „Impuls”, Krakow 2010, p. 487.

³ E. Bilińska-Suchanek, *Resistance against School. Growing up in the Perspective of Resistance Paradigm (Opór wobec szkoły. Dorastanie w perspektywie paradygmatu oporu)*, Oficyna Wydawnicza „Impuls”, Krakow, 2003.

⁴ More information: H.A. Giroux, L. Witkowski, *Education and Public Sphere. Ideas and Experiments in Radical Pedagogy (Edukacja i sfera publiczna. Idee i doświadczenia pedagogiki radykalnej)*, Oficyna Wydawnicza Impuls, Krakow 2010; L. Witkowski, *Identity and Change. Epistemology and Developmental Profiles in Education (Tożsamość i zmiana. Epistemologia i rozwojowe profile w edukacji)*, Wydaw. Naukowe Dolnośląskiej Szkoły Wyższej, Wrocław 2010; Z. Kwieciński, *Social Pathology of Education (Socjopatologia edukacji)*, IRWiR PAN, Edytor, Warsaw 1992.

of ideological world, hidden programmes, disguised mechanisms of power, constraint, dominance, discredit, discrimination and conditions thereof⁵.

Resistance in the Polish Dictionary means opposing, resisting others' will and violence. Resistance can be shown, faced, overcome, one can also surrender to resistance, accept something, agree to something; it is also treated as an obstacle and difficulty of a psychological character, with is related with the need to overcome with regard to something or in the context of own resistance (one can be faced with resistance from other persons). Resistance is characterised with: helplessness, futility, forlornness, weakness, obstinacy⁶.

The topic of resistance is presented in numerous pedagogical studies, often in the context of interdisciplinary trends and with regard to authors the following should be mentioned: H.A. Giroux 1991⁷; T. Szukdlarek 1993⁸; L. Witkowski 2000⁹; P. McLaren 1994¹⁰;

⁵ A. Krause, *Theoretical Inspirations of Special Pedagogy – Critical Pedagogy (Teoretyczne inspiracje pedagogiki specjalnej – pedagogika krytyczna)*, „Studia Edukacyjne”, No. 25, 2013, pp. 9–10.

⁶ *Polish Dictionary (Słownik języka polskiego)*, Volume II, ed. M. Szymczak, Warsaw 1979, p. 532.

⁷ H.A. Giroux, *Reproduction. Resistance and Accommodation (Reprodukcja. Opór i akomodacja)*, [in:] „Absent Discourses” („Nieobecne dyskursy”), part I, ed. Z. Kwieciński, Wydawnictwo Uniwersytetu Mikołaja Kopernika, Toruń 1991; H.A. Giroux, L. Witkowski, *Education and Public Sphere. Ideas and Experiments in Radical Pedagogy (Edukacja i sfera publiczna. Idee i doświadczenia pedagogiki radykalnej)*, Oficyna Wydawnicza „Impuls”, Krakow 2010.

⁸ T. Szukdlarek, *Knowledge and Freedom in American Postmodern Pedagogy (Wiedza i wolność w pedagogice amerykańskiego postmodernizmu)*, Oficyna Wydawnicza „Impuls”, Krakow 1993.

⁹ L. Witkowski, *Education and Humanities. New Humanistic Contexts for Modern Teachers (Edukacja i humanistyka. Nowe konteksty humanistyczne dla nowoczesnych nauczycieli)*, Wyd. IBE, Warsaw 2000.

¹⁰ P. McLaren, *The Ritual Dimensions of Resistance: Clowning and Symbolic Inversion (Rytualne wymiary oporu – błąznowanie i symboliczna inwersja)* „Absent Discourses” („Nieobecne dyskursy”) part 1, ed. Z. Kwieciński, Wydawnictwo Uniwersytetu Mikołaja Kopernika, Toruń 1994.

Z. Melosik 1995¹¹; Z. Kwieciński 1995¹²; E. Bilińska-Suchanek 2003¹³; A. Oleszkowicz 2006; B. Śliwerski 2008¹⁴; E. Bielska 2013¹⁵; S. Pasikowski 2014¹⁶ and others. Resistance contexts usually concern socio-culture, mainstream and academic education; whereas, it is difficult to find academic publications regarding the category of resistance in the world of persons with disability.

The aim of the article is to provide interdisciplinary outlook on the phenomenon of resistance and inspirations for special pedagogy. With reference to L. Witkowski, it is worth underlining that the category of resistance discloses dimensions engaging all kinds of pedagogy¹⁷ – special pedagogy as well. Years ago, the aforemen-

¹¹ Z. Melosik, *Postmodern Controversies Regarding Education (Postmodernistyczne kontrowersje wokół edukacji)*, Wyd. Edytor, Poznan-Toruń 1995.

¹² Z. Kwieciński, *Dynamics of School Functioning. Empirical Study in Educational Sociology (Dynamika funkcjonowania szkoły. Studium empiryczne z socjologii edukacji)*, Wyd. UMK, Toruń 1995.

¹³ E. Bilińska-Suchanek, *Resistance against School. Growing up in the Perspective of Resistance Paradigm (Opór wobec szkoły. Dorastanie w perspektywie paradygmatu oporu)*, Oficyna Wydawnicza „Impuls”, Krakow 2003; E. Bilińska-Suchanek, *A Teacher and Resistance (against) Educational System (Nauczyciel i opór (wobec) systemu edukacji)*, Wydawnictwo Adam Marszałek, Toruń 2013.

¹⁴ B. Śliwerski, *Islands of Educational Resistance (Wyspy oporu edukacyjnego)*, Oficyna Wydawnicza „Impuls”, Krakow 2008.

¹⁵ E. Bielska, *Conceptions of Resistance in Contemporary Social Sciences. Main Issues, Concepts, Solutions (Koncepcje oporu we współczesnych naukach społecznych. Główne problemy, pojęcia, rozstrzygnięcia)*, Wydawnictwo Uniwersytetu Śląskiego, Katowice 2013.

¹⁶ S. Pasikowski, *Issues Regarding Resistance in the Light of Selected Contexts of Sociological Theory in the Pedagogical Perspective (Zagadnienia oporu w świetle wybranych kontekstów teorii socjologicznej w kierunku perspektywy pedagogicznej)*, [in:] *Resistance in Culture. Tradition; Education; Modernity (Opór w kulturze. Tradycja – edukacja–nowoczesność)*, ed. E. Bilińska-Suchanek, Oficyna Wydawnicza „Impuls”, Krakow 2014.

¹⁷ L. Witkowski, *About the Condition and Issues Related with Reception of the American Radical Pedagogy in Poland. An Attempt to Provide Personal Experience and Reflection on “the Generational Experience” (O stanie i problemach recepcji amerykańskiej pedagogiki radykalnej w Polsce. Próba świadectwa osobistego i refleksji o „doświadczeniu pokoleniowym”)*, [in:] *Education and Public Sphere. Ideas and Experiments in Radical Pedagogy (Edukacja i sfera publiczna. Idee i doświadczenia pedagogiki radykalnej)*, ed. H.A. Giroux, L. Witkowski, Krakow 2010, ss. 37–38.

tioned author demanded “theoretical and research-oriented approach so that activities could be undertaken in order to draw nearer the moment of arrival of a significant change in thinking and practical action, late to the Polish pedagogy, concerning the phenomenon of interactive resistance in educational situations”¹⁸. In contemporary times, by paraphrasing Witkowski, one can demand the moment of arrival of a significant change in theoretical and practical thinking and acting, late to the Polish special pedagogy, concerning the phenomenon of resistance in the world of persons with disability. Then, contexts of critical pedagogy are indicated by Krause, who writes: “Nothing prevents this disclosure from occurring also in special pedagogy. This discipline, after a revalidation period of “digging out”, catches up with theoretical backlog, searches its academic identity at the interface of many academic disciplines, uses inspirations exceeding “effective repair” of a human being and separates from didactic and therapeutic dominance. It can be said that a new special pedagogy is created, voluntarily resigning from the privilege of hermetic “yard-mentality”, locality of understanding and interpreting, trenching around the fact by concealing a lack of competences with the specific character of the disability. This return to pedagogy, basic issues with education and bringing up a human being, education systems and conditions of the individual – society relation, predominantly manifested the necessity of new outlook on the special pedagogy (...)”¹⁹.

Resistance in the interdisciplinary meaning

The special pedagogy as a sub-discipline of pedagogy is situated in the area of social sciences, whereas, irrespectively of the formal

¹⁸ L. Witkowski, *Between Pedagogy, Philosophy and Culture. Studies, Essays, Drafts. (Między pedagogiką, filozofią i kulturą. Studia, eseje, szkice.)* v. III, Wyd. IBE, Warsaw, p. 240.

¹⁹ A. Krause, *Theoretical Inspirations of Special Pedagogy – Critical Pedagogy (Teoretyczne inspiracje pedagogiki specjalnej – pedagogika krytyczna)*, „Studia Edukacyjne”, No. 25, 2013.

allocation, it is treated both, as social science and humanities²⁰. The topic of resistance is undertaken in many academic fields, for example philosophy, humanities and social sciences: pedagogy, psychology, sociology, social politics, social work, law, anthropology and economics. Another part of the article shall present an outline of the phenomenon of resistance in philosophy, sociology, psychology and pedagogy.

Resistance is a commonly known category of human behaviours and moral obligations in philosophical thought, where intensiveness can be observed especially in terms of political discussions led by Ancient philosophers. For example, Socrates noticed in a human being the ability to differentiate between good and evil, justice and injustice. Whereas, an act of injustice refers to hurting, putting pressure and punishing²¹. In the public activity arena, Socrates presented civil disobedience, opposed democratic class layers, ideologists of which were senior sophists²². Similarly Cicero, as an example of a philosopher of liberal thought, discussed issues regarding injustice, dissent and resistance as acts of anger and dissatisfaction in situations of putting pressure on people²³.

J. Habermas discussed the topic of social conflicts and found reason therefor in injustice and power; furthermore, he postulated for changes especially in the area of social narration and educational space. Moreover, he demanded that pedagogues focused not only on educating individuals in order to obtain maturity and autonomy, but also took into consideration maturity of the society in this pro-

²⁰ D. Podgórska-Jachnik, *Emancipatory Pedagogy v. Special Pedagogy – Key Categories in Emancipatory Discourse of Disability (Pedagogika emancypacyjna a pedagogika specjalna – kluczowe kategorie w emancypacyjnym dyskursie niepełnosprawności)*, [in:] *Interdyscyplinarne Konteksty Pedagogiki Specjalnej*, no. 10/2015, p. 16.

²¹ A. Paja, R. Padoł, *Philosophical Issues. A Selection of Texts (Zagadnienia filozofii. Wybór tekstów)*, Wyd. III. WSP w Krakowie, Krakow 1977, p. 233.

²² *History of Philosophy (Historia filozofii)*. Volume 1, translated by B. Kupis, Wyd. Książka i Wiedza, Warsaw 1962, p. 158.

²³ Ciceron, *On the Commonwealth. On the Laws (O państwie. O prawach)*, translated by I. Żółtowska, Wydaw. Antyk, Kęty 1999.

cess, since an individual cannot fulfil themselves independently²⁴. Habermas' emancipatory postulates correspond with the approach of the French philosopher M. Foucault, who divides activities saturated with resistance into activities aimed at liberation and the ones taking a liberal form. Foucault undertakes numerous resistance-oriented considerations and philosophical grounds allow him to analytically change interpretation according to the principle that human life is changeable similarly as political and ideological trends, social interactions and education. The main thread oscillating around the resistance comprises the category of discourse defined as a template of thinking e.g. about a subject, who once can have a privileged position and other time can be discriminated. Thus, the discourse is variable, yet, certainly depicts the power-knowledge constellation. Therefore, power is in the knowledge and knowledge is in the power. Thus, discourse can be both, a tool and a result of exercising power as well as an impediment, trap, centre of resistance or a starting point for opposing strategy. Foucault undertakes, in fact, issues regarding resistance against power, the issue of constituting power, recognises subtle techniques of disciplining students, the scale of control, supervision, exclusion etc.²⁵. Foucault's approach to power is of a relative character, since he analyses power relations and not the power itself, which is, according to the author, abstract and does not exist. In other words, exercising power constitutes modification of other persons' activities with own activities²⁶.

In sociology resistance is defined in micro and macro-social functional, structural, interpretative and critical analysis. The sociological conception of resistance is most often compared with the

²⁴ B. Śliwerski, *Contemporary Theories and Trends in Education (Współczesne teorie i nurty wychowania)*, Impuls, Krakow 2010, pp. 243–259.

²⁵ B. Śliwerski, *Contemporary Theories and Trends in Education (Współczesne teorie i nurty wychowania)*, Impuls, Krakow 2010, pp. 313–321.

²⁶ M. Foucault, *The Subject and Power (Podmiot i władza)*, translated by J. Zycho-wicz, Wydawnictwo „Lewą Noga”, 9, 1998, p. 184.

reproduction theory based on Marxist and Neo-Marxist theory²⁷. In his conceptions P. Bourdieu presents crucial terms related with the phenomenon of resistance e.g.: reproduction, habitus and symbolic violence. The basic thesis of reproduction constitutes statement that the education system, through the agency of own reproduction, reproduces the existing social and class structure. In general, it can be considered that an objective feature of the education system in conditions of the society's class separation comprises a specific duality of functioning. In such conditions, democratisation of education remains fictional, since there is a kind of symbolic violence, which, in consequence, leads to establishing existing social order, that is, reinforcing existing class divisions. The mechanism of symbolic violence is identified with phenomena such, as: pedagogical activity, pedagogical authority, pedagogical work. Moreover, Bourdieu introduces an interesting thread indicating that understanding and learning about the world is usually done physically and thus, is of practical rather than free, intentional and conscious character. The human body has an ability to subject to conditioning, as it adopts socially imposed features. In consequence, it means that a human being learns about the world through socialised body²⁸. Habitus means dispositions treated as an effect of action (e.g. learnt during childhood – primary habitus), or schemes of reactions and behaviours based on social experiences (secondary habitus). These activities are reflected in the lifestyle, given predispositions, tendencies or inclinations of a particular group of persons functioning in a specific culture (school, family and professional habitus were also stipulated). Habitus is also a compound of a defensive mechanism, that is, a tendency of approaches, internalised dispositions, imple-

²⁷ E. Bielska, *Conceptions of Resistance in Contemporary Social Sciences. Main Issues, Concepts, Solutions (Koncepcje oporu we współczesnych naukach społecznych. Główne problemy, pojęcia, rozstrzygnięcia)*, Wydawnictwo Uniwersytetu Śląskiego, Katowice, 2013, p. 177.

²⁸ P. Bourdieu, *Pascalian Meditations (Medytacje Pascaliańskie)*, translated by K. Wakar, Oficyna Naukowa, Warsaw 2006, 194.

mented in the sphere of human habits. Bourdieu believes that the phenomenon of habitus involves steering activities aimed at a specific objective despite the fact that this objective is not or does not have to be conscious²⁹. Therefore, resistance can concern issues defined with symbolic violence, which refers to the class of privileged society and subordinate society. It should be noted that privileged society perceives its situation as natural or beneficial, since it sees social reality in categories established by dominant classes in order to legitimize their dominant positions. Education constitutes an example thereof, which instead of counteracting social divisions, reinforces them. Educational opportunities of a student to a great extent depend on adjusting their habitus to habitus required by the education system, habitus of higher classes, middle class and dominant class³⁰.

The issues concerning resistance can be found in the R. Merton's adaptation model, which determines social system as a source of human's behaviours that disrupt social order. Merton's anomie theory concerns the phenomenon of resistance in the context of social adaptation, domineering axioms and rules. In this case, the essence consists in the fact that a human does not have to agree with rules that aim to achieve given objectives in a particular manner (in compliance with principles generally accepted in the society). What is interesting, possibilities and the manner of pursuing an objective can change depending on the role fulfilled by a given individual. Merton differentiates five reactions that can characterise the same person depending on the conditions and situation they function in: conformism, ritualism, innovation, withdrawal, rebellion. The last three categories are in majority distinguished with breaking rules in pursuing the objective and causing a change, among which the most intensive opposition occurs in the category of rebellion, which can

²⁹ P. Bourdieu, *Reproduction. Elements of the Education System Theory (Reprodukcja. Elementy teorii systemu nauczania)*, translated by E. Neyman, PWN, Warsaw 1990.

³⁰ A. Matuchniak-Krasucka, *Pierre Bourdieu's Concept of Habitus (Koncepcja habitusu u Pierre'a Bourdieu)*, [in:] *Internetowy Magazyn Filozoficzny HYBRIS*, no. 31, 2015, p. 92.

be activated in the process of socialisation³¹. Similarly, E. Goffman undertakes the issue of resistance as an adaptive category, however, he analyses this phenomenon in the context of protecting and establishing individual identity in the conditions of direct relation with a total institution. The rebellion constitutes one of the adaptive techniques, which involves conscious opposition to the requirements of the institution's personnel and rejecting undertaking activities aimed at cooperation. Nevertheless, the presented tactics forces to continuously engage in relations with the organisational structure of the institution. The paradox of this situation is that, on the one hand, a given person protects their individuality and on the other hand, while negating the institution, the person establishes own identity. Resistance can also adopt a form of withdrawal, which is related with dissociating from the environment, ceasing engagement in matters considering colleagues (peers) and not paying attention to the presence of others³².

Moreover, J. Szczepański's conception of individuality, which corresponds with previously discussed adaptive conception, is also interesting. Individuality is "executed" in the process of locating oneself in the social environment, that is, aiming in one's lifetime to order people and things in compliance with the idea of self and own attitude to others. "The definition of self always includes a picture of own difference from others, comparing own value with value of others and thus, covers elements of own uniqueness and exclusivity (...). Locating oneself in the world comprises a principle sense and aim of human's existence as an individual being"³³. This mechanism provides grounds for the individual principle of ordering the world,

³¹ R. Merton, *Social Theory and Social Structure (Teoria socjologiczna i struktura społeczna)*, translated by E. Morawska, J. Wertenstein-Żuławski, PWN, Warsaw 2002, pp. 221–252.

³² E. Goffman, *Characteristics of Total Institutions (Charakterystyka instytucji totalnych)*, translated by Z. Zwoliński, [in:] *Elements of Social Theories (Elementy teorii socjologicznych)*, ed. W. Derczyński, A. Jasińska-Kania, J. Szacki, Wydawnictwo PWN, Warsaw 1975, p. 165.

³³ J. Szczepański, *On Individuality (O indywidualności)*, Instytut Wydawniczy Związków Zawodowych, Warsaw 1988, p. 45.

which is created by each person individually irrespectively of the fact, if this process is conscious or unconscious. Szczepański's conception is consistent with the interdisciplinary narration on the resistance and has an emancipatory character, since individuality is treated as a human's life mechanism comprising a generator or resistance and pursue of autonomy. Resistance usually occurs in a situation with characteristics of "evil", which occurs where a human starts influencing other human in compliance with existing templates and rules of communal life. Therefore, "evil" is calculated in any form of social functioning and thus, generates human suffering resulting from a hurtful position e.g. exclusion and marginalisation. Szczepański claims that emancipatory individuality, identity, authenticity constitute the need of determining own value and the resistance can constitute a determinant of changes³⁴.

Resistance in psychology is discussed in theories such, as: psychoanalytical, cognitive, behavioural-cognitive, attribution, gestalt, family systems, reactance, transtheoretical model of change etc. The category of resistance has a significant place in S. Freud's psychoanalysis and refers to protective and denial mechanisms as well as sources and blockades hindering change in the process of treatment and therapy³⁵. On the other hand, E. Fromm underlines the emotional factor of the phenomenon of resistance, by underlining anxiety character related with the process of development and hindering and inhibiting undertaking new initiatives and changes³⁶. Psychoanalytical conceptions usually connect occurrence of resistance with unwanted situations occurring in interpersonal relations.

The psychological aspect of individual resistance of adolescents towards school was discussed by M. Porębska years ago, who drew particular attention to negativism, obstinacy and disobedience. The

³⁴ J. Szczepański, *On Individuality (O indywidualności)*, Instytut Wydawniczy Związków Zawodowych, Warsaw 1988, pp. 281–289.

³⁵ S. Freud, *Ego and Defence Mechanisms (Ego i mechanizmy obronne)*, Wydawnictwo PWN, Warsaw 1997.

³⁶ E. Fromm, *The Art of Listening. Therapeutic Aspects of Psychoanalysis (O sztuce słuchania. Terapeutyczne aspekty psychoanalizy)*, Wydawnictwo PWN, Warsaw 1996.

author introduces a category of resistance behaviours by referring to individual's reactions related with the unwillingness to social requirements and influences of a behavioural character. Thus, the individual resistance comprises discretionary, as unintentional pursuit, which means that it can be conscious and unconscious, related with free will and independence as well as unconscious protective processes and mechanisms³⁷.

The aspect of feelings and experiences is discussed by A. Oleszkowicz, who does not actually use the term *resistance*, but *rebellion*, and in her studies concentrates on youth rebellion. She defines rebellion as a need and willingness to oppose and withdraw, by distinguishing: external rebellion (open objection) and internal rebellion (the individual does not reveal their feelings directly). Thus, the rebellion consists of judgements, feelings and emotions expressing objection against noticed relations, dependencies, living conditions and the need to change them³⁸.

Interesting issues regarding psychological resistance (reactance) are presented by J. Brahm, who locates the discussed phenomenon in cognitive and emotional reactions, claiming that this is "a motivating condition targeted at reclaiming eliminated freedom or freedom threatened with elimination"³⁹. The conception of reactance provides background for understanding human behaviours aimed at reclaiming the freedom of choice. Brahm proved that a person in a situation of a threat to their freedom feels intensely unpleasant emotions and discomfort and calls this condition reactance. Therefore, it constitutes a specific motivation to reclaim "taken" freedom,

³⁷ As cited in: S. Pasikowski, *Individual Resistance. Theories, Classifications, Assessment in Psychology (Opór indywidualny. Teorie, klasyfikacje, diagnozowanie w ujęciu psychologicznym)*, „Teraźniejszość – Człowiek – Edukacja”, No. 68, 2014, p. 45.

³⁸ A. Oleszkowicz, *Teenage Rebellion. Conditions. Forms. Consequences (Bunt młodzieńczy. Uwarunkowania. Formy. Skutki)*, Wydawnictwo Scholar, Warsaw 2006, pp. 60–65.

³⁹ As cited in: M. Dudek, *On the Psychological Reactance and Its Possible Implications on the Policy of the Criminal Law (O psychologicznej reaktancji i jej możliwych implikacjach dla polityki prawa karnego)*, „Czasopismo Prawa Karnego i Nauk Penalnych”, Year XV, 2011.

which is manifested with intensified willingness to do what has been forbidden also through actual activities undertaken to that end. What is more, the object of the ban starts being treated as more attractive than before it has been covered with restrictions⁴⁰. The theory of reactance comprises an adequate area of analyses of the phenomenon of resistance e.g. against change, in a situation of planning preventative measures or in the context of pedagogy⁴¹.

The perspective of change or, in fact, the necessity to undertake “some” activity forcing change and crossing individual boundaries is related with J. Koziellecki’s transgression theory. While interpreting theoretical assumptions it should be noticed that resistance occurs in situations, in which habitual actions prove to be ineffective and a human aims to change their position or wants to survive. The transgression model constitutes a kind of a critical response to psychoanalytical and behavioural theory. However, transgression belongs to unspecified terms, as it refers to both, creative, innovative, above-average abilities and possibilities of going “beyond”, as well as to expand own territory, aim to expand possessed knowledge or a fight for personal freedom. The author underlines that in this case creative thinking and creativity are irrelevant, since transgression covers both, constructive and destructive actions. An important factor of transgression constitutes “aiming at undertaking new altruistic activities, expanding freedom (emancipatory transgression) or attempts to prolong individual’s life (temporal transgression)⁴². Emancipatory transgression means intentional attempts to extend individual freedom and plays a significant role in “beyond” type of actions. It differs however, from pursuit aimed at

⁴⁰ As cited in: M. Dudek, *On the Psychological Reactance and Its Possible Implications on the Policy of the Criminal Law (O psychologicznej reaktancji i jej możliwych implikacjach dla polityki prawa karnego)*, „Czasopismo Prawa Karnego i Nauk Penalnych”, Year XV, 2011, pp. 125–126.

⁴¹ E. Bielska, *Conceptions of Resistance in Contemporary Social Sciences. Main Issues, Concepts, Solutions (Koncepcje oporu we współczesnych naukach społecznych. Główne problemy, pojęcia, rozstrzygnięcia)*, Wydaw. UŚ, Katowice 2013, p. 160.

⁴² J. Koziellecki, *Transgressive Conception of a Human (Koncepcja transgresyjna człowieka)*, Wydawnictwo PWN, Warsaw 1987, pp. 57–60.

reclaiming previously lost freedom, as pursuits take a protective form. In the case of restricting freedom, the aforementioned psychological reactance arises, that is, a state aimed at reclaiming eliminated or threatened options⁴³. Therefore, overcoming oneself takes an individual and collective dimension, inventive and expansive activities, exceeding typical boundaries, revolutionary activities opposed to what is, activities with which the individual or the group shape new structures or destroy already stabilised structures, create positive or negative values⁴⁴.

Resistance in pedagogy

The interest in the phenomenon of resistance in the Polish pedagogy was especially high in the 80s and 90s of the 20th century due to numerous academic dissertations written by L. Witkowski, who concentrated on, among others, studies written by American scientists: H.A. Giroux and P. McLaren. Those authors reinterpret traditional assessment of school failures, pathology or learned helplessness and the emancipatory optics allowed them to separate the category of resistance⁴⁵. Giroux claims that not noticing and marginalising students' resistance by teachers, improper identification of their behaviours leads to numerous conflicts in the process of socialisation, which, in consequence, pushes the individual in the ranks of persons submissively subjecting themselves to the influence of the power⁴⁶.

⁴³ J. Koziński, *Transgressive Conception of a Human (Koncepcja transgresyjna człowieka)*, Wydawnictwo PWN, Warsaw 1987, pp. 57–60. p. 73.

⁴⁴ J. Koziński, *Transgressive Conception of a Human (Koncepcja transgresyjna człowieka)*, Wydawnictwo PWN, Warsaw 1987, pp. 57–60, pp. 10–11.

⁴⁵ E. Bilińska-Suchanek, *A Teacher and Resistance (against) Educational System (Nauczyciel i opór (wobec) systemu edukacji)*, Wydawnictwo Adam Marszałek, Toruń 2013 p. 66.

⁴⁶ H.A. Giroux, *Reproduction. Resistance and Accommodation (Reprodukcja. Opór i akomodacja)*, "Absent Discourses" („Nieobecne dyskursy”), part I, ed. Z. Kwieciński, Toruń 1991.

The resistance in school environment can be analysed from several perspectives: determinants, educational, psycho-emotional and functional results; directions of development: activity, passivity, aggression, helplessness, exclusion, marginalisation, as well as from the perspective of responsibility, morality, law, humanism. E. Bilińska-Suchanek believes that such dimension determines cognitive thinking and activity aimed at explanations regarding situations, relations, scope and interpretation of this phenomenon in education⁴⁷. Z. Kwieciński treats education as a whole of institutions of organised education and upbringing, at the same time distinguishing the role and meaning of school, experiences shaping competences and identity of a person⁴⁸. Simultaneously, he underlines that education can be perceived as an institution limiting or blocking development of children and youth⁴⁹. T. Lewowicki points out that school is a place, where resistance occurs both, in case of students and teachers, who feel lost, helpless, disregarded, unappreciated or treated instrumentally⁵⁰. This perspective shows teachers' authoritarianism, fictional ritualism, pretences of own efficiency, confidence, resourcefulness, which, as a result becomes dangerous⁵¹. The critical analysis of the educational environment and demanding changes constitutes a consequence of studies concerning youth resistance conducted by e.g. the aforementioned E. Bilińska-Suchanek,

⁴⁷ E. Bilińska-Suchanek, *Resistance against School. Growing up in the Perspective of Resistance Paradigm (Opór wobec szkoły. Dorastanie w perspektywie paradygmatu oporu)*, Oficyna Wydawnicza „Impuls”, Krakow 2003.

⁴⁸ Z. Kwieciński, *Between Pathos and Decadence. Social and Pedagogical Studies and Drafts (Między patosem a dekadencją. Studia i szkice socjopedagogiczne)*, Wydawnictwo Dolnośląskiej Szkoły Wyższej Edukacji TWP. Wrocław 2007, pp. 21–22.

⁴⁹ Z. Kwieciński, *Social Pathology of Education (Socjopatologia edukacji)*, PAN, IRWiR, Warsaw 1992.

⁵⁰ T. Lewowicki, *Issues of School Pedagogy: School; Transformations of the Institution and Its Functions (Problemy pedagogiki szkolnej: szkoła – przemiany instytucji i jej funkcji)*, [in:] *General Pedagogy and Sub-Disciplines (Pedagogika ogólna i subdyscypliny)*, ed. L. Turoś, Wydawnictwo Żak, Warsaw 1999, pp. 175–176.

⁵¹ L. Witkowski, *Challenges of Authority (Wyzwania autorytetu)*, Oficyna Wydawnicza „Impuls”, Krakow 2009, p. 23.

who discusses the mechanisms of dominance, power and disobedience both, with regard to students and teachers. The author refers to the emancipation and empowerment, claiming that pursuing authorship constitutes a human's basic motivational tendency. This is the motivation to act and the need to present own authorship that can occur in case of e.g. interactive resistance that increases and intensifies as a result of teacher's mistakes e.g. pressure, hurry, premature attempts to achieve educational results⁵². Identification of the phenomenon of resistance depends on change, therefore, the resistance constitutes a certain activity allowing change e.g. unjust, hurtful position, situation and the approach in the critical pedagogy trend enables analysis of opposing behaviours⁵³.

Inspirations for social pedagogy

The interdisciplinary constellation of resistance combines many theoretical trends: philosophical, sociological, psychological and pedagogical and the discussed phenomenon refers to both, an individual and groups of people. The fragmentary draft of undertaken analysis located in the resistance paradigm constitutes only a contribution to deeper reflection introducing into hidden areas of the world of persons with disabilities, as well as an introduction to more in-depth studies conducted by the author. Resistance behaviour interpreted as problematic, attributed to disabled students (students with special needs, which can constitute an act of their objection, an expression of the voice of suffered injustice, violation of dignity, a manifestation of feelings and an attempt to introduce change (e.g. at school, centre, care, rehabilitation, therapeutic establishment), gain special importance.

⁵² E. Bilińska-Suchanek, *Resistance against School. Growing up in the Perspective of Resistance Paradigm (Opór wobec szkoły. Dorastanie w perspektywie paradygmatu oporu)*, Oficyna Wydawnicza „Impuls”, Krakow 2003, p. 67.

⁵³ T. Szkudlarek, *Challenges of Critical Pedagogy and Anti-Pedagogy (Wyzwania pedagogiki krytycznej i antypedagogiki)*, Oficyna Wydawnicza „Impuls”, Krakow 2010 p. 26.

Certainly, the resistance has a “causal power” aimed at changing own position or situation, as well as reveals the power of transgression and emancipation. Furthermore, resistance comprises a phenomenon consistent with social conflict, marginalisation, exclusion, misunderstanding, violence, abuse of power and actions with features of regression and destruction.

Introduction of discourse concerning resistance to special pedagogy would enable revealing the topic of e.g.: coercion, dominance, indirect (and even direct) violence, and to activating processes of emancipation and change. Moreover, it is worth mentioning that discreditable practices of pretence in education⁵⁴, hidden activities and pressing problems of pedagogy⁵⁵ are known. For example, multi-context situations related with transferring students from one school to another (as e.g. a consequence of students’ behaviour and allegedly low level of adaptation)⁵⁶ as well as issues regarding liquidation of special establishments etc. At this point, one could ask many questions regarding resistance: is it noticeable, properly interpreted, are behaviours of persons with disability perhaps treated as maliciousness, ingratitude, functional inability, aggression, difficult behaviour or maybe as a mental illness? What happens, when persons with disability show resistance? And maybe this form of rebellion and dissent is not suitable in case of such persons?

⁵⁴ See: M. Dudzikowa, K. Knasiecka-Falbierska, *Perpetrators and/or Deceptive Activities in School Education (Sprawcy i/lub działań pozornych w edukacji szkolnej)*, Oficyna Wydawnicza „Impuls”, Krakow 2013.

⁵⁵ Z. Gajdzica, ed., *The Disabled in the Public Space Reserve (Człowiek z niepełnosprawnością w rezerwacie przestrzeni publicznej)*, Oficyna Wydawnicza „Impuls”, Krakow 2013.

⁵⁶ B. Grzyb, *Conditions Related with Transferring Disabled Students from Integrated Schools to Special Schools (Uwarunkowania związane z przenoszeniem uczniów niepełnosprawnych ze szkół integracyjnych do specjalnych)*, Oficyna Wydawnicza „Impuls”, Krakow 2013; B. Gumienny, *Changes in the Education Profile of Students with Severe Intellectual Disabilities with Linkages (Zmiany profilu kształcenia uczniów z głęboką niepełnosprawnością intelektualną ze sprzężeniami)*, „Problemy Edukacji, Rehabilitacji i Socjalizacji Osób Niepełnosprawnych”, Volume 19, No. 2, 2014.

Other perspective forces teachers, special pedagogues, therapists and trainers to look at the area of presented resistance, to insightfully notice their problems, difficulties, implications – especially in continuously changing political and educational-social reality.

Special pedagogy, whose main axis comprises disability, closely cooperates with many areas of knowledge, using their achievements and experiences⁵⁷. Certainly, the contemporary situation and quality of life of persons with disability creates new possibilities of development and new perception of social participation, many of those activities are characterised with emancipatory features – group or individual liberation from life oppression caused by disability⁵⁸. Thus, pedagogical insightfulness and sensitivity are important, as they require critical monitoring of activities undertaken with regard to persons with disability, especially in the educational space. As assumed, education should be beneficial, however, it happens that it is saturated with elements of violence, power, discrimination, stigma, marginalisation or reproduction. In such circumstances resistance occurs: a phenomenon neglected in special pedagogy⁵⁹, and requiring detailed research exploration.

In conclusion, it should be stated that the phenomenon of resistance should constitute a factor engaging the special pedagogy,

⁵⁷ I. Chrzanowska, *Special Pedagogy. From Tradition to Contemporary Times (Pedagogika specjalna. Od tradycji do współczesności)*, Oficyna Wydawnicza „Impuls”, Kraków 2015, p. 18.

⁵⁸ D. Podgórska-Jachnik, *Emancipatory Pedagogy v. Special Pedagogy – Key Categories in Emancipatory Discourse of Disability (Pedagogika emancypacyjna a pedagogika specjalna – kluczowe kategorie w emancypacyjnym dyskursie niepełnosprawności)*, „Interdyscyplinarne Konteksty Pedagogiki Specjalnej”, no. 10/2015, p. 16.

⁵⁹ It should be underlined that in the re-socialisation pedagogy, the issue of resistance is discussed, in particular, in the context of school negativism, demonstrated in active or passive reactions of students to the influences of the education system; See: A. Stankowski, *School Negativism of Youth Not Socially Adjusted (Negatywizm szkolny młodzieży niedostosowanej społecznie)*, Wyd. UŚ, Katowice 1991; A. Stankowski, N. Stankowska N. *Selected Problems of Social Pathology and Re-socialisation. Pedagogical Drafts (Wybrane problemy patologii społecznej i resocjalizacji. Szkice pedagogiczne)*, Wyd. APRINT, Katowice 2005 et al.

which by deriving benefits from interdisciplinary studies, should conduct a theoretical and research discourse in the critical and emancipatory paradigm. This paradigm provides opportunity to undertake studies aimed at transforming e.g. education of persons with disabilities, therapy, rehabilitation, social or professional activation etc. Quoting Szczepański, one should postulate for such a dimension of research, which shall enable recognising areas (reserves: establishments, centres, institutions, environments), in which “a person influences other person in compliance with existing templates and rules of communal life”⁶⁰. Therefore, it is crucial to start empirical narration concerning exercising rights of persons with disability, hidden programmes, using coercion, discipline, punishment, labelling, especially in educational and special upbringing establishments.

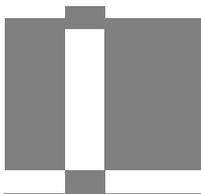
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⁶⁰ J. Szczepański, *On Individuality (O indywidualności)*, Instytut Wydawniczy Związków Zawodowych, Warsaw 1988, pp. 281–289.

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The meanings of intellectual disability in the Internet users' discourse¹

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In the following article, the author presents an analysis of meanings projected onto intellectual disabilities by the Internet users by referring to the cultural model of disability, the theory of social constructivism, as well as, to the post-structuralist discourse theories. In accordance with the cultural model of the disability theory, the author perceives intellectual disability as generated by social practices, and as a “product” of discourse. A discourse understood as a “system of statements” and as a practice that shapes the subjects which it refers to. From this perspective, the intellectual disability is perceived as a phenomenon created by its continuing interpretations. By applying the critical discourse analysis, the article presents an answer to the question: how is intellectual disability defined and interpreted within the Internet users' discourse, what meanings are projected onto intellectual disability by the network users? The presented means of comprehending and perceiving intellectual disability, its revealed meanings included in the Internet user's discourse determine the contemporary assortment of practices regarding how society responds to otherness.

KEY WORDS: meanings of intellectual disability, discourse, social constructivism, cultural model of disability

¹ This text includes a part of studies, meanings of intellectual disability in the online space, which were published in full in the book: *Experiences of Disability in Meeting Spaces (Doświadczenia niepełnosprawności w przestrzeniach spotkania)*, J. Belzyt, J. Doroszuk, A. Woynarowska. Wydawnictwo Naukowe Katedra, Gdańsk 2015.

Disability comprises an inseparable element of human existence. Very differently experienced, perceived and felt, it has ceased to be an element of individual experience or personal tragedy and became a phenomenon inseparably consistent with social reality and given culture. Disability constitutes a permanent element of social scenery and its presence in the culture and social life determined by the norm-centred discourse, forces members of a given group to take some standpoint. Recognising disability as “a social fact”² requires a given community to establish social mechanisms of dealing with this fact. Groups of disabled persons emancipating themselves and environments of disabled persons aware of own rights fight for the opportunity to fulfil the idea of an independent life. Nowadays, social media give a chance of swift unification and joining forces. Appearing initiatives and social movements: Chcemy całego życia (We want a whole life), Komitet Społeczny #Jesteśmy (#WeAre Social Committee), Rodzice osób niepełnosprawnych (Parents of the Disabled), Koalicja 21 (Coalition 21) or Autyzm Polska (Autism Poland) constitute a group putting pressure on decision makers and demand an actual, not apparent, exercise of rights included in the UN Convention on the Rights of Persons with Disabilities. The disabled fight for a voice that would be meaningful in the public discourse, validating their alternative versions of reality and alternative manners of existence. Currently, we witness such activity, a kind of civil rebellion of parents of disabled adult children, who are incapable of independent existence, whose voice has remained unnoticed and unheard. The sit-in protest at the Sejm of the Republic of Poland is aimed at increasing funds on rehabilitation and existence, but predominantly demonstrates the situation of living with disabilities to the citizens of our country. Heated discussions in the media, online³ reminded abled citizens of our country of the exist-

² See: A. Gustavsson, E. Zakrzewska-Manterys, *Disability in Social Reflection (Upośledzenie w społecznym zwierciadle)*, Wydawnictwo Żak, Warsaw 1997.

³ Currently, in the online space, in social media, there is a heated discussion regarding the protest of parents of disabled children. The majority of commenters support the protest. The value added of the protest comprises media interest in the

ence of disability and forced them to take a relevant standpoint. Once again one can ask a question, what "an ordinary citizen" knows about disability, how do they understand it and what kind of meaning do they associate therewith?

Studies presented herein were inspired by my long-lasting fascination with studies on the discourse perceived in the perspective of linguistic and social practice. Practice, which orders the world, constructs social reality and shapes the subject it discusses. Practice, which is a tool of constraint, exclusion or emancipation. The studies were inspired by texts on the intellectual disability, which I, as "an ordinary citizen", found on the Internet and in which I, as a researcher, discovered a variety of clashing meanings in the discourse of the Internet users commenting thereon, providing information on the contemporary understanding of the phenomenon of intellectual disability.

Meanings, language and discourse. Intellectual disability as a creation of cultural practices

The social world both, real and cyber, is continuously filled with meetings, experiences and meanings. Meanings, that is, linguistic interpretations with which we give sense to everything that surrounds us and due to which we reconstruct experiences and express thoughts. The theory of social constructionism assumes that the social world is created during its continuous interpretations. Social reality has a value of reality only so far as it is equipped with meanings.⁴ According to the conception of P. Berger and T. Luckmann,

fate, life and existence of the disabled, as well as appearance therein of a public/virtual discourse of many reports and voices of the disabled themselves. Their silence has been broken. The debate over the protest transformed into a debate over disability. The situation and the discourse of the protest of parents of the disabled happening in the social media space shall constitute a subject of studies and analyses in another text.

⁴ J. Niżnik, *Foreword (Słowo wstępne)*, [in:] P. Berger, T. Luckmann, *Social Establishment of Reality (Społeczne tworzenie rzeczywistości)*. Warsaw. PIW 2010, p. XVI.

solely in those meanings and through the agency thereof the social reality can exist. Specific phenomena can be perceived as processes, facts and relations solely so far as they obtain meaning, some symbolic content. A human functions in their own world by referring to what they know about this world, therefore, by referring to their knowledge. Boundaries of their knowledge constitute, in practical sense, boundaries of their reality.⁵ In terms of this theory authors assume that language is the most important system of signs in human society. Language originates from direct contacts, yet, it can be easily separated therefrom, generated knowledge is constructed during language negotiations, by evaluating and correcting own judgements and mutually negotiating meanings. The identity and personality are socially constructed.⁶ Language typifies experiences and allows implementing them into broader categories, and, as a result, they have meaning not only for an individual, but also for other persons. With this typification, experiences gain anonymity, since a typified experience can be repeated by anyone, who fits into a given category.⁷ Through the agency of language, one can refer to the whole world at any time and exceed the reality of everyday life. Any important part of language that joins various spheres of reality can be recognised as a symbol.⁸ Furthermore, language creates semantic fields, that is, spheres of meanings, the scope of which is limited linguistically. A social knowledge is created, which is passed on from generation to generation and which is available to an individual in everyday life.⁹ People live in common everyday life world equipped with specific knowledge and they know that others share at least some of this knowledge.¹⁰ In G.H. Mead's opinion,

⁵ Ibidem, p. XVII.

⁶ L. Miś, *Constructivism, Constructionism in Sociology, Social Work, Therapy. (Konstruktywizm, konstrukcjonizm w socjologii, pracy socjalnej, terapii.)* Zeszyty Pracy Socjalnej 14/2008, pp. 27–47.

⁷ P. Berger, T. Luckmann, *Social Establishment of Reality (Społeczne tworzenie rzeczywistości)*. Warsaw. PIW 2010, pp. 55–57.

⁸ Ibidem, p. 59.

⁹ Ibidem, p. 60.

¹⁰ Ibidem, p. 61.

due to language we become self-aware and thus, we have a sense of own individuality and can look at ourselves from the outside, the way others see us. A key element of this process comprises a symbol. A symbol is something that replaces something else. According to Mead, people in their interactions use common symbols and meanings.¹¹ In terms of Gadamer's idea, a human belongs to the language. The language describes and decodes us in any communicative event, reveals the manner of our private or environmental experience of the world. Each understanding has, in fact, a character of a linguistic event.¹² As written by Gadamer, rather everything what is reflects in the language. Something that cannot be met anywhere else, since this something is us, appears in the language and only therein. Finally, language is not a mirror at all. What we notice therein, does not reflect our being or not being in general, however, it comprises an interpretation and feeling what is happening with us, as in real dependencies of work and rule, as in everything else which our world consists of.¹³

Language, interaction or communication are sometimes determined as a discourse.¹⁴ Discourse constitutes a communicative activity, in which meanings are continuously constructed. As written by A. Duszak, a user and a text as a process, dynamic act of creating and interpreting meanings in context, occur in the centre of interest¹⁵. Communicative practices are usually related with negotiations and compromises which constitute a result of requirements of the current context and more general social and cultural principles. In the discourse, the power of a group can either be undermined or respected. Social norms can be creatively modified or overcome and such communicative "disruptions" can contribute to the establish-

¹¹ A. Giddens, *Sociology (Socjologia)*. Warsaw 2005, p. 42.

¹² H.G. Gadamer, *Truth and Method (Prawda i metoda)*, translated by B. Baran, Krakow 1993, "Inter Esse", p. 88.

¹³ Ibidem, p. 88.

¹⁴ See: T.A. van Dijk, *Discourse as Structure and Process (Dyskurs jako struktura i proces)*, translated by G. Grochowski, Warsaw 2001.

¹⁵ A. Duszak, *Text, Discourse, Intercultural Communication (Tekst, dyskurs, komunikacja międzykulturowa)*. Warszawa 1997, p. 28.

ment of a new social order.¹⁶ The discourse can be understood as a system of knowledge, which constructs the reality surrounding us and gives sense to everything surrounding us. N. Fairclough perceives discourse as varied manners of representing various aspects of the world: processes, relations and structures of material world, mental world: thoughts, feelings, believes, as well as social world.¹⁷ T. van Dijk believes that discourse can be described in categories of social activities performed by users of languages, who communicate between themselves in various situations and within a specific society and a given culture.¹⁸ On the other hand, M. Foucault perceives discourse as “a system of human statements”, as a practice shaping objects discussed by the discourse. It is a system of knowledge, competences and/or thoughts, which is embodied within social practices having a given place in the real world. ¹⁹ Poststructuralism, as stated by Z. Melosik, “gives priority to the theory of discourse as a method of analysing social reality. Discourses are treated as socially constructed “systematic arrangements of relations” within which ideas, statements, practices and institutions obtain a new meaning and their own “reality”. We do not speak through discourses, the discourses speak through us. Therefore, discourses “stabilize” continuous inflow of phenomena and impressions in “selectively recognisable forms”. They stipulate assumptions concerning the image the reality wants to adopt in order to “be a reality and determine the manners of studying thereof, as well as standards of truth and falsehood. Thus, discourses “put the world in order”.²⁰ Furthermore, as Z. Melosik continues, “therefore, the aim of

¹⁶ See: T.A. van Dijk, *Discourse as Structure and Process (Dyskurs jako struktura i proces)*, Warsaw 2001.

¹⁷ N. Fairclough, *Analyzing Discourse. Textual Analysis for Social Research*, London and New York, 2004, p. 124.

¹⁸ T. van Dijk, *Discourse as Structure and Process (Dyskurs jako struktura i proces)*, PWN, Warsaw 2001, pp. 9–10.

¹⁹ M. Foucault, *The Archaeology of Knowledge (Archeologia wiedzy)*, translated by A. Siemek, PIW, Warsaw 1977, p. 10.

²⁰ Z. Melosik, *Poststructuralism and Society (Reflections on the M. Foucault's Theory) (Poststrukturalizm i społeczeństwo (refleksje nad teorią M. Foucaulta))*, [in:] *Education*

the discursive practice is to obtain power over meanings (and replacing certain "speakers" with others), and each discourse participates in the fight for validation in the society of stipulated "versions of reality" at a cost of alternative versions. Such validation constitutes "an operation of closing", protects certain interpretations and marginalises and forces others to keep silence with social sanctions. Thus, metanarratives are determined, through which the society live; whereas, alternative versions of reality are repressed. Alternative "versions of reality" are delegitimized by excluding discursive practices constructing them.²¹

In 1994, Tom Shakespeare called for paying more attention to cultural representations of the disabled. Inspired with feminist debates, he discussed various theoretical approaches and suggested that "the disabled are objectified by cultural representations". As cultural representations he understood theatre, literature, pictures, films and media.²² In the following years, scientists in the Anglo-Saxon world such, as: R. Garland-Thomson, R. McRuer, D.T. Mitchell and S.L. Snyder, T. Siebers²³ published a wide assortment of cultural and literary analyses presenting the effect of perceiving "disability as a source of culture". In 2006 S. Snyder and D. Mitchell introduced the conception of "cultural model of disability". In their assumptions "the cultural model ensures fuller conception than the social model, in which "disability" means only discriminating meetings. Defining the cultural model allows theorising a political act of change, which stipulates disability as a place of resistance and

and Social Change (Edukacja wobec zmiany społecznej), ed. J. Brzeziński, L. Witkowski, Poznań-Toruń 1994, p. 200.

²¹ Ibidem, p. 203.

²² T. Shakespeare, *Cultural Representation of Disabled People: Dustbins for Disavowal?*, *Disability & Society* 9.3 (1994), pp. 283–299

²³ See: Rosemarie Garland-Thomson, *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature*. Columbia University Press. 1997; Sharon L. Snyder, David T. Mitchell, *Cultural Locations of Disability*, Chicago. University of Chicago Press, 2006; Robert McRuer, *Crip Theory: Cultural Signs of Queerness and Disability (Cultural Front)*. New York University Press, 2006; Tobin Siebers, *Disability Theory (Corporealities: Discourses Of Disability)*, University of Michigan Press, 2008.

a source of previously suppressed culture”²⁴. Moreover, in Snyder’s and Mitchell’s perspective, the approach based on the cultural model has a tendency to recognise the identity and body as constructed.²⁵ A. Waldschmit referring to the Anglo-Saxon conception of a cultural model of disability draws attention to the fact that in the perspective of this model, the disability is not perceived through the prism of a single fate, as in the individualistic-reductionist model of disability. It is also not a regular effect of discrimination and exclusion as in the social model. On the contrary, the cultural model questions the other side, commonly not threatened “normality” and studies, how practices of (de-)normalisation lead to the social category that has been called “disability”.²⁶ As further explained by this author, the cultural model of disability should not treat disability as an unequivocal category of pathological classification, which automatically, in a form of causal link, causes social discrimination. On the contrary, this model takes into consideration disability and normality as effects generated by academic knowledge, media and daily discourses. ²⁷In each culture, in a given moment, such classifications depend on structures of power and historical situation, are dependent and determined by hegemonic discourses. In short, the cultural model recognises disability not as a given individual or fact, but describes it as a discourse or process, experience, situation or event. Both, disability and ability refer to dominant symbolic orders and institutional practices of creating normality and deviation, known and unknown. By assuming a constructivism and discursive character of the disability, the following factors can be taken into consideration: the historical and cultural perspective of creating processes of inclusion and exclusion, stigma, as well as socio-cultural models of experiencing and identity, creating meanings and

²⁴ Sharon L. Snyder, David T. Mitchell, *Cultural Locations of Disability*, Chicago. University of Chicago Press, 2006, p. 10, own translation.

²⁵ *Ibidem*, p. 10.

²⁶ A. Waldschmit, *Disability Goes Cultural*, [in:] *Culture-Disability-Theory*. ed. A. Waldschmit, H. Berressem, M. Ingwersen. Bielefeld, 2017, p. 22, own translation

²⁷ *Ibidem*, p. 24.

social practices, power and resistance.²⁸ Whereas, B. Borowska-Beszta states that "the cultural model of disability in its broadest sense covers particular cultures of disability".²⁹

The cultural model of disability describes the intellectual disability as a product of cultural practices³⁰, as a socially and discursively constructed phenomenon. While considering the intellectual disability in the perspective of a cultural model and social constructionism, one can recognise it as a certain social construct and a product of meanings created within social relations, dependent on people's knowledge and experiences, and context.³¹ Whereas, with regard to the conception of symbolic interactionism, as was already noticed in 1997 by A. Gustavsson and E. Zakrzewska-Manterys, disability is also defined by reference to the meaning we attribute to various forms of physical or mental deviations.³² As written by A. Gustavsson, there are many evidences that everyday life of the disabled depends on the meanings other attribute to their disability.³³ In terms of the aforementioned definitions of discourse and in the perspective of a cultural model of disability, I deem the intellectual disability as a social phenomenon defined, interpreted and constructed in discourses, in a specific manner of using the language and speaking thereof. Generated disability discourse forwards various ideas, beliefs and meanings constituting grounds for relevant social practice. Situations are defined and interpreted through the

²⁸ Ibidem, p. 23.

²⁹ B. Borowska-Beszta, *Disability in Cultural and Theoretic Contexts (Niepełnosprawność w kontekstach kulturowych i teoretycznych)*, Oficyna Wydawnicza Impuls, Krakow 2012.

³⁰ D. Goodley, *Disability Studies. An Interdisciplinary Introduction*. Sage Publications. Los Angeles, London, New Delhi 2017, own translation.

³¹ T. Żółkowska, *Social (De)valorisation of the Role of A Disabled Person (Społeczna (de)waloryzacja roli osoby niepełnosprawnej)*, [in:] *The Disabled in the Public Space Reserve (Człowiek z niepełnosprawnością w rezerwacie przestrzeni publicznej)*, ed. Z. Gajdzica, Oficyna Wydawnicza Impuls, Krakow 2013, p. 40.

³² A. Gustavsson, E. Zakrzewska-Manterys, *Disability in Social Reflection (Upośledzenie w społecznym zwierciadle)*, Żak, Warsaw 1997, p. 12.

³³ Ibidem, p. 116.

agency of a specific understanding presented in meanings or recognition of intellectual disability. During the communication process of persons discussing this issue, we deal with not only an exchange of communications and negation of meanings, but also with partners influencing each other in the discussion to undermine mutual beliefs. Deconstruction of those meanings, disclosure of dominant ideologies and social practices constitute areas of studies most frequently conducted in the area of the cultural disability model.

The Internet as a space for social communication, exchanging and constructing meanings

The Internet has become a part of life of contemporary communities and it could be stated that it is a parallel space, where human communities live an alternative life. The Internet has opened a new dimension of human co-being, cyberspace or cyber world dimension, which is created by all users thereof. Due to the developing technology, communication via the Internet has been increasingly common. Moreover, the Internet globalised communication allowing users around the world to communicate with each other. W. Gustowski defines the Internet as a multimedia and global communication channel enabling bilateral communication, used for sending image, sound and text, as well as a new society existing in the virtual space³⁴.

The network constitutes means of communication and producing knowledge, which is nowadays a parallel cyberspace, where social life takes place. As summarised by B. Aouil, the Internet is characterised and distinguished with the possibility of bilateral communication, swiftness and ease of exchanging and sending information. The Internet is a community with which, through the agency of tools thereof, it is possible to communicate, process in-

³⁴ W. Gustowski, *Communication in Social Media (Komunikacja w mediach społecznościowych)*, Wydawnictwo NOVAERES, Gdynia 2012, p. 31.

formation without losing value thereof and gain access thereto irrespectively of living conditions and cultural differences³⁵. The Internet has many advantages such, as: ease of use, anonymity, accessibility, equality of the roles of a sender and a recipient. This anonymity and a lack of censorship encourages communication users to freely express their thoughts which, on the one hand, discloses opinions free of political correctness, which perhaps would not be spoken "face to face"; however, on the other hand, it opens the space for the hate speech. In the online space, where a word rules next to an image, we deal with dialogicality, exchange of thoughts and opinions, creating meanings. On the Internet anyone can be a sender and a recipient. As noticed by W. Gustowski, every group member communicates with others for some reason: to obtain information, get to know new people, find love, find appreciation, confide, find help, discuss, entertain and so on. It is also true that each community is based on technology. Without "a physical network infrastructure" there would be no "global communication forum"³⁶. The network enables discussing various topics, playing games with others online, searching for love or creating a better image of oneself. The Internet users have an opportunity to learn about topics and threads that are foreign to them in the real world, therefore, the network and contents included therein as an element of public discourse, create, transfer and consolidate knowledge on many social phenomena. Moreover, the network user has an opportunity to comment on any topic or thread they happen to come across in the cyberspace at a given moment. Such an anonymous comment discloses ways of understanding many social phenomena. One of them comprises the way of perceiving, understanding and recognising intellectual disability. The cyberspace can be also perceived as a kind of culture text, which generates meanings.

³⁵ B. Aouil, *Communication in the Internet – Tools, Characteristics and Features (Komunikowanie się w Internecie – narzędzia, specyfika i właściwości)*, [in:] *Social Communication in Virtual World (Komunikacja społeczna w świecie wirtualnym)*, ed. M. Wawrzak-Chodaczek, Wydawnictwo Adam Marszałek, Toruń 2008, p. 11.

³⁶ *Ibidem*, p. 94.

Methodology of own tests

In this article I would like to present answer to the question: how is the intellectual disability defined and interpreted in the Internet users' discourse, what meanings are given thereto by network users? Conducted by me analyses were inspired with comments online regarding the intellectual disability. Those comprise comments given to articles, topics and threads regarding the intellectual disability. Articles resulted in activating meanings, discussing comments regarding intellectual disability given by "ordinary persons", citizens. Analysed comments refer to four³⁷ articles published online: text by Sylwia Chutnik, *What does "normality" mean? (Co to jest „normalność”³⁸?)*, which discusses the issue of (non-)acceptance of otherness/disability in the public space, the article by Aneta Wawrzyńczak, *How do mothers of children with the Down syndrome live? (Jak żyją matki dzieci z zespołem Downa?)³⁹*. Text by Dorota Karaś, *Next to my house, they call me: Down. In theatre no one has ever said anything bad to me (Pod domem krzyczą na mnie: ty Downie. W teatrze nikt nie powiedział mi nigdy nic złego)⁴⁰*, which presents the occupational activation project of Gdańsk Fundacja Ja Też (Me Too Foundation), thanks to which persons with the Down syndrome work at the Gdańsk Shakespeare Theatre, at the customer service office; and the article by M. Kossobucka, *What is the Down syndrome and what is the risk of falling ill? (Czym jest zespół Downa i jakie jest*

³⁷ Analysed comments to two first articles come from 2014; in order to update the material, I added to analyses comments to randomly selected articles on disability from 2016 and 2017. However, first impression from the analysis shows a lack of significant changes in the discourse and an appearance of threads resulting from social and political events.

³⁸ <http://www.styl.pl/magazyn/felietony/sylwia-chutnik/news-co-to-jest-normalnosc,nId,1084492> [access: 30.10.2014].

³⁹ <http://kobieta.wp.pl/kat,132000,title,Jak-zyja-matki-dzieci-z-zespolem-Downa,wid,14490561,wiadomosc.html?ticaid=113a9a> [access: 30.10.2014].

⁴⁰ <http://trojmiasto.wyborcza.pl/trojmiasto/1,35612,20923616,mt-w-gdanskim-teatrze-szekspirowskim-pracuja-osoby-z-zespolem.html> [access: 7.05.2018].

ryzyko zachorowania?)⁴¹ As I have already mentioned, as a member of community I also function in the parallel space, that is, the Internet. I read, publish, discuss. And as a member of this community, as "the average Joe", I come across texts on disability. As a researcher, I curiously read comments and with great interest search for the answer to the question: what does a Pole know about disability? What kind of knowledge do they have, how do they construct and discuss this social phenomenon? As a consequence of meanings free from political correctness, then, various social practices are generated with regard to the disabled. One can ask why these particular articles? Since I "came across" them online as any other ordinary citizen. Why only four? Since my intention was not to study the whole virtual discourse of disability, but to disclose meanings included in those randomly read texts. I treated comments of the Internet users as "a social text"⁴² and used a critical analysis of the discourse. The critical analysis of the discourse comprises a form of critical social researches "studying manners of reducing our freedom by our own thinking categories blocking noticing what could have been".⁴³ It is aimed at educating people that language is not something natural, a neutral tool, but a carrier of a system of individuals' beliefs and values dependent on their positions and broader social and historical conditions.⁴⁴ It includes an element of a detailed analysis of the text, whereas, "a text" is understood as spoken interactions, a "multimodal" text on the television and the Internet,

⁴¹ <http://wyborcza.pl/7,75398,20829541,czym-jest-zespol-downa-i-jakie-jest-ryzyko-zachorowania.html> [access: 7.05.2018].

⁴² S. Talija as cited in K. Starego, *Discourse (Dyskurs)*, [in:] *Discursive Construction of Subject. Contribution to Pedagogy of Culture Reconstruction (Dyskursywna konstrukcja podmiotu. Przyczynek do rekonstrukcji pedagogiki kultury.)* M. Cackowska, L. Kopciewicz, M. Patalon, P. Stańczyk, K. Starego, T. Szkudlarek, Wydawnictwo Uniwersytetu Gdańskiego. Gdańsk 2012, p. 34.

⁴³ Calhoun as cited in, Duszak A., Fairclough N., *Critical Analysis of Discourse (Krytyczna analiza dyskursu)*. PWN, Krakow 2008, p. 10.

⁴⁴ A. Grzymała-Kazłowska, *Sociologically Oriented Discourse Analysis in Comparison with Contemporary Studies on Discourse (Socjologicznie zorientowana analiza dyskursu na tle współczesnych badań nad dyskursem)*. Kultura i Społeczeństwo, 1/2004, p. 26

in written and published texts.⁴⁵ Forms of text analysis used in the critical analysis of the discourse greatly differ from each other, they can be based on an intertextual and interdiscursive analysis, a text analysis or a semiotical analysis of the image. Selection of a method depends on a particular draft of studies.⁴⁶ Within the critical analysis of the discourse, in this research project, I conducted a qualitative analysis of the contents of comments, which allowed discovering meanings given to the intellectual disability, polemic within various manners of understanding, “fight for meanings” and declared social practices following specific meanings. The fight for meanings constitutes an attempt to convince to own understanding and an attempt to impose own conception of the intellectual disability. From the analysed material I selected particular areas of meanings forming categories of perception and understanding, I contrasted them to find “a social contrast” and a clash of various conceptions. Then, I disclosed “clashing” points, that is, polemics. Presenting long fragments of comments is purposeful, as it provides an evidence of language contemporarily used by “an ordinary citizen” attempting to grasp the essence of disability.

Definitions, meanings and interpretations of the intellectual disability in the Internet users’ discourse

Conducted analysis discloses an attempt to cope with the definition of “the other” – a human with the Down syndrome, handicapped, disabled. Naming their otherness, attributing some meanings thereto, fitting in known analogies. It is an attempt to linguistically “grasp” the essence of otherness of the individual discussed, it constitutes a kind of response to the experience of “anxiety induced by the Other”⁴⁷ in a meeting. In the thick of various

⁴⁵ A. Duszak, N. Fairclough, op. cit., p. 18.

⁴⁶ Ibidem, p. 18.

⁴⁷ See: B. Waldenfels, *Topography of Foreign: Studies on the Phenomenology of Foreign* (*Topografia obcego: studia z fenomenologii obcego*), Warsaw, Oficyna Naukowa, 2002.

comments, one was especially interesting to me: *this is a boring topic, who cares?*⁴⁸ This opinion, certainly not isolated, perhaps shows a not-so-comfortable truth on our society in the times of integration, that is, the issue of intellectual disability is somebody else's problem.

Analysed comments present a wide variety of manners of defining intellectual disability, as well as polemics carried between authors of this discourse. The said discourse becomes a field to fight for meanings and a place of undermining opinions. Nevertheless, the variety of comments polarises meanings and creates explicit three pillars of meanings of a person with intellectual disability. These are: a person with intellectual disability/better; a person with intellectual disability/the same; a person with intellectual disability/worse, abnormal, deviant.

A person with intellectual disability, **better person** is someone who loves the whole world, is sensitive and makes the world truer. We can learn from such a person gifted with the ability to love and a person who knows the truth. The thread of learning from persons with intellectual disability: the ability to love, the skill of looking at the world "truly" and noticing what is the most important very frequently occurs in comments. Furthermore, thus defined persons with intellectual disability are a gift from God and a trace of His presence on the earth, as God hides in them. As can be read in the comments:

Some people are stupid, I have worked with the disabled with the Down syndrome and I think that such persons **are not so much different from abled persons, the only difference is that they are disabled; besides that they are great, they joke and laugh.** If anyone thinks otherwise, they should not speak. Regards, the Internet user.⁴⁹

For 30 years I have taught in a special school, which was also attended by children with the Down syndrome. I have always asked the head-

⁴⁸ <http://kobieta.wp.pl/kat,132000,title,Jak-zyja-matki-dzieci-z-zespolem-Downa,wid,14490561,wiadomosc.html?ticaid=113ca7> [access: 30.10.2014].

⁴⁹ <http://kobieta.wp.pl/kat,132000,title,Jak-zyja-matki-dzieci-z-zespolem-Downa,wid,14490561,wiadomosc.html?ticaid=113ca7> [access: 30.10.2014].

master to allocate as many of such children to my class as possible. Why? – because they **are nice, kind, loving, sensitive, no aggression, they love the whole world.** They are always smiling, they can enjoy anything, they are sensitive to music, art, willing to do all activities. You cannot shout at them, because due to their sensitivity, they will not listen. “My” children were writing beautifully, reading, telling stories. Of course, there were exceptions, but completely healthy children also have troubles with reading. The principle is that you have to treat them as you treat children normally, do not do things instead of them and do not continuously remind them of the **illness.** Now I am on retirement, I miss children and youth, but especially those with the “Down syndrome”, who were always smiling, waited for me at school doors, noticed that I am sometimes sad, wanted to cheer me up. They were **simply kind, sensitive children, and if a little different?** So what!⁵⁰

I have someone close with the Down syndrome and this is a person, who **gives me a lot of joy and happiness,** like no-one else. I love her very much. **We, people should learn from such people – sincerity, simplicity, smile and, above all, love, because no-one can love as they can.** Comments given by people, who do not know such persons, but write about them, are sad...⁵¹

At work I have a girl with cerebral palsy, a colleague has an autistic son, other colleague a son with the Down syndrome....and so what...**all of them are valuable, sensitive people, even if other than us...** They also need human kindness, warmth and smile... it is up to us, so-called normal, how they are going to look at and perceive the world.....you might not empathise with them, but **you should not be afraid of them.**⁵²

Listen Michał, I address these words to you: I have graduated from philosophy, I have met many intelligent people, I recognise a sensitive and wise person at first sight – **such as you, and you are much more intelligent than many people. You are great,** you have excellent and

⁵⁰ <http://kobieta.wp.pl/kat,132000,title,Jak-zyja-matki-dzieci-z-zespolem-Downa,wid,14490561,wiadomosc.html?ticaid=113ca7> [access: 30.10.2014].

⁵¹ Ibidem.

⁵² Ibidem.

accurate observations. **You are a valuable** person and you do something great. Huge respect, keep going Michał. Do not worry about the stupid people, who shout at you at the housing estate; unfortunately, they are less intelligent than you and they know nothing.⁵³

Some time ago I was at holidays with my son, when we met a 5 year old girl with the Down syndrome. **She was exceptionally cute**, always smiling, friendly. Such children are less clever, but they wholeheartedly **love the world and we should learn this from them**.⁵⁴

A person with intellectual disability is perceived as **the same**, constitutes an attempt to grasp the category of otherness in the field of familiarity. Therefore, the comments include an element of eliminating the difference, a person with the intellectual disability is "the same as us, they do not differ from us – able persons at all", they are humans just as we are. The community of humanity is added with one more mutual element: being ill. Illness is a denominator for all people and the intellectual disability is degraded to an illness and becomes a common experience, we are the same, since all of us have some kind of illness. The same human beings, so they have equal rights and deserve to be treated equally. As written by the Internet users:

This is **the same child** as any of us!!!! Being **ill** is not their whim!!!! They also deserve love and respect!!!! With reference to Zośka's comment... You are pitiful writing something like this!!!! I wonder, if you were happy, if you had the Down syndrome and your mother gave you away somewhere!!!! It is apparent you know nothing about life and your thinking is shallow!!!! Regards to all mothers and kiddos.⁵⁵

At the waiting room, at the orthodontist I met a girl with the Down syndrome, **a cute child**, pretty, nice, polite... At the stop I met a blind

⁵³ <http://trojmiasto.wyborcza.pl/trojmiasto/1,35612,20923616,mt-w-gdanskim-teatrze-szekspirowskim-pracuja-osoby-z-zespolem.html> [access: 7.05.2018].

⁵⁴ <http://trojmiasto.wyborcza.pl/trojmiasto/1,35612,20923616,mt-w-gdanskim-teatrze-szekspirowskim-pracuja-osoby-z-zespolem.html> [access: 7.05.2018].

⁵⁵ <http://kobieta.wp.pl/kat,132000,title,Jak-zyja-matki-dzieci-z-zespolem-Downa,wid,14490561,wiadomosc.html?ticaid=113ca7> [access: 30.10.2014].

young woman, I walked her home, because she was standing as if waiting for help. **A super nice, joyful** girl, student of the Polish philology. **I think that the last thing such persons need is pity... Some kind of grievance "you are so poor"...** I cannot image such rudeness and I know that people can act like this... Instead of asking out of pure kindness, if we can help, **approaching them as equal**, rather than "poor thing", over whom you have to fuss...⁵⁶

A person with intellectual disability, **worse**, is an abnormal deviant, someone who threatens with their otherness. They are opposed to a better normal person, they are unknown and incomprehensible. In the Internet users' comments, one can notice a lack of knowledge and a stereotypical knowledge developed thereon; there are also comments regarding experiences of others' reactions to the intellectual disability in the public space, as well as own opinions regarding those reactions. In those opinions, a person with intellectual disability is somebody, who is poor and unhappy, inducing compassion and pity, somebody from whom you "can be infected with disability", oversexed and thus, a dangerous, aggressive, suffering and salivating dimwit, not independent. Furthermore, opinions on the Godly interference in the birth of a child with disability can be observed; as opposed to the previous comments, God does not give a gift, God does not hide in disability, He is cruel and, in fact, punishes with birth of a disabled child.

My mother-in-law (60 years) has been strongly criticising me since she found out I have been attending general development classes with my son (he was born prematurely) and at these classes I sometimes meet children with the Down syndrome. **She claims that, if I "stare", something bad may happen to my baby boy.** The woman is educated, she is a lawyer. Awful...⁵⁷

:(**poor children**:(((a heart breaks!!!!!!!!!!!!⁵⁸

⁵⁶ Ibidem.

⁵⁷ Ibidem.

⁵⁸ Ibidem.

Children with the Down syndrome: ok, they are nice and acceptable, but they will grow up! **And an adult with the Down syndrome: this is a problem!** Who will take care of them, when their parents are gone?⁵⁹

Well, is it normal that a young man with the Down syndrome, when he notices a woman on the bus almost pokes her eye out with a crazy "whip", or a girl with the Down syndrome hovering around a guy at a PKP waiting room, staring at him as if hypnotised and ready for anything? **Is it normal? You cannot stop or control it from a certain age.**⁶⁰

This is the truth! **Those people are oversexed!** Near me, there is a day care centre for the disabled. When I am waiting at the stop I often see that girls with the Down syndrome chat up strange men and boys even salivate when they see women. Why do you not write about the fact **that they can be dangerous?**⁶¹

As far as persons with the Down syndrome. **They are not and will not be normal.**⁶²

A few days ago, at Biedronka I saw a mother with a girl at the age of 3–4 years with the Down syndrome, the mother could not do shopping peacefully, the girl was shouting, cast herself onto the floor. I thought **to myself, for what sins was this child given and that the mother is suffering,** how can God look at this, why both of them **were punished.** At my housing estate there are many mothers with children on wheelchairs, they are shouting, salivating, bending every possible way. Why??????⁶³

On the other hand, the text by S. Chutnik encouraged reading Internet users to attempt answering the question: what is otherness and normality and why does the intellectual disability come up in

⁵⁹ <http://www.styl.pl/magazyn/felietony/sylwia-chutnik/news-co-to-jest-nor-malnosci,nId,1084492> [access: 30.10.2014].

⁶⁰ <http://www.styl.pl/magazyn/felietony/sylwia-chutnik/news-co-to-jest-nor-malnosci,nId,1084492> [access: 30.10.2014].

⁶¹ Ibidem.

⁶² Ibidem

⁶³ <http://trojmiasto.wyborcza.pl/trojmiasto/1,35612,20923616,mt-w-gdanskim-teatrze-szekspirowskim-pracuja-osoby-z-zespolem.html> [access: 7.05.2018].

the context of abnormality? The comments include the following questions: who is the Other? Who is he? What criteria define otherness and familiarity?

Maybe it is US who are others? Maybe WE only think we are normal? **What does normality really mean???** Calling each other names?, A lack of interpersonal communication? Not smiling at everybody? A “rat race”?, etc.??? And what if we have the ability to work, but we get nothing from it... We (supposedly healthy) love only ourselves, people with the Down syndrome love others and even more, they prove it with their simple, because carefree joyfulness...⁶⁴

The word “normal” means compliant with the norm, therefore, someone over the median, thus, as majority. In itself it does not have a pejorative meaning. Worse, if this word is given such meaning. All geniuses, the wisest people are also abnormal; even their fate proves that they are perceived as such. Thus, in such a context I would like to say that each **“abnormality” can be interesting, if it distinguishes us from the crowd.**⁶⁵

In the said discourse one can notice polemics and undermining each other’s interpretations. I can even state that there is a kind of fight for understanding the situation of persons with intellectual disability, a fight for abandoning hurtful definitions, a fight for changing meanings. The Internet users accuse one another of a lack of tolerance, knowledge and acceptance of otherness. They postulate for starting a change in the way of thinking of the Other from learning what otherness mean and learning to accept it. They point out social arrogance and ignorance with regard to this social issue. Those comments are made by persons who do not agree with this social arrogance and ignorance, a lack of knowledge or discrimination. In polemic comments we read as follows:

A person learns by copying, irrespectively of the race and place where they live. This is a way of learning about the world, about everything

⁶⁴ <http://www.styl.pl/magazyn/felietony/sylwia-chutnik/news-co-to-jest-normalnosc,nId,1084492> [access: 30.10.2014].

⁶⁵ Ibidem.

that is new. **I teach children and adults that disability is in every person; no one is 100% able.** Everyone should start with themselves, with the willingness to **learn what is different, unknown, even terrifying, but only in the beginning. Later, it is only a norm.** Let us copy wise, good or simply normal attitudes.⁶⁶

A lot of people are simply uneducated dimwits. **They are afraid to be infected with the Down syndrome, diabetes** etc. They are the ones we should avoid, because you can get infected with stupidity!!!⁶⁷

I have a question. Who is responsible for the contents of comments? If I find one more comment **offending** persons with the Down syndrome, I will accuse WP of **intolerance**. Each portal should control the contents of posted comments. And now the essence: for me, having an ill sister with the said syndrome is a sense of life. And I think it has been planned in advance. Even if I had all the reaches of the world and I would not have my sister, life would be senseless to me. It is incomprehensible, how those persons can fight with suffering, illness. I could do anything for her.⁶⁸

Perception of social practices

The Internet users participating in the discussion often ask about the sense of life of persons with the disability⁶⁹, they also point out the support system and discuss in a manner characteristic for the online space, the approach of our society to the disabled. Recent social and political events include not only parents' protest at the Sejm, but also another debate on tightening the anti-abortion act. This comprises proceeding of the ban on terminating pregnancy

⁶⁶ Ibidem.

⁶⁷ Ibidem.

⁶⁸ <http://kobieta.wp.pl/kat,132000,title,Jak-zyja-matki-dzieci-z-zespolem-Downa,wid,14490561,wiadomosc.html?ticaid=113ca7> [access: 30.10.2014].

⁶⁹ In the book, *Experiences of Disability in Meeting Spaces (Doświadczenia niepełnosprawności w przestrzeniach spotkania)*, in the chapter written by myself, I discuss the discourse of abortion applied by the Internet users in comments to articles by S. Chutnik and A. Wawrzyńczak.

in case of a serious and irrevocable foetal damage.⁷⁰ These events are reflected in comments and proclaimed views on said social practices undertaken with regard to the disabled also originate from meanings attributed to the disability itself. The Internet users allow choosing abortion and criticise for this solution. Radical users believe that persons, who decide to give birth to a disabled child should do so at their own cost, since disability is a burden on state. They offend each other criticising their way of thinking. The discussion is initiated by the post:

And women **murderers** want to kill such people before birth. The same ones that steal the logo of Solidarity and adopt bees after the murder is done⁷¹.

The discussion started with an ideological statement “women murderers” raises a subject of a lack of system solutions, sufferings of “irrevocably damaged” children and questions about the sense of suffering, the society’s stigmatising attitude to the disabled, as well as refers to the philosophical and ethical issue: when a being becomes a human? In reply to the above post we can read the following:

Surely a **Catholic**?⁷²

If EVERYONE was guaranteed with the **future**: rehabilitation, education, health care and predominantly, a job (occupation giving opportunity to leave home), perhaps it would be different⁷³.

No, in fact you are wrong. If you think that the Down syndrome is a disability that pregnant women are afraid of, you are mistaken. They are afraid of children without brain, without cerebral cortex, without the most important organs, children whose life will consist of only suf-

⁷⁰ Debates on the ban on abortion appearing in the public space require separate analyses. In this text I only signal the thread, without delving into the ideological and linguistic postulates of engaged parties.

⁷¹ <http://trojmiasto.wyborcza.pl/trojmiasto/1,35612,20923616,mt-w-gdanskim-teatrze-szekspirowskim-pracuja-osoby-z-zespolem.html> [access: 7.05.2018].

⁷² Ibidem.

⁷³ Ibidem.

fering. They do not want to condemn children to **years of suffering** (or only hours), after which they will be slowly dying. You have no idea what you are writing about. How many families with such children are you helping? In which hospice for such infants are you volunteering? And perhaps you have already adopted a child with tetraplegia, severe intellectual disability (does not speak, does not see, does not think, does not hear, because the hearing nerve does not function); howls or squeals all day long, is frail, too frail for a wheelchair, covered in bed-sore, with refractory epilepsy. Give an address: many people will willingly turn to you for help.⁷⁴

On the one hand, they bawl out **not to abort**, but when someone with the Down syndrome does something, is an actor, then, the same trash that protected against abortion, **bawl out: DOWN!**⁷⁵

Why, when the human's beginning is unlucky and medicine can detect it, this human development has to be continued until the end, for their **misfortune, suffering**; after all, **a human has not yet been formed**, there is only matter, nothing more, is it not better to stop this unlucky process of nature.⁷⁶

Another thread of quite a turbulent exchange of opinions is directed at the rights of the disabled and the unfavourable social policy, which is confronted with "encouraging to giving birth to disabled children".

Children with moderate disability are in minority, and persons like Michał, with mild disability, constitute perhaps a permille. Besides, on the one hand, Kaczor encourages to give birth to children with the Down syndrome and on the other hand, "colleagues got to the group therapy workshops, but for me there is no place for now". **This is how our Polish pro-family policy look like: give birth, give birth and what then, it does not matter.** And parents of such children living a normal life are the least important.⁷⁷

⁷⁴ Ibidem.

⁷⁵ Ibidem.

⁷⁶ <http://wyborcza.pl/7,75398,20829541,czym-jest-zespol-downa-i-jakie-jest-ryzyko-zachorowania.html> [access: 7.05.2018].

⁷⁷ <http://trojmiasto.wyborcza.pl/trojmiasto/1,35612,20923616,mt-w-gdanskim-teatrze-szekspirowskim-pracuja-osoby-z-zespolem.html> [access: 7.05.2018].

Whereas, other user deems persons with disability as useless bread eaters and a burden for the state and claims that anyone, who decides to give birth to a disabled child should bring them up at their own cost. In this thread, the Internet users also clash with their opinions.

If someone **consciously** gives birth to a child with the Down syndrome or other developmental defect, they should **cover the costs of treatment with their own funds**. The state should not sponsor **production of invalids**. Let us remember that the expensive treatment of developmental defects causes shortages in money for other methods of treatment. That is why I believe that, if you want to have a child with the Down syndrome or e.g. a serious heart defect, then, sponsor them **at your own cost**.⁷⁸

You are an imbecile and I do not wish on you or on your children ever having to take such a difficult decision... and maybe it would be good... You have no guarantee on living in health and full fitness until the end of life. By analysing your way of thinking, if you, God forbid, had an accident and became an invalid unable to provide for yourself, then, you should be euthanized. Will you not agree?⁷⁹

You are the imbecile, because you do not understand, what has been written. **I simply disagree with playing "sweet children with the Down syndrome" at my cost**. I wish it on no one, but there are situations when you have to face the truth, even if it is brutal. With regard to persons already living, I have never written that the disabled should be eliminated. You added it yourself; perhaps, you have such hidden wishes. Persons who were a victim to an accident paid social insurance and should be covered with protection.⁸⁰

Comments added to articles disclose a certain fragment of social mechanisms of dealing with otherness of the disabled. Mechanisms based on meanings and discourses. An unproductive bread eater,

⁷⁸ <http://wyborcza.pl/7,75398,20829541,czym-jest-zespol-downa-i-jakie-jest-ryzyko-zachorowania.html> [access: 7.05.2018].

⁷⁹ Ibidem.

⁸⁰ Ibidem.

unnecessary element of the society or a rightful citizen having the right to support and a dignified life?

The Internet users also review the Polish social reality of the relation with disability and to be precise, present their manner of perception.

A nice article about nice people, **only comments are disgusting**. Those are Catholics full of compassion and love for fellow human beings. It is wonderful, how people are encouraged to give birth to disabled children and later call after them "look, a Down". Only conceived children are important and what then? This is parents' business, usually a heroic mother, because only one in eight loving daddies stays with the family and the rest vanish. Surely, they go to the rotten West with a mission to profess Polish, Catholic values. There, patriots. It is a pity that what is a cultural norm in the liberal West, seems to be a sensation in Poland!⁸¹

Summary

Analyses carried out by me, situated in the cultural model of disability, concerning the methods of defining and interpreting the intellectual disability, meanings attributed thereto, present a great diversity of social understanding of this phenomenon, or "a social fact".⁸² Authors of analysed comments are first of all, parents and persons connected with the environment of persons with intellectual disability and persons who have professional experience and maintain private contacts with persons with intellectual disability. In their comments they present an interpretation of own experiences and usually those are far from the stereotypical perception of the intellectual disability. The second group of authors of analysed comments consists of persons who have never dealt with persons

⁸¹ <http://trojmiasto.wyborcza.pl/trojmiasto/1,35612,20923616,mt-w-gdanskim-teatrze-szekspirowskim-pracuja-osoby-z-zespolem.html> [access: 7.05.2018].

⁸² See: E. Zakrzewska- Manterys, A. Gustavsson, *Disability... (Upośledzenie...)*, op. cit.

with intellectual disability. They saw or rather “watched” them in public places, experienced a random meeting “face to face”, swift, superficial, inclining to run away. Those authors, referring to the theory of Berger and Luckmann, by describing this Other, used typifying schemes, and in particular, by interpreting this “encounter with otherness”, they referred to the sphere of meanings, which the society attributes to persons defined as handicapped/abnormal. The cultural imperialism referred to by C. Barnes and G. Mercer, where “able normality”⁸³ constitutes a privileged and desirable status is very visible in those comments. Despite this being the year 2014, it is worth referring to the model of social representations of disability established in 1995 by the London-based researchers, since, in spite of the fact that almost twenty years have passed, it remains up-to-date. In 1995, a group of researchers of the London School of Economics presented a two level model of social representations of the intellectual disability. This model shows that the first level of representation was established on the grounds of social representations treated as obvious and understandable, rooted in the tradition of social awareness of a society or a group. At this level, one can find traditional social constructions of the intellectual disability, which associate/identify people with intellectual disability as stupid, dangerous, condemned to God’s punishment, unhappy, helpless etc. At the second level of the model there are people in everyday social interactions with others engaged in discussions and disputes. In these everyday life struggles and in experiencing the intellectual disability, people act in a shared social reality including, together with many others deemed as obvious, traditional social representations, own, different definitions resulting from their individual experience.⁸⁴ Online comments of the second group of authors can be deemed as those from the first level of social representations of the intellectual disability, obvious and stereotypical. As

⁸³ C. Barnes, G. Mercer, *Disability (Niepełnosprawność)*. Warsaw, Sic, 2008.

⁸⁴ See: A. Gustavsson, E. Zakrzewska-Manterys, *Disability... (Niepełnosprawność...)*, op. cit.

presented by carried out analyses, those stereotypical and socially obvious meanings of disability "are well", conditioning social dislike and full of disdain superiority among people copying them. Comments of the first group of authors, who develop own and different manners of interpretations and join discussions as well as disputes with the representatives of obvious meanings have one basic aim to change the meaning and, in consequence, negative social practices. Clashing of opinions, as observed, has been continuing for a very long time and the first level of social representation is very well established. I believe that the discourse in the Internet space is deprived of political correctness, since users thereof are anonymous and they can express their opinions freely. This fragment of comments found online, to my mind, presents very up-to-date manners of social understanding of the intellectual disability and certain variety of attitudes, which are, nevertheless, subject to polarisation. The intellectual disability ceases to constitute otherness and remains so. A person with intellectual disability is discriminated in the public space and is accepted therein. They have the right to live and, as useless bread winners wasting social money they are deprived of this right. Negotiating and constructing meanings of the intellectual disability, experiencing a meeting with the Other, becoming accustomed to their otherness, those are simply everyday tasks that belong to the public space. Studying those meanings and discourse in the reality that is changing on a daily basis, must continue, since, referring once again to the A. Gustavsson's view, there are many evidences that everyday life of the disabled depends on the meanings others attribute to their disability.⁸⁵

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⁸⁵ Ibidem, p. 116.

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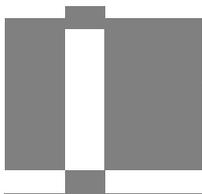
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Education of pupils with multiple disabilities in the Czech Republic

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Currently, recognition of the right of all people to education is considered completely natural. Since the mid-1990s, in the Czech Republic, the issue of educating people with multiple disabilities has been increasingly addressed. The main purpose of this study is to characterise the approach to education of persons with multiple disabilities in the Czech Republic. The article contains interpretations of the concept of multiple disabilities, both in the Czech literature and in international literature, with particular emphasis on the Czech approach.

KEY WORDS: multiple disabilities. The Czech Republic, early intervention, education system

Foreword

Education of pupils with multiple disabilities both in Poland and in the Czech Republic has undergone major changes in the last 20 years. Czech special needs educators, reforming the Czech education system, have been exploring the problem of educating pupils with disabilities since the early 1990s. Before that, disabled pupils were educated in general schools, however, as Zenon Gajdzica claims, it was natural and often implicit integration. It was not

accompanied by institutional support, mainly because in many places, there were no special needs institutions nearby¹. When discussing the education of students with multiple disabilities, we should first define what kind of disability it actually is and what major educational and support needs are associated with it². Multiple disabilities are the object of interest of medical and health sciences, social sciences (psychology, special needs education, sociology) and legal sciences (law)³.

Both the Polish and the Czech literature have different names and definitions for multiple disabilities. There are terms like: conjugate disability (cz. "vícenásobné postižení") or coupled disability (cz. "kombinované postižení"). According to Marzenna Zaorska⁴, when analysing the dilemma of multiple disabilities, the following issues should be considered: "the qualitatively different character of multiple disabilities, which, if specific disabilities are combined, causes a condition whose quality is different than the condition caused by only one of the multiple disabilities⁵". The author defines multiple disabilities as "[...] a condition, excluding intellectual disability, that is characterised by at least two serious defects in the construction of human body"⁶.

¹ Z. Gajdzica, *Opinie polskich i czeskich nauczycieli na temat przemian kształcenia uczniów niepełnosprawnych intelektualnie*, „Człowiek – Niepełnosprawność – Społeczeństwo” 2012, no. 15.

² M. Zaorska, *Aktualne problemy edukacji i rehabilitacji osób z niepełnosprawnością sprzężoną*. „Niepełnosprawność. Tyflosurpedagogiczne konteksty edukacji i rehabilitacji” 2012, no. 7, p. 9.

³ B. Marcinkowska, *Sprzężona niepełnosprawność – próba analizy fenomenu*, „Niepełnosprawność. Dyskursy pedagogiki specjalnej” 2016, no. 21, p. 10.

⁴ M. Zaorska, *Aktualne problemy edukacji i rehabilitacji osób z niepełnosprawnością sprzężoną*. „Niepełnosprawność. Tyflosurpedagogiczne konteksty edukacji i rehabilitacji” 2012, no. 7, p. 9.

⁵ M. Zaorska, *Psychopedagogiczne uwarunkowania specjalnej edukacji i terapii osób z niepełnosprawnością sprzężoną*, „Człowiek – Niepełnosprawność – Społeczeństwo” 2013, no. 1, p. 64.

⁶ M. Zaorska, *Psychopedagogiczne uwarunkowania specjalnej edukacji i terapii osób z niepełnosprawnością sprzężoną*, „Człowiek – Niepełnosprawność – Społeczeństwo” 2013, no. 1, p. 64.

The difficulties underlying multiple disabilities are due to the fact "that [...] it is not a simple sum of the component disabilities, but rather a separate and complex construct⁷„. The population of persons with multiple disabilities is very diversified, due to its various components and their intensities, and it is not possible to develop a single characteristic model of a persons with multiple disabilities⁸.

Over the last few years, multiple disabilities have been frequently discussed in the Czech literature on the subject. Theoretical deliberations and studies focus mainly on deaf-blind pupils. The problem of the education of pupils with multiple disabilities is discussed by Czech educators and psychologists (Ludiková 2001, 2001; Souralová 2000; Hlaváčová 2003; Vítková 2004; Opatřilová 2005). The Czech literature defines multiple disabilities, for example as a condition in which "a person who suffers from two or more impairments at the same time"⁹. Maria Vítková believes multiple disabilities to be the total of human limitations in all the spheres of experience and means of expression. Emotional, cognitive, physical as well as social and communicational skills are significantly reduced and altered¹⁰.

Considering the above, this article has two basic goals. The first is an attempt to systematise basic knowledge about the education of children and youth with multiple disabilities and to identify the main directions of its transformation in the Czech Republic. I focus in particular on the legal aspects of the education of pupils with multiple disabilities, especially on the Czech law on special needs

⁷ A. Twardowski, *Pedagogika osób ze sprzężonymi upośledzeniami*, [in:] *Pedagogika specjalna*, ed. W. Dykcik, Wydawnictwo Naukowe UAM, Poznań 2006, p. 290.

⁸ B. Marcinkowska, *Wczesne wspomaganie rozwoju dziecka z niepełnosprawnością sprzężoną*, [in:] *Wczesne wspomaganie rozwoju dziecka z uszkodzonym wzrokiem i dodatkowymi niepełnosprawnościami*, ed. G. Walczak, MENiS, Warszawa 2005.

⁹ M. Sovák, *Defektologický slovník* (3. vydání), Nakladatelství H&H, Jinočany 2000, p. 158.

¹⁰ M. Vítková, *Integrativní speciální pedagogika: Integrace školní a speciální* (2. rozšířené a přepracované vzdání), Paido, Brno 2004, p. 325.

education. I am interested in how the process of educating pupils with multiple disabilities is developed. The second goal of the article is theoretical. The basic objectives and problems associated with the education of those pupils in the Czech educational system are highlighted. There are two reasons behind the choice of the Czech Republic as the country of interest. First of all, the Czech Republic has a two-track system, with two separate tracks for abled and disabled pupils – only 3% of pupils considered to be disabled attend special schools¹¹. Secondly, to look back at the history of the Czech State, it has an extensive network of special schools with a long tradition of providing care and education to persons with multiple disabilities.

The article is divided into three main parts. The first part analyses the concept of the education of pupils with multiple disabilities (areas of the educational process / objectives of the education / educational categories of multiple disabilities). The second part discusses the system of education of pupils with multiple disabilities in the Czech Republic, focusing on the Law no. 82/2015 JoL (the School Law). The third part is devoted to early intervention in children with multiple disabilities.

Education of pupils with multiple disabilities – basic assumptions

Education is defined as the total of educational activities, including teaching and raising, and it is a complex process¹². Persons with multiple disabilities have existed in various societies from the beginning of human history. Nonetheless, for ages, special institutions addressed only the problem of providing care, rehabilitation and education to persons with single disabilities. Not enough attention

¹¹ G. Szumski, *Integracyjne kształcenie niepełnosprawnych*, Wydawnictwo Naukowe PWN, Warszawa 2009.

¹² W. Okoń, *Nowy słownik pedagogiczny*, Wydawnictwo Żak, Warszawa 2007, p. 93.

was paid to persons with multiple disabilities, neither in theoretical deliberations, nor in practice¹³. The unique and complex character of multiple disabilities means that such children require unique, usually special and highly specialist, assistance. Marzenna Zaorska¹⁴ stresses the fact that it is not enough to adjust the teaching content and organise education or psychological and pedagogical assistance, but the most important thing is to understand the essence of a given disability and possible expectations as to the effectiveness of a pupil's development, and education focused on a pupil with multiple disabilities. Maria Vítková¹⁵ identifies three areas that need to be taken into consideration when developing an educational process for pupils with multiple disabilities:

- Analysis of the existing situation, which is determined by the parents' influence and the financial condition of the family. It is important to collect information from the persons who have been taking care of a child until now. Attention should be paid to various areas of the child's behaviour (perception, social development, emotionality, sensory-motor integration and basic life situations).
- The goal should be determined – the most important being to provide for the child's basic needs, and then, depending on the circumstances, subsequent requirements should be identified.
- Special educational means should be provided.

The basic goal of the education of pupils with multiple disabilities is to strengthen their ability and capacity to become as self-sufficient and independent in everyday life as possible. Education

¹³ M. Zaorska, *Rehabilitacja i edukacja osób z niepełnosprawnością sprzężoną w kontekście historycznym i stan obecny*, [in:] *Historyczne dyskursy nad pedagogiką specjalną*, ed. J. Bleszczyński, D. Baczała, J. Binnebesela, Wydawnictwo HAMAL, Łódź 2008, p. 79.

¹⁴ M. Zaorska, *Niepełnosprawności sprzężone w obliczu aktualnych przemian w systemowych rozwiązaniach edukacyjnych*, „*Niepełnosprawność. Dyskursy pedagogiki specjalnej*” 2014, no. 14, p. 104.

¹⁵ Vítková M., *Integrativní speciální pedagogika: Integrate školní a speciální (2. rozšířené a přepracované vzdání)*, Paido, Brno 2004.

should be based on a the limited possibilities of a disabled child, and it should respect its needs and abilities. Dagmara Opatřilová¹⁶ lists the main goals of the education of children with multiple disabilities:

- Optimal development of the child's personality, respecting individual differences in every child;
- Achieving the desired level of education that fulfils a certain level of a child's socialisation.
- Developing and accommodating educational needs to the specific nature of disability.

Štefan Vašek¹⁷ claims that the basic objective of the education of pupils with multiple disabilities is to be particularly careful about an individual approach, special methods and modifying the teaching content as compared to pupils with single disability. Alicia Vančová¹⁸ defines two categories of multiple disabilities, based on the type of disability, the consequences for the development of personality and socialisation, and the need for special educational assistance¹⁹:

- Mild multiple disabilities: a group of persons capable of achieving such level of education as to be able to be fully professionally active or use supported employment. Education is mainly performed in general primary schools. Persons with such disabilities should be able, with minor or no assistance, to be self-sufficient and live on their own.
- Severe multiple disabilities: such persons who need more specialist support in terms of education and rehabilitation. They mainly attend special schools, and their education is often limited to elementary content, according to the individual needs

¹⁶ D. Opatřilová, *Metody práce ujedniců s těžkým a více vadami, nakladatelství Masarykova univerzita, Brno 2005.*

¹⁷ Š. Vašek, A. Vančová, G. Hatos, *Pedagogika viacnásobne postihnutých*, Sapientia, Bratislava 1999, p. 4.

¹⁸ A. Vančová, *Edukácia viacnásobne postihnutých*, Sapientia, Bratislava 2001.

¹⁹ The author stresses the fact that not all types of multiple disabilities may be classified under the same category.

of a given person. It is necessary to use alternative and assisted means of communication.

In the Czech Republic, strategic measures concerning the education of pupils with multiple disabilities on the respective stages of their learning process promote general and integration education. The current tendency is to integrate disabled persons in education. Segregation is being replaced by integration and inclusion, the main goal being to integrate pupils with multiple disabilities with the school environment, and improve their future prospects.

The educational system for pupils with multiple disabilities in the Czech Republic

Currently, the Czech Republic is undergoing dynamic changes in terms of the practice and theory of special education of persons with multiple disabilities. Activities addressed to the disabled are supported by the national authorities, in close cooperation with non-government organisations. The Czech model of the education of persons with multiple disabilities is quite institutionalised, as a result of the establishment, in the year 1993, of the Government Committee for the Disabled (cz. Vládní výbor pro zdravotně postižené občany), which regularly participates in coordinating initiatives aimed at improving the social, legal and economic situation of the disabled in the Czech Republic. It is also worth noting that, with the Government Committee support, since 1992, the Czech Republic has been regularly developing new assistance plans for the disabled. The latest one – the National Plan for the Creation of Equal Opportunities for the Disabled in 2015–2020 (Národní plán podpory rovných příležitostí pro osoby se zdravotním postižením na období 2015–2020) is supposed to promote and support integration of the disabled and implementation of the Convention on the Rights of Persons with Disabilities²⁰.

²⁰ T. Kasprzak, *Specyficzny rodzaj niepełnosprawności jako sytuacja trudna w rodzinie. Osoby głuchoniewidome i ich rodziny w Republice Czeskiej*, „Rodzina wieloproblemo-

In the Czech Republic, the basic document that guarantees the right to care and education is the Constitution. In Article 1 of the Czech Constitution, we can read about the rights and freedoms of a person and citizen, and its Article 10 states that all the international agreements on human rights and basic freedoms that have been ratified and published and are binding on the Czech Republic, are directly effective and have precedence over the national law.

The problem of the education of children with multiple disabilities is particularly important in the contemporary concept of special education in the Czech Republic. In the 1980s, children with multiple disabilities were released from compulsory education and directed to social care institutions. In the early 1990s, the legislation governing the education of pupils with multiple disabilities changed. In the contemporary concept of the access to education of persons with multiple disabilities, the theory of original and secondary impairments of the Czech professor Miloš Sovák is being replaced by the "synergy effect" – a child is assigned to the education and rehabilitation system according to his degree of disability. Also, the type of disability that is the major obstacle to a child's development is taken into consideration.

Multiple disabilities were described in 1997, in the Bulletin of the Ministry of Education, Youth and Sport of the Czech Republic. The bulletin says that: "a pupil is considered to have multiple disabilities, if he or she suffers from two or more causative and independent types of disability which, due to their depth and consequences, justify the pupil's inclusion in the special education system"²¹. In the Czech educational system, pupils with multiple disabilities are divided into three groups²²:

- The first group are pupils with intellectual disability, which is the decisive factor in the choice of the teaching methods for them and determines their level of education.

wa. Roczniki Socjologii Rodziny. Studia socjologiczne i interdyscyplinarne 2017, vol. XXVI-XXVII, pp. 168-174.

²¹ Věstník MSMT ČR č. 8/1997, č.j. 25602/97-22

²² Vítková M., *Integrativní speciální pedagogika: Integrace školní a speciální (2. rozšířené a přepracované vzdání)*, Paido, Brno 2004.

- The second group are pupils with a combination of physical, sensory and speech disorders. A certain part of this group are deaf-blind children.
- The third group are pupils diagnosed with autism/autistic symptoms.

In 2011, in special educational institutions, 17,589 pupils were diagnosed with multiple disabilities. The most frequent combinations of disabilities are: intellectual disability + verbal communication disorders (6,173 pupils); intellectual disability + motor disability (5,510 pupils); verbal communication disorders + motor disability (3,316 pupils)²³. The most important legal acts, apart from the Czech Constitution, that govern the education of children with multiple disabilities are:

- The Act no. 82/2015 JoL on Preschool, Secondary, Higher, Vocational and Other Education – the School Law (o předškolním, základním, středním, vyšším odborném a jiném vzdělávání – školský zákon), and the following regulations:
 - The Decree of 2 June 2016 amending the Ordinance no. 72/2005 Sb. on the provision of school counseling in schools (Výhláška ze dne 2 června 2016 kterou se mění výhláška č. 72/2005 Sb. o poskytování poradenských služeb ve školách a školských poradenských zařízeních);
 - Dekret nr 27/2016 JoL on the education of children, pupils and students with special educational needs, and talented pupils (Výhláška č. 27/2016 Sb. o vzdělávání žáků se speciálními vzdělávacími potřebami a žáků nadáných).

In the Czech Republic, compulsory education starts at the age of 6 years and lasts for nine years (Zákon 561/2004 Sb. o předškolním, základním, středním, vyšším odborném a jiném vzdělávání – školský zákon). The school is divided into two stages: grades I-V and VI-IX (nine years of education). A pupil with multiple disabilities and intellectual disability, at the request of his legal guardian and on a written recommendation from psychological counselling services, attends

²³ J. Voženílek, J. Michalík, *Atlas činnosti speciálněpedagogických center v ČR*, Vydavatelství Univerzita Palackého v Olomouci, Olomouc 2013, p. 103.

a special school. Pupils with multiple disabilities but without intellectual disability attend general schools or special schools that meet their needs associated with their two or more disabilities.

There are also institutions that provide specialist support, mainly to the families of pupils with multiple disabilities. These institutions function within schools, and they are: psychological counseling services (pedagogicko-psychologická poradna) and special education centres (speciálně pedagogické centrum). Their basic function is to provide free-of-charge educational assistance at the request of the parents or legal guardians of a pupil²⁴.

The diversity, individual nature and special educational needs of pupils with multiple disabilities require careful planning of their education. It is necessary to develop a detailed individual educational plan (cz. individuální vzdělávací plán) for every pupil. According to the Decree no. 27/2016 JoL on the education of children, pupils and students with special educational needs, and talented pupils, the school principal may, upon a written recommendation from the school counseling centre, approve an individual educational plan for a pupil with multiple disabilities, which is a binding document that provides for:

- Information on the content, scope, process and means of providing special educational care.
- Information of the implementation of the educational goals, content of the curriculum, choice of educational procedures, pupil evaluation methods.
- List of compensation and rehabilitation activities, and teaching aids.
- Assistant teacher who, in particular: helps pupils adapt to the school environment, helps pupils communicate with teachers, helps pupils take care of themselves.
- Assistance in communicating by means of a non-verbal system. The school ensures a communication system that meets the needs of pupils.

²⁴ Vyhláška 116/2011 Sb., o poskytování služeb ve školách a školských poradenských zařízeních.

- The Czech sign language translator. The translator assists throughout classes and during school assemblies, trips or extra classes organised by the school.

An individual educational plan should be developed without delay, in any case not later than within a month after submission of a request by the legal guardian of a pupil. An educational plan may be supplemented and adjusted to a pupil's needs at any time during a school year. The school principal is responsible for developing and implementing an individual educational plan. The plan is developed in cooperation with the school counseling centre, the pupil and the legal guardians of a minor pupil. The school counseling centre and teachers evaluate implementation of the educational plan at least once a year. The Decree 27/2016 Dz.U. (vyhláška č. 27/2016 Sb., o vzdělávání žáků se speciálními vzdělávacími potřebami a žáků nadaných) ensures education of pupils with multiple disabilities through:

- integration in primary school classes or in schools for students with various kinds of disabilities, based on an individual educational plan;
- formation of a class for pupils with multiple disabilities in a special school;
- formation of a class for pupils with disabilities in a general school or special school for pupils with other disabilities.

Assistant teachers (cz. Asistent pedagoga) is an educator who works with children, pupils and students with special educational needs, if they are not able to sufficiently take care of themselves. The basic duties of an assistant teachers are to: (1) work individually with a pupil, (2) create conditions for teamwork, (3) support a pupil who is not able to fully engage in lessons.

Early intervention (raná péče) for children with multiple disabilities in the Czech Republic

The problem of early intervention (cz. raná péče) concerning children with disabilities, as one of the efforts towards normalisation of life and integration, developed globally in the 1970s. In the

Czech Republic, the concept started becoming popular in the 1990s, when, at the initiative of Teresa Hradlikova, Barbara Kašova, Teresa Sklemickova and Jan Vachulov, under the direction of Professor Oldřich Čálek, support for the parents of children with visual impairments was offered. An approach developed that took into consideration both a child and his parents and other family members. The Czech early intervention model is based on the principle of “accompaniment” (cz. provazeni) and it is built on three pillars: (1) supporting the child’s development, (2) supporting the family, (3) supporting the social integration of the child and his family.

Oldřich Matoušek defines early intervention as “a set of combined social, health care and psychological services. It is addressed to children in preschool age whose disability poses a major threat to their development. The intervention covers both children and their parents, and takes place in the child’s natural environment.”²⁵ In the Czech law, early intervention is understood as social field work, with a social worker going to the field. In legislation, early intervention is considered to be a social service and the entity responsible for its implementation is the Ministry of Labour and Social Affairs, pursuant to the Law no. 108/2006 JoL on Social Services, as amended (Zákon č. 108/2006 Sb.o sociálních službách). The law defines early intervention as field and/or outpatient care provided to children below 7 years of age and his family.

Early intervention measures are addressed to two groups of children and their families:

- from the moment of detecting a disability (including the prenatal age) to four years of age in the case of children with health disabilities or threatened by disability
- from the moment of detecting a disability (including the prenatal age) to seven years of age in the case of children with multiple sensory, physical and intellectual impairments.

Early intervention focuses mainly on detecting and preventing a disability, and stimulating development. It extends to all kinds of

²⁵ O. Matoušek, *Metody a řízení sociální práce (vydanie drugie)*, Portál, Praha 2008, p. 168.

intervention that are needed in the early years of a child's life. It is also important to know how the potential of a child with multiple disabilities may be used not only for his personal development but also for his better involvement in the society. Thus, proper methods of social and educational integration ought to be sought. According to Josef Slowík, early intervention does not evaluate a child's impairments and limitations, to the contrary – it focuses on his positive possibilities. The author claims that a child with disability (also with multiple disabilities) should be treated as if he was healthy – a child should not be regarded as special because of his disability, and sympathy for or frustration about his condition should be avoided²⁶. The target of early intervention is the family and parents are team partners. Intervention is mainly provided at the child's home. The family system is treated as a complex and integrated whole. Respect for a child's individuality and his cultural, social and educational uniqueness is the foundation of early intervention in the Czech Republic²⁷.

Working with the parents of children with multiple disabilities (consultations, social and educational counselling, developing strategies of alternative and assisting communication, helping to choose the right preschool or special school) is not different than working with other families. Every family has the right to receive the same amount of time or information. Each of the problems of a child with multiple disabilities should be dealt with individually.

Summary

The existing system of the education of pupils with multiple disabilities was developed in the early 1990s to enable those pupils to attend compulsory education. In the Czech Republic, pupils with

²⁶ J. Slowík, *Speciální pedagogika*, Grada Publishing a.s, Praha 2007, p. 151.

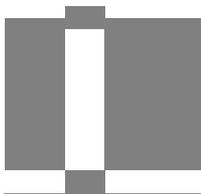
²⁷ T. Hradliková, *Raná péče pro rodiny s dětmi se zrakovým postižením a kombinovaným postižením*, Středisko rené péče, Praha 1998.

multiple disabilities may be educated in a segregation system (historically the oldest), but also they may be provided with individual teaching. The goal of educating pupils with multiple disabilities is to provide them with as many competencies as possible. In the Czech society, the problem of educational activity of pupils with multiple disabilities is the object of interest and concern for researchers. Significant support to pupils with multiple disabilities and their parents is provided by psychological counselling services and special education centres. Pupils with multiple disabilities are a very diversified group, which is why the degree and form of the teaching process must be individual.

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Parents facing the choice of a form of education for their disabled child

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Being a parent is not only fulfilling a mother's or father's role, but above all, a responsible task. This is because, parents face numerous and varied duties. The execution of parental obligations towards the child serves best interest of the child, as well as does the exercise of the rights in different areas of life, among others in child's education. The parent is obliged to secure the right to education for their child, but he also has the right to decide how to implement this important child's right. This right in the situation of a disabled child acquires particular importance, especially in the matter of choosing the form of their education. Parents' possibility to make decisions is manifested as early as at the stage of the child's diagnosis, because it depends on them whether it will be carried out and whether its results will be available to a school. It is the parent who decides where the child fulfils their schooling obligation, and chooses the form of special education for their child, a disabled student. The kind of school they will choose for their children, a special school or an integrated class, or maybe inclusive education is conditioned by many factors, and each of them can be the most important for a particular parent.

The subject of the present survey report includes the opinions and experiences of parents in the area of a choice of a form of education for their disabled child. The reasons of their earlier decisions and the level of accuracy of their choice were determined thanks to the assessment of a given form of education performed by the parents.

KEY WORDS: parents of a child with disability, student with disability, forms of special education

Introduction

Each child has an indisputable right to education, which is supposed to serve its development and preparation for life in suitable conditions¹. At a certain age, they also have to undergo the duty of fulfilling schooling obligation. The implementation of the rights and obligations of children is provided by legal regulations (act and relevant ordinances)². Protection of the rights of children is a duty of the institution of the state and their parents. Compliance with legal obligations towards children is assessed by virtue of law. Parents are aware of this fact, and child neglect may result in limitation or deprivation of parental authority. They are also aware of their rights due to being a parent, concerning decisions about their child. Unfortunately, in specific situations, they do not know or remember about all their rights, and they do not make full use of them. In the area of children education, a parent is required to provide their child with a possibility to fulfil schooling obligation including: registration a child at school, as well as ensuring that children attend school and prepare for their classes. They also have a number of rights related to having a child who is a student. They have a possibility to participate in school activities and be a partner in the interaction with teachers. Above all, they have the right to decide about their child at school, in the education, including the selection of the form of education. This decision was left to the parents by the legislator, which is strongly emphasized in legal provisions and in the literature of the subject: "(...) parents always decide on the educa-

¹ Convention on the Rights of the Child, adopted by the United Nations General Assembly on November 20, 1989, Journal of Laws 1991, No. 120, item 526.

² Act of Education System dated September 7, 1991, consolidated text, Journal of Laws 2004, No. 256, item 2572. The legislator, for the sake of individual areas of functioning of educational institutions, qualifications of people employed in them, and proceedings towards children and young people staying there, establishes specific provisions in the form of ordinances. The author's reflection is that on one hand there is a need for the change in the regulations, and on the other hand, a certain lack of sense of security in connection with the changes in people affected by these changes appears.

tion path of their child. Nowadays, the indication of the need for special education is no longer related to the place of its implementation"³. Therefore, the final decision about children's form of education is made by their parent.

This decision is of great importance with regard to the development and well-being of children. Assuming that the parent knows his child best and receives support from specialists, they have the opportunity to assess in which environment the child has the greatest chance of development and will feel safe. Undoubtedly, it is a difficult, complex decision, conditioned by many factors. Among these factors, which were most often mentioned by parents were: parents' attitude towards a given form of education, existing possibilities and limitations, as well as parents' experiences. In addition, numerous general factors that determine the choice of education for a disabled students are indicated and they include, among others: system of identification of special education needs and ways of satisfying them, system of financing special education, demographic and spatial factors, ethical and cultural issues⁴. The possibility of parents to decide about the choice of education for their children is undoubtedly considered to be of vital importance. This issue is treated as a natural situation because of parents' rights and their responsibility for the child. At the same time, the threat posed by the lack of qualifications of a parent in the area of education of a student with disability is noticed. There are also some experts postulating that the excessive number of parents' rights to decide about their child's educational future may "in extreme cases lead to violation of the best interest of a disabled student"⁵. Therefore, there

³ I. Chrzanowska, *Pedagogika specjalna. Od tradycji do współczesności*, Oficyna Wydawnicza „Impuls”, Kraków 2015, p. 590.

⁴ A. Zamkowska, *Wsparcie edukacyjne uczniów z upośledzeniem umysłowym w stopniu lekkim w różnych formach kształcenia na I etapie edukacji*, Politechnika Radomska, Wydawnictw, Radom 2009.

⁵ A. Zamkowska, *Wsparcie edukacyjne uczniów z upośledzeniem umysłowym w stopniu lekkim w różnych formach kształcenia na I etapie edukacji*, Politechnika Radomska, Wydawnictw, Radom 2009, p. 56.

is a justified concern that parents, fearing changes in the child's life caused by the diagnosis and opinion or a bad stereotype of a special school, and being at the same time without sufficient knowledge and support, or guided by the experiences of other parents, will take an unfavourable decision concerning the education path for their child.

The number and diversity of education forms is also not insignificant for the decision concerning the choice of one of them for disabled children. It should be remembered that the special education system is an integral part of the education system in Poland. Currently, a disabled child can fulfil their schooling obligation in three types of schools: special, integrated and mainstream ones. Choice of a school "should be preceded by a reliable diagnosis of their needs and capabilities and take into account the decisions of parents or legal guardians"⁶. This is an important issue because of the fact that "people with disabilities with a disturbed development may reveal greater difficulties in meeting school requirements than it happens in case of the general population"⁷. Hence, the need to consider the possibilities and limitations of children and school. Each of the proposals of education forms of students with disability (class in a special school, integrated class, class in a mainstream school) is described from the angle of its strong and weak points⁸. In

⁶ D. Apanel, *Teoria i praktyka kształcenia integracyjnego osób z niepełnosprawnością w Polsce w latach 1989–2014*, Oficyna Wydawnicza „Impuls”, Kraków 2017, p. 10.

⁷ I. Chrzanowska, *Pedagogika specjalna. Od tradycji do współczesności*, Oficyna Wydawnicza „Impuls”, Kraków 2015, p. 533.

⁸ See I. Chrzanowska, *Pedagogika specjalna. Od tradycji do współczesności*, Oficyna Wydawnicza „Impuls”, Kraków 2015, pp. 532–591; A. Zamkowska, *Wsparcie edukacyjne uczniów z upośledzeniem umysłowym w stopniu lekkim w różnych formach kształcenia na I etapie edukacji*, Politechnika Radomska, Wydawnictwo, Radom 2009, pp. 21–54; A. Zamkowska, M. Snopek, *Rozwój kompetencji nauczyciela wspomagającego ucznia z autyzmem*, „Edukacja Ustawiczna Dorosłych” 2017, no. 3, pp. 95–105; J. Lipińska-Lokś, *Edukacja uczniów z niepełnosprawnością – możliwości i ograniczenia*, [in:] *pedagogika wczesnoszkolna. Uczeń i nauczyciel w zmieniającej się przestrzeni społecznej*, ed. I. Kopaczyńska, M. Magda-Adamowicz, M. Nyczaj-Drag, Wydawnictwo Adam Marszałek, Toruń 2014, pp. 248–264.

order to make a decision, it is necessary to answer the question, what is the most important for the child, and what is important for the parent when it comes to the child's functioning in the school environment, in their education? Perhaps the upbringing function of the school is more important than the educational one, although it may sound paradoxical? Perhaps acquiring social skills will be more important than acquiring knowledge and typically school skills? The answer to these questions will undoubtedly contribute to the adequacy of choosing the form of education for a disabled child.

Parental choices of the form of education for a disabled child in the light of own research

Subject, method and technique of research and the study group

The subject of the diagnosis included the opinions and experiences of parents in the area of choosing a form of education for a disabled child. Moreover, the determinants of their decisions and the level of validity of choice were determined thanks to the assessment of the child's form of education by the parents.

The research referred to the previous decisions and current opinions of parents of students attending various forms of special education (classes in a special school, integrated classes in a mainstream school, classes in a mainstream school, single students pursued individual education). In total, the diagnosis covered 15 parents (12 mothers and 3 fathers, aged from 30 to 61 years⁹, having different levels of education, characterized by a different family situation) of disabled students¹⁰ attending classes IV-VI of primary

⁹ Among the mothers of disabled students there was one grandmother of a boy, for whom she was a surrogate parent, hence the advanced age of the study woman.

¹⁰ The students experienced different types and levels of disability. However, the dominating disability was mild intellectual disability. The students were also

school. The study took place in the years 2015–2017 in schools situated in the area of Zielona Góra.

The performed research had a nature of a qualitative study. It employed the method of individual cases and the standardized interview technique. The presented results are only a part of a wider study concerning the functioning of disabled students in the school environment.

Results of the study

The life of a parent includes important moments determined by the stages of the development of their child: the first word spoken by the child, their first step, the first day in the kindergarten or the first day at school, the First Communion Day. Many of these important moments in life are preceded by a stage of preparation and decision-making. The study clearly showed that the parents, among those moments important in their life and in the life of their child, placed the moment of starting school and the issue of the choice of an appropriate form of education. It is clearly emphasized in the statement of one of the mothers: *“As soon as Matthew came into the world, we tried to plan everything considering his disability. From the beginning, we knew that his school will also be selected with regard to his health condition. Actually, when he was four years old, we already decided that it will be an integrated school, after we saw his progresses in the integrated kindergarten, (...) we were 100% convinced to the integrated kindergarten, that this was the best choice (...) The first day at school was a true event! (...)”*. Another mother confessed: *“We could not wait, we bought an attire for formal events and a backpack as early as at the beginning of the holidays, we planned everything, (...). After the celebration of a new school year, we all went to a special dinner, the grandmother and the godfather came all the way from Krakow (...)”*. Many other parents also

affected by sensory disability (of sight or hearing), physical disability and chronic illnesses. In a few cases, the students also had multiple disability.

emphasized the importance of the first day at school, indicating at the same time that going to school was a proof of a normal life despite being marked by the child's disability and many doubts about the child's educational success. This issue was particularly pronounced in the statements of parents of children who were to start education in the form of integrated special education: *„I went with my son for the celebration of a new school year, I was proud, as probably every parent of a first-grade student ... but me in a special way ... (...) because to a normal school, as other normal kids and their parents (...) please do not judge me, I am still fighting it (...) I will probably never accept this handicap (...)*”. Many other parents emphasized that going to school is a fact in the child's biography, and entering the role of a student by their disabled child is a manifestation of a natural, and it will not be an exaggeration to say, a normal course of life. Normal? Such thinking is guided by the idea of equalization of lives of disabled people. And at this moment it is to be hoped that it is closer and closer to universal realization. Nevertheless, the parents themselves pointed at some differences in the course of the preparation stage of able-bodied children and disabled children to fulfil their schooling obligation. In the opinion of parents, disabled children more often have to prove that they can become a student and are subjected to more different diagnoses. They are assessed with regard to their school readiness, the need for special education and they are qualified to its appropriate form. The procedure of enrolling a disabled student to school in the opinion of their parents is more time-consuming and complex and requires a greater involvement of the parent.

The surveyed parents repeatedly stress their commitment to the child's affairs. They know that, in theory, each parent should show interest in the situation of their child, but in the case of parents of disabled children, they most often assess this involvement as a greater one. Arguing this, they point at the following issues:

- a) a disabled child often requires a constant presence and care of the parent, so that the latter is “forced” to constantly accompany the child – regardless of their age and most often

- inadequate degree of independence, at the expense of even resignation from own professional activity;
- b) the range of parental activities towards a disabled child is wider, as it covers not only nursing, care, and upbringing activities, but also requires non-standard medical visits, a continuous and systematically performed rehabilitation activity (conducted independently and in cooperation with therapists);
 - c) having a disabled child requires more “financial outlays” related to their specific needs (in terms of care, therapy, and then also education), which often involves the need to increase the time for professional activity and gainful work by the other parent;
 - d) the range and intensity of care and nursing activities towards a disabled child are often not subject to the principle of their reduction as the child and its independence grow, and therefore their parent is a “full time” guardian of their child, bears more effort (physical, mental)), is more often exposed to fatigue and negative emotions. Undoubtedly, the parents of disabled children are exposed to the burnout syndrome, although they do not describe their state using this term;
 - e) being a parent of a disabled child causes participation in numerous and various specific situations, resulting from the child’s health condition and development, their life situation – and, naturally, “taking care” of them and making decisions which parents of “standard” children do not have to face or these decisions in case of their children are much simpler, less complicated and time-consuming.

The parents, in addition to raising the issue of their enormous commitment to the affairs of the child, and the difficulty of being a parent of a child with special needs, also indicated the magnitude of responsibility for the child. They experienced that the sense of their responsibility did not decrease as the child grew up. They talked about constant thinking about a child, about their affairs, about their future, which is created every day, in every decision,

both the one concerning an apparent triviality and the one influencing the key elements of the child's life. In the parents' opinion, such a significant element in the child's life is their education, schooling, which constitutes the basis of adult life. Parents admitted that the moment when their child went to school caused them feel strong emotions. They were aware of the gravity of the situation and their own responsibility for making the right decision regarding the choice not only of a school for the child, but above all a form of their education. It was for them a stressful situation, in most cases they did not feel safe and secure, they often experienced doubts and, as they repeatedly called it, helplessness and fatigue with a situation often lasting too long (even up to three months) as for a so obvious decision.

What is interesting, and at the same time striking and in fact alarming, a few parents were not aware of their right to decide about their child's education path, and when they learnt about such a right, they most often treated it as only a formality in a conversation with a "specialist, official" or they could not use it in a carefully considered way, relying on the advice of another person, mainly an employee of the Psychological and Pedagogical Counselling Centre: *"I think it's a misunderstanding when someone who is not familiar with teaching children, is supposed to decide about it"*, or they made a hasty decision, and then, probably after consideration or "guidance", they changed it. Mother of Ewa with Down syndrome thought that if she could decide herself, then: *"I will decide so that it is comfortable for me (...) a special school is just a few steps away, close to home, Ewa will sleep longer and will come back alone, as she knows the road, (...) she goes there to play or for a festival"*. Another mother said: *"Adam always differed from other children. (...) He received an opinion about the necessity of special education, so I knew he would go to a special school. (...) A neighbour, a kindergarten teacher said that he does not have to go to a special school, he might attend an integrated one. (...) Maybe better, I thought, because people will not point their fingers at him that everyone attends school X¹¹, and he a special one"*.

¹¹ The school number has been changed, as well as the names of students in the interests of anonymity of the respondents.

The study, however, showed the dominance of the group of parents who knew about the possibility of deciding about the choice of education for their child. They wanted to make this decision in a thoughtful way, so they became interested in the subject of education of disabled children in advance, often using the support in deciding about the plans concerning their child's education. It was very often professional help, provided by a specialist. Mother of Asia said: *"During the therapy, I talked with Mrs. Ania, a speech therapist, I was wondering about possibilities of therapy later at school. Mrs. Ania said that regardless of the form of education, Asia will always be provided with additional sessions. We talked a lot, not just about this therapy, but about schools in general. (...) Mrs. Ania was such a guide for these schools (...), she helped in making the decision"*. Mother of Karol with hearing impairment made a decision about a special institution for her son after a conversation and suggestions of a kindergarten teacher, who presented a lot of arguments for this form of education, at the same time indicating an example of an adult deaf person who after education in an integrated school went to a centre for the deaf and after years, claims to have such a good life, just because completed the education at a centre for the deaf. Another mum indicated the role of the staff in a psychological and pedagogical counselling centre and a teacher from school in making her decision about education of her chronically ill (epilepsy) daughter with intellectual disability. In turn, the mother of another intellectually disabled 12-year-old girl with reduced mobility initially indicated full independence in terms of decision-making about her daughter's education, but at the end of the conversation she admitted that she was not left alone, confirming the previously mentioned experience of the mother of the girl with epilepsy: *"I know the rule, nobody here to help you but yourself; besides I am fully responsible for the child. (...) Well, at university there was something about the disabled. (...) I knew something, but long time has passed, it has changed, so I was learning again (...) I was reading wise books, visited a pedagogical library, I searched on the Internet (...). I think they were fed up with me in the counselling centre, as I was too inquisitive (...). As I opted for inclusive education,*

I was at the school to talk with the headmaster and the counsellor". The use of Internet sources in making decisions concerning children's education was indicated by many other parents who visited Internet fora, discussed on blogs, got to know the offer of schools during virtual travels.

Nevertheless, parents appreciated more a direct contact with other parents of disabled children, especially those who are or were students of a given form of education. Then they could benefit from the experience of these parents, who were experts in the field which the parent was interested in at the moment, who answered to practically all questions being of concern, which helped to dispel doubts, it was possible to get advice, and what is very important: *"see the effects of this education, the progresses of the boy (...). It convinced me (...) and it does not matter that someone thinks badly about a special school (...)"*. The meeting point between these two groups of parents was most often the common membership in an association or periodic meetings during therapeutic activities for children in a specialized care centre. The source of information about the education of disabled students and at the same time a kind of help in the decision of the parent to choose a form of education for their disabled child is also checking the institution offering a given form of education during a parent's visit to this institution. Parents often indicated situations (*"Open Doors Days"*, demonstration lessons, events integrating the school with the local community), when they went to a given school, to get information about it, to be able to convince themselves about the quality of its functioning, and finally, by observing students, to answer to a question about a good place of their child in the given school.

The studies has demonstrated a long and challenging road of the parents to make a decision about choosing a form of education for their disabled child. While making the decision, the parents were convinced of the appropriateness of their decision, after all, they devoted so much time and commitment to this choice. When choosing the best, in their opinion, education path for their own child, they considered so many issues. Parents, presenting the rea-

sons of their choices, pointed to numerous and varied explanations. It is worth presenting selected parents' statements, illustrating the most characteristic premises of the indications:

- a) "Best interests of the child were the most important for me, their benefits from this school, here and now, but still (...) in perspective (...), education, work, family";
- b) "a disabled child has to adapt, has to deal with life (...), to have as little difficulty as possible (...) both the child and the parents (...) the school must be appropriate (...) the one which would be good for a student";
- c) "I made a decision, (...) my wife too, together, if we decide, we bear responsibility, we decide (...)".

Now, it is worth expanding the obtained results with an analysis. One could say that the determinants of parental choices should be perceived in three aspects. The first are best interests of the child, perceived as a value in themselves. And indeed, parents choose this form of education that in their beliefs will fully consider the needs, possibilities and limitations of their child. They think about a school, which will rise to the challenge, fulfilling its functions towards students, also, and perhaps above all, the disabled ones. It is important for parents to have their child in a friendly school, but they also consider their choice in a long term, expecting the school to prepare their child for adulthood, and to fulfil the resulting life roles. They want their son/daughter to learn a profession allowing them to find a job. They see their child surrounded by their own family, close friends, who can be a support in everyday life. Such perception of the child's adulthood eliminates parents' thinking about its marginalization or social exclusion. This motivation should be assessed as the most desirable. In the second presented premise of the parental choice, the parent's demanding attitude, and misinterpretation of the assumption of education of disabled children seem to be evident. Indeed, it is not the child who has to adapt to the school's requirements, as the school has a legal obligation to work properly with a student with special educational needs. The student should be provided with the conditions to be able to succeed, have as

little difficulty as possible. This, however, has to be the effect of the work of the student, school and parent. "(...) *the school must be appropriate, good, cannot cause difficulties for the child and the parent*", says the parent, who appears to be the one who is most often most aware, does not listen to the opinion of the school and does not perceive teachers as partners to work with the child but even enemies, who brings little to the life and development of their child. In the third approach to the determinants of the parents' choices, parents themselves, their emotions and attitudes are perceived. They are the decision makers, they are responsible, but for what? Who are they responsible for?, here comes the question. Analysis of numerous statements of a parent unfortunately shows a situation unfavourable both for them and their child. Perhaps the lack of acceptance of a disabled child and themselves in the role of a parent of a disabled child actually results in a concern to "take care of" themselves instead of the child. Lack of acceptance of the life situation, fear of the opinion of other people may expose the parent to making wrong decisions that may have negative impact not only on his life, but primarily on the functioning of their child.

This situation, similarly to the previous one, requires a specific intervention at the present time, earlier both required preventive measures to prevent unfavourable decisions and choices of parents. The first situation, where best interests of the child underlie parents' decisions, is worth being shown as an example of good practice.

This is all the more important, because the study demonstrated a certain relationship between the determinants of parents' decisions about the choice of the child's education and their assessment of the adequacy of these decisions. Analysis of the parents' statements: their opinions and declarations of experience indicates, however, the ambiguity in assessing the adequacy of the decision to choose a school for their child. Here are the parents' statements confirming this conclusion:

- a) "We wanted best interests of the child and here they are. (...) The boy goes to school as if he had wings. (...) he has friends, a girl-friend ☺, good teachers. (...) They advised us against

a special school, but we knew that everyone has their own place, Tomek too, if he is so special, let the school also be ... exceptional, special. (...) Cross my heart it is a good school and our choice was good”;

- b) “badly adapted, overrated school, not open to students’ needs (...). We don’t go, because they don’t want us there (...) but we don’t need them either. Soon it will be over (...). And all our troubles will be so far away! (...) we made a wrong choice”;
- c) “we made a choice because we had such a right and it was important for us not to make him attend a special school. (...) we imagined this in a slightly different way (...). The integrated class turned out to be a label and we wanted to avoid it. (...) we are thinking about change, maybe this inclusion? (...) This is important! You are looking for something again! (...) yes, it’s important for me ... (...) Maybe there is no best decision in our situation (...)”.

It should be added that the assessment of the adequacy of the parents’ decisions was made, among others, thanks to the analysis of their statements assessing the form of education attended by their child. The parents made this assessment by considering the following criteria:

- a) compliance of the school offer with its implementation, the parent, while choosing a school, was guided by the school’s offer directed to their disabled child. Then, he was convinced that the school had adequate opportunities to meet special educational needs of the student. Daily education verified the level of compliance of the student’s/their parents’ expectations and school’s possibilities/limitations (especially in the area of teachers’ competences, additional classes, use of appropriate teaching methods and means, and adjusting the requirements to the student’s abilities);
- b) place of the student in the school community, the parent expects a good position for their child in the school, in the class among peers and in the relationship with the teachers. They

appreciate the commitment of teachers to the student's affairs and their personality traits. They want their child to enjoy friendly feelings of their peers and participate in class activities. Suffer and want change if their child feels bad at school and among the peers;

- c) parental sense of support in the school environment, the parent perceives a school and teachers in a more positive way, if they feel good in this environment, and they have the conviction that they co-decide about the matters of the school and their child. Not without significance is the feeling of receiving support for their child and themselves in fulfilling the role of a parent, and in dealing with a child.

The study showed differences in the process of making decisions about choosing a form of education for a disabled child by the parents, the consequence of these decisions being the participation of children in various forms of special education. The results of the research indicated numerous and different determinants of the decision, the choice of child's form of education. They allowed for conclusions about the diversified but also ambiguous assessment of the adequacy of the made decision, the choice of the child's education path.

Summary

Undoubtedly, the parent's decision on choosing a form of their child's education is difficult and complex. The parents themselves do not feel prepared to make it. They lack support in this area. Therefore, a reflection appears: who, where, to what extent and in which way should provide parents with this support? They will always seek information at one's risk, it is good, if they get it from a specialist, a competent person who has reliable knowledge in a given area and who has the ability to advice people in a difficult situation. This support related to information is necessary, without

it the data for the task, which is the choice, will not be full, so the choice itself may not be correct. It becomes particularly important to inform about legal normalization, including the rights and obligation. Ignorance of the law is a significant obstacle to functioning. It constitutes a threat in the individual, family and social dimension.

Moreover, the emotional support of the parent is not without significance, as the situation of making decisions and the resulting consequences in the form of change is a difficult situation. Such a situation carries a sense of deprivation, danger and overload. A parent in this situation needs support in overcoming a difficult situation, in dealing with own negative emotions and in making rational judgement and right decisions.

Schools and counselling centres, which welcome/are going to welcome a disabled student, will face a huge challenge. Since it is so important for a parent to feel supported at key moments of their own and their child's life, these institutions should provide them and their child with a proper position in the assistance system. This is not a new issue, since cooperation with parents is one of the most important tasks of the teacher and the entire team of specialists dealing with the child. However, this is a difficult task that requires focusing on its implementation. At the same time, there is a need to extend the scope of cooperation, which is indicated by both teachers and specialists, and parents of children¹²

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¹² See P. Plichta, I. Jagoszewska, J. Gładyszewska-Cylulko, B. Szczupał, A. Drzazga, B. Cytowska, *Specjalne potrzeby edukacyjne uczniów z niepełno sprawnościami. Charakterystyka, specyfika edukacji i wsparcie*, Oficyna Wydawnicza „Impuls”, Kraków 2017, pp. 188–189; *Kształcenie uczniów z niepełnosprawnościami o specjalnych potrzebach edukacyjnych. Informacja o wynikach kontroli*, NIK, KNO-4101-01-00/2012, Warszawa 2012, pp. 54–55; Z. Gajdzica, *Sytuacje trudne w opiniach nauczycieli klas integracyjnych*, Oficyna Wydawnicza „Impuls”, Kraków 2011, pp. 179–181.

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The assessment of progress in acquiring the basic school skills by the student with a moderate intellectual disability

ABSTRACT: Jacek Sikorski, *The assessment of progress in acquiring the basic school skills by the student with a moderate intellectual disability*, Interdisciplinary Contexts of Special Pedagogy, No. 22, Poznań 2018. Pp. 323–338. Adam Mickiewicz University Press. ISSN 2300-391X. DOI: <https://doi.org/10.14746/ikps.2018.22.18>

The following article addresses the issue of assessing intellectual disability from the interdisciplinary, especially psycho-pedagogical, point of view. It pays special attention to the students with a moderate intellectual disability and the difficulties which they have in acquiring such basic school skills as reading, writing and counting. However, the main aim of the research was to show all of the changes (progress) in the above-mentioned basic school skills in reference to the observed student with a moderate intellectual disability, which have occurred during the 10 months' time as a result of applying both, educational and therapeutic actions and an attempt to indicate the school's education opportunities based on the results of the research and teacher's opinions.

KEY WORDS: psychological and pedagogical assessment, student's competences, a student with intellectual disability

Introduction

The process of assessing a child with intellectual disability with regard to particular development areas requires taking into consid-

eration an interdisciplinary approach: medical, psychological, pedagogical and social¹.

On the grounds of the special pedagogy a properly constructed assessment allows to fully learn about the needs of a child with disability both, the ones of an educational and therapeutic character².

“The assessment is based on:

- recognising abilities and deviations in development on the grounds of observed symptoms;
- stipulating reasons of mechanisms and consequences of developmental irregularities and difficulties in obtaining knowledge and skills”. “The assessment describes: the pace, rhythm and dynamics of a child’s development”³.

The assessment should be explicit, accurate and reliable. Accuracy thereof and recommendations (qualifying and pedagogical) determine influences of a rehabilitation character⁴.

The assessment constitutes an interdisciplinary process associated with cooperation of experts in many areas (in particular, a psychologist and a pedagogue); therefore, the assessment proceedings

¹ See: L. Bobkowicz-Lewartowska L., *Intellectual Disability. Assessment, Education and Upbringing* (*Niepętnosprawność intelektualna. Diagnozowanie, edukacja i wychowanie*), Harmonia Universalis, Gdańsk 2011, p. 60.

² B. Trochimiak, U. Gosk, *Pedagogical Assessment of Students with Special Educational Needs* (*Diagnoza pedagogiczna uczniów ze specjalnymi potrzebami edukacyjnymi*), [in:] *Special Didactics in Preparing for Education Students with Special Educational Needs* (*Dydaktyka specjalna w przygotowaniu do kształcenia uczniów ze specjalnymi potrzebami edukacyjnymi*): academic textbook, ed. J. Głodkowska, Wydawnictwo Akademii Pedagogiki Specjalnej, Warsaw 2012, p. 140.

³ J. Hanisz, E. Grzegorzewska, *Descriptive Assessment of Student’s Development: Assisted Exercises and Tests; Integrated Education in Classes 1–3* (*Ocena opisowa rozwoju ucznia: ćwiczenia wspomagające i sprawdziany: kształcenie zintegrowane w klasach 1–3*), Wydawnictwa Szkolne i Pedagogiczne Spółka Akcyjna, Warsaw 2008, p. 15.

⁴ J. Głodkowska, *Learning about a Special School Student. Educational Sensitivity of Children with Mild Mental Disability; Assessment and Interpretation* (*Poznanie ucznia szkoły specjalnej. Wrażliwość edukacyjna dzieci upośledzonych umysłowo w stopniu lekkim: diagnoza i interpretacja*), Wydawnictwa Szkolne i Pedagogiczne Spółka Akcyjna, Warsaw 1999, p. 30.

are long-lasting and related with adjusting the study procedure to the age and abilities of the child with disability⁵.

The assessment process executed in order to present the abilities of a child or possible progress in the scope of various skills, is always of a specialist character and, as has already been mentioned, requires cooperation of various experts and is usually executed in clinics. Results of given assessments enable learning about difficulties of a given child as well as indicating reasons for such difficulties. Thus, the multi-disciplinary assessment gives a chance to fully learn about the child's abilities, progress in a given area and difficulties they have⁶.

Taking into consideration the character of this study, it is especially important to draw attention to the process of psychological and pedagogical assessment from the point of view of a child with moderate intellectual disability.

As underlined by J. Sowa "psycho-pedagogical assessment comprises stating the status of intellectual development by a team of experts on the grounds of a diagnosis obtained as a result of many research methods and techniques as well as the analysis of the child's life history and their environmental situation"⁷.

Therefore, ongoing cooperation between experts, especially a psychologist and a pedagogue, is necessary in the assessment process, since:

- (psycho-physical) abilities of a tested child with disability are conditioned individually, are not fully known or unknown,

⁵ A. Wójcik-Rudnicka, D. Kohut, *Psychological and Pedagogical or Psycho-pedagogical Assessment? (Diagnoza psychologiczna i pedagogiczna czy psychopedagogiczna?)*, [in:] *A Child with Special Needs in Interdisciplinary Therapy (Dziecko o specjalnych potrzebach w kręgu interdyscyplinarnej terapii)*, ed. D. Kohut, Oficyna Wydawnicza „Impuls”, Krakow 2013, p. 91.

⁶ B. Skalbani, *Pedagogical Assessment. Selected Research Areas and Practical Solutions. (Diagnostyka pedagogiczna. Wybrane obszary badawcze i rozwiązania praktyczne)*, Oficyna Wydawnicza „Impuls”, Krakow 2011, pp. 25–26.

⁷ J. Sowa, *An Overview of Special Pedagogy (Pedagogika specjalna w zarysie)*, Wydawnictwo Oświatowe FOSZE, Rzeszów 1998, p. 111.

- permanent changes in the child's development occur under the influence of various stimuli,
- there is a deficit in standardised assessment tools with regard to persons with disability⁸.

In order to present the potential of a child with intellectual disability or changes with regard to a given area (skills), experts: a psychologist and a pedagogue base on the so-called informal assessment techniques (interview, conversation with the child's parents, observation), as well as specific: adjusted to the age and ability of the given child in tests⁹.

The aim of the psychological assessment is to stipulate the level of intellectual functioning of a person tested, emotional and motivational processes¹⁰, orientation and executory: perception and motor functions, significant from the point of view of acquiring school techniques such, as: motor activity (low and high), visual perception, hearing perception, orientation in space, as well as in the scheme of own body, stipulation of handedness (laterality) and cooperation of all of the aforementioned functions. Furthermore, it is important to determine the psychological condition and socialisation of a given child¹¹.

⁸ T. Oleńska-Pawlak, *Structure of Psycho-pedagogical Assessment in Individual Revalidation (Struktura diagnozy psychopedagogicznej w rewalidacji indywidualnej)*, [in:] *Assessment and Individual Revalidation of a Child with Special Educational Needs (Diagnoza i rewalidacja indywidualna dziecka ze specjalnymi potrzebami edukacyjnymi)*, ed. M. Klaczak, P. Majewicz, Wydawnictwo Naukowe Akademii Pedagogicznej, Krakow 2006, p. 8.

⁹ A. Wójcik-Rudnicka, D. Kohut, *Psychological and Pedagogical or Psycho-pedagogical Assessment? (Diagnoza psychologiczna i pedagogiczna czy psychopedagogiczna?)*, [in:] *A Child with Special Needs in Interdisciplinary Therapy (Dziecko o specjalnych potrzebach w kręgu interdyscyplinarnej terapii)*, ed. D. Kohut, Oficyna Wydawnicza „Impuls”, Krakow 2013, p. 91.

¹⁰ B. Skałbiana, *Pedagogical Assessment. Selected Research Areas and Practical Solutions. (Diagnostyka pedagogiczna. Wybrane obszary badawcze i rozwiązania praktyczne)*, Oficyna Wydawnicza „Impuls”, Krakow 2011, p. 26.

¹¹ I. Czajkowska, *Pedagogical Assessment and Observation (Diagnoza i obserwacja pedagogiczna)*, [in:] *Corrective and Compensatory Classes at School (Zajęcia korekcyjno-*

On the grounds of pedagogy “the object of assessment comprises difficulties and failures of a student in the process of obtaining knowledge and school skills, reasons thereof and negative consequences to development”¹².

The pedagogical diagnosis is aimed at:

- learning about students’ difficulties (both, in the educational and upbringing aspect),
- determining the level of knowledge and skills with regard to the binding core curriculum,
- determining the pace of acquiring knowledge,
- learning about the student’s approach to school duties, their level of motivation to undertake an intellectual effort¹³.

According to E. Górniewicz the following elements are included in the pedagogical assessment:

- “recognising the phenomenon,
- assessment thereof from the point of view of adopted development standards,
- development forecast”¹⁴.

As underlined by the aforementioned author, in the process of pedagogical diagnosis, the following factors should be taken into consideration:

- reading level assessment – knowledge of letters, ability to read aloud (senseless text, combined text), reading pace, reading

kompensacyjne w szkole), I. Czajkowska, K. Herda, Wydawnictwa Szkolne i Pedagogiczne Spółka Akcyjna, Warsaw 1989, p. 52.

¹² I. Czajkowska, *Pedagogical Assessment and Observation (Diagnoza i obserwacja pedagogiczna)*, [in:] *Corrective and Compensatory Classes at School (Zajęcia korekcyjno-kompensacyjne w szkole)*, I. Czajkowska, K. Herda, Wydawnictwa Szkolne i Pedagogiczne Spółka Akcyjna, Warsaw 1989, p. 51.

¹³ L. Bobkowicz-Lewartowska L., *Intellectual Disability. Assessment, Education and Upbringing (Niepełnosprawność intelektualna. Diagnozowanie, edukacja i wychowanie)*, Harmonia Universalis, Gdańsk 2011, p. 60.

¹⁴ E. Górniewicz, *Pedagogical Diagnosis of Specific Difficulties in Reading and Writing (Pedagogiczna diagnoza specyficznych trudności w czytaniu i pisaniu)*, Wydawnictwo Adam Marszałek, Toruń 2009, p. 32.

technique, reading correctness: identification and interpretation of errors in reading and understanding read text,

- writing level assessment – copying, writing from listening, from memory, assessment of the correctness of writing together with interpretation, assessment of the level of graphical record,
- family environment assessment,
- prognostic assessment¹⁵.

In the case of students with intellectual disability, a reliable assessment aimed at evaluating progress e.g. in learning, requires the assessor to be fully familiarised with the learning process of the aforementioned group of persons and their difficulties such, as:

- slow or very slow pace of work,
- difficulties with concentration,
- speech impediments,
- difficulties with understanding statements, orders, tasks,
- significantly lower graphomotor skills,
- impeded ability to conduct analysis and synthesis,
- difficulties in acquiring school techniques (reading, writing, counting),
- hindered or low level of understanding: contents of sentences, read text, concepts, rules and definitions,
- difficulties with memorisation,
- low level of independence,
- hindered understanding,
- a lack of motivation to obtain education at school,
- low ability of using gained knowledge in practice¹⁶.

¹⁵ E. Górniewicz, *Pedagogical Diagnosis of Specific Difficulties in Reading and Writing (Pedagogiczna diagnoza specyficznych trudności w czytaniu i pisaniu)*, Wydawnictwo Adam Marszałek, Toruń 2009, pp. 33–54.

¹⁶ P. Jurkiewicz, B. Rola, *A Model of Work with a Student with Mild Intellectual Disability, Improving Effectiveness of Education of Students with Special Educational Needs (Model pracy z uczniem upośledzonym umysłowo w stopniu lekkim, Podniesienie efektywności kształcenia uczniów ze specjalnymi potrzebami edukacyjnymi)*. Training materials part II, the Ministry of National Education, Warsaw 2010, pp. 139–140.

While conducting pedagogical assessment it is also necessary to be familiar with the difficulties of students with intellectual disability in the scope of acquiring basic school techniques i.e.: reading, writing and counting.

In literature it is underlined that the difficulties regarding basic school skills (reading and writing) of students with intellectual disability result from a general damage to the intellect and to a large extent are caused by irregularities in the area of perceptual-motor functions. Furthermore, it is noticed that these difficulties do not solely depend on the level of psychological and motor disorders, but also on the child's educational stage. Especially at the first stage, that is, early childhood education, difficulties in remembering particular letters of alphabet and connecting them with a given sound are observed. During reading and writing students with (mild) intellectual disability confuse letters of similar sound and graphic sign. Moreover, the following errors are observed: adding words, letters or syllables, as well as changing the order thereof or omitting them altogether. The reading technique is quite lowered, usually the technique of syllabication or spelling (lettering) dominate and children have difficulties with conducting synthesis of read words. Reading and writing is done in a very slow pace. Lowered reading technique, slow pace and errors hinder understanding of read text. Learning how to write correctly is very difficult for students with intellectual disability. Usually technical, spelling, grammatical and lexical errors are observed. Letters are written in an unshapely manner and the handwriting is very uneven, shaky. There are also difficulties with adhering to the rules of spelling in writing. It is worth adding that speech impediments experienced by the aforementioned group of students to a large extent translate into acquiring school techniques mentioned above¹⁷.

¹⁷ G. Tkaczyk, *Methodology of Primary School Education and Upbringing in a Special School (Metodyka nauczania i wychowania początkowego w szkole specjalnej)*, Wydawnictwo Uniwersytetu Marii Curie-Skłodowskiej, Lublin 1997, pp. 294–296.

Students with mild intellectual disability, and especially with moderate intellectual disability also have difficulties with learning mathematical material.

These difficulties occur, in particular, in activities such, as: noticing similarities (analogies), generalising, abilities of using algorithms, mathematizing as well as copying, noticing regularities and schematising. There are difficulties with understanding the notion of a number, learning the first ten numbers and making mathematical calculations. Students with mentioned disability work slowly, quite hesitantly, require teacher's approval and have a difficulty with correcting errors indicated in the task¹⁸.

Therefore, the process of assessing a student with intellectual disability (especially moderate disability) is executed in order to present their abilities or potential changes in the scope of a given skill, requires taking into consideration individual abilities of the assessed person, adjusting test tools (in fact, establishing them independently), ongoing observation of undertaken activities, following the child's workflow.

The final result of a reliably conducted assessment comprises determining the level of functioning of a child with the said disability (indicating their abilities and difficulties, presenting changes and progress) in the scope of various skills. Results of conducted assessment shall provide grounds for planning educational and therapeutic activities for the student.

Methodology of own tests

The results of conducted psychological and pedagogical assessments (usually presented in the decision on the need of special edu-

¹⁸ H. Siwek, *Mathematical Abilities of Students of a Special School. An Outline of Theory and Propositions of Methodological Solutions (Możliwości matematyczne uczniów szkoły specjalnej. Zarys teorii i propozycje rozwiązań metodycznych)*, Wydawnictwa Szkolne i Pedagogiczne, Warsaw 1995, pp. 5–27, 60.

ation) to a great extent determine discussion on the further education path of students with intellectual disability. Therefore, the study was aimed at learning about changes (progress) that occurred in the scope of acquiring school skills by a girl with moderate intellectual disability, at a younger school age, as a result of conducted educational and therapeutic activities and an attempt to indicate a possibility (a form) of educating the tested student on the grounds of obtained results and teacher's opinion.

Thus, the following research question was formulated:

What kind of change in the scope of basic school skills: reading, writing and counting was observed within the 10 months as of the first test conducted on the student, as a result of conducted educational and therapeutic activities?

The applied test method was a method of individual cases. Within the aforementioned method, the following documents were analysed: medical opinion, decisions on the need of special education, schools' opinions and speech therapist's opinion, on the grounds of which the tested child was characterised. The pedagogical assessment (both, the first and the second) was conducted by the article's author in one of the psychological and pedagogical clinics located in the Lesser Poland Voivodeship. In the pedagogical assessment the internal test tools used in clinics as well as selected worksheets included in the publication *"Development Assessment of a Student with Moderate Intellectual Disability: Worksheets"* (*"Diagnoza rozwoju ucznia z niepełnosprawnością intelektualną w stopniu umiarkowanym: karty pracy"*) by A. Tanajewska and R. Naprawa were used. The conducted assessment allowed stipulating the progress (changes) in the scope of acquiring basic school techniques (reading, writing and counting) by the tested girl with moderate intellectual disability.

The person tested was a student with moderate intellectual disability at younger school age, attending an integration class. The establishment attended by the girl is located in the Lesser Poland Voivodeship. Detailed information on the tested student has been presented below.

Analysis of an individual case

As has already been mentioned, a person tested was a girl at younger school age with diagnosed moderate intellectual disability attending primary school with integration branches.

The first opinions of school attended by the student imply that at the beginning, the girl was reserved, did not undertake any communication activity with her peers, did not participate in games with her colleagues. During lessons she did not show any activity, worked slowly and required teacher's assistance in performing tasks. She had a significant difficulty with identification of letters and digits. With time, progress was observed in the scope of school techniques, especially writing (copying letters, properly joining and placing letters in ruling), however, reading and learning mathematical material continued to be significantly difficult. Moreover, she also had difficulties with concentration and understanding orders. In order to improve the situation the girl participated in compensatory classes. It was noticed that she reacted differently during individual classes – clearly made a connection with the teacher, was much more open and undertook verbal activity.

The tested student was diagnosed with: mutism and oligophasia. The speech therapist's opinion implies that the girl's statements are quite scarce, chaotic and she has difficulty with constructing them. Furthermore, the tested girl's speech is characterised with:

- elision,
- substitutions,
- simplifications of groups of consonants,
- devoicing,
- distorted articulation of sibilants.

Furthermore, a lowered mobility of the articulative apparatus as well as quite significant irregularities in the scope of auditory analysis and synthesis of words were noticed.

In order to accurately picture intellectual abilities of the student, presenting results of psychological as well as pedagogical assess-

ments conducted twice, with a special distinction of changes in the scope of acquiring basic school skills: reading, writing and counting, was focused on.

Results of the first psychological test

The result of the first psychological test indicates student's moderate intellectual disability (the first decision on the need of special education was issued with the diagnosis: mild intellectual disability due to the fact that it was the child's first test). Moreover, the conducted psychological test implies that the student has difficulties with:

- abstract, cause and effect thinking,
- executing intellectual operations, in particular: abstraction and generalisation, which translates into the ability to create concepts,
- thinking on the grounds of analogy,
- inference,
- memorisation,
- understanding orders.

Disorders in the scope of auditory phonological memory were also noticed.

Moreover, the student has communicative difficulties – shows a problem with formulating statements, has a very small vocabulary.

The psychological test implies that the girl is a kind, calm person with positive attitude to the surrounding reality.

The result of the first pedagogical test

The conducted pedagogical test proved that the girl:

- cannot read – difficulties in reading result from incomplete knowledge of letters and inability of conducting the process of words' synthesis;
- understands contents of short stories (presented by the person conducting the test), however, requires assistance while formulating response – guiding questions,

- has difficulties with writing – a problem with copying the graphic shape of letters (small and capital), words are written incorrectly, in a distorted manner;
- did not acquire the core curriculum in Polish from 1st and 2nd class of primary school;
- with regard to mathematical skills the girl did not fully learn counting to twenty (she showed difficulty with recognising certain numbers), she does not identify all basic geometric figures, however, she understands special relations, classifies, compares objects, numerical groups, operates with numbers (adding and deducting numbers over the threshold of ten) on the grounds of specific information;
- works in a slow pace,
- shows communicative difficulties.

During the pedagogical test the student did not show verbal activity, she was very shy, required motivation, full instruction, assistance from the person conducting the test.

In the recommendations of the decision on the need of special education the necessity to adjust educational process (contents, methods of education, forms and didactic materials) to individual abilities of the student as well as participation in therapeutic classes: revalidation and speech therapy were underlined.

Another psychological and pedagogical test was conducted after 10 months as of the first test. Thus, what kind of changes, in particular, in the scope of school techniques (reading, writing and counting) were observed at the tested student as a result of educational and therapeutic activities conducted at the school?

The result of the second psychological test

The result of the second psychological test confirmed the student's moderate intellectual disability. Furthermore, the psychological test revealed that:

- the student's development proceeds inharmoniously,
- the girl obtains better results in categories such, as:

- social situations - understanding them,
- visual and motor learning,
- noticing relations such, as: a part - whole.

Whereas, lower results are obtained in categories such, as:

- understanding verbal and non-verbal material,
- general knowledge and vocabulary.
- visual functions of the student are weakened, whereas, perceptual-motor-auditory functions are disordered.
- the student does not undertake to perform tasks, which are difficult for her.

In contact with the other person the girl smiles, attempts to communicate, especially nonverbally (body language, gesture).

The result of the second pedagogical test

The result of the second pedagogical test revealed that:

- the tested student continues to have difficulties in reading, however, there has been a noticeable progress in this scope; the girl started reading simple, one-syllable words, conducting a synthesis thereof;
- similarly as during the first test, it was noticed that the girl is able to concentrate on a presentation of a short text and answer questions asked by the person conducting the test, given answers suggest almost full understanding of the text;
- it was noticed that the student does not have significant difficulties with putting together a comic and constructing simple sentences on this topic;
- the tested student continues to have difficulties in writing. A particular difficulty with writing digraphs was observed. Other letters are in majority written correctly. Difficulties with writing simple words from listening and from memory were observed within attempts made to write. Whereas, writing from an example was not difficult to the student;

- there were noticeable changes in the scope of mathematical skills: the girl learnt counting almost up to 100 and writing numbers almost up to 40, and attempts to multiply. The girl continues to make operations on numbers only on the grounds of specific information;
- the student improved in the scope of communication. The girl is more open. While constructing a statement she continues to base on single words, however, she starts to communicate with full sentences.

During the test, significant changes were noticed in the student's behaviour. The student was smiling, cooperated willingly, performed tasks with engagement. Nevertheless, she required permanent observation, hints and assistance of the person conducting the test.

The opinion given by the special pedagogue working with the student on a daily basis implies that the difficulties in the scope of school techniques: reading and writing have remained, yet, teachers and therapists notice progress in this scope. Not only with regard to educational, but also emotional sphere, as well as with regard to the development of speech.

Final conclusions

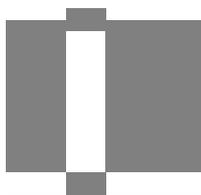
As has already been mentioned, the aim of the conducted tests was to learn about changes in the tested student with moderate intellectual disability that happened within a period of 10 months as of the test conducted for the first time in the scope of acquiring basic school skills, as a result of executed educational and therapeutic activities and to make an attempt to stipulate the possibility of education on the grounds of obtained results and teacher's opinion.

The result of the conducted pedagogical assessment confirmed the girl's small, yet, significant progress in the scope of acquiring school techniques (reading, writing and counting), which comprises an element of undertaken educational and therapeutic activities

executed both, at school and outside the school. The fact of a noticeable progress in this scope, as confirmed by teachers and experts working with the student on the daily basis, is significant. After a period of 10 months, the first signal of changes happening in the child's functioning constituted a significant progress in the scope of communication. The girl cooperated willingly, gave answers to questions asked, worked diligently and with engagement. Nevertheless, it was noticed, as also underlined by the special pedagogue working with the student, that during performing tasks the girl required permanent supervision, assistance in undertaken activities, which proves incomplete ability of the student to independent work (also during a class). Thus, a question, whether education of the tested student with moderate intellectual disability in the conditions of an integrated class constitutes a beneficial solution and if it equips the student with necessary knowledge and skills should be asked. The special pedagogue's opinion implies that continuing education in the integration class shall have a beneficial impact on her emotional and social development, as well as on the acquisition of school techniques. However, despite assurances, there are still doubts, if, in fact, the education in the aforementioned conditions provides the student with the possibility of full development, i.e. if it prepares the student (as far as possible) to live independently in the society, in the future? The answer to this question does not seem fully unequivocal and an attempt to indicate the best form of education for the tested student at this stage (in my opinion) is not fully possible, as it is an aggregate of many factors. Everything depends on the student's family environment, its engagement and awareness of the rehabilitation process, on the school - teachers working with the child, their approach and knowledge on the issue of education of persons with intellectual disability (especially moderate disability), but especially on experts: psychologists, pedagogues, speech experts, pedagogical therapists, professional counsellors, employees of the psychological and pedagogical clinic and their mutual cooperation.

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From the decision on special education eligibility to an individual educational and therapeutic plan

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In my article I would like to show the complicated way from the decision about special education to individual educational and therapeutic plan. I am going to show how government statements are sometimes hard and complicated for parents, teachers and other specialists, who are looking after the children with special educational needs. I try to show everyday life in my job – teacher, specialist of pedagogical therapy. I hope my article will help and change our reality.

KEY WORDS: decision on special education eligibility, disability, special educational needs, special education, individual educational and therapeutic plan (IETP)

Foreword

In the Polish educational system, pupils eligible for special education may attend special schools, preschools or other institutions, or they may be taught in integration classes, within the framework of inclusive education¹. Because of the diversity of available meth-

¹ I. Chrzanowska, *Pedagogika specjalna. Od tradycji do współczesności*. Impuls, Kraków 2015; Szumski G *Integracyjne kształcenie niepełnosprawnych*. Wyd. Akademii Pedagogiki Specjalnej i Państwowe Wydawnictwo Naukowe, Warszawa 2013.

ods, the various elements of the system should be analysed so as to determine the quality of education – regardless of the choice of a particular school. Inclusive education in mainstream schools was introduced in Poland only several years ago, and there are still questions and doubts about effective pupil support. When a pupil eligible for special education comes to a mainstream school, the team of his teachers, based on the Regulation of the Polish Minister of Education on the terms of providing education and care to children and youth with disabilities, socially excluded or threatened by social exclusion², must develop an Individual Educational and Therapeutic Plan (IETP). This is a difficult job for mainstream school teachers who are not special educators. In this article, I want to present the problems that arise from the submission by a child's parent or legal guardian of a request for a decision on special education eligibility until development of an IETP as well as examples of good and bad practices and my practical experience in a psychological and educational counselling centre, associated with the development of those documents.

IETP – Individual Educational and Therapeutic Plan

On 1 September 2015, the Regulation of the Polish Minister of Education of 24 July 2015 on the terms of providing education and care for children and youth with disabilities, socially excluded or threatened by social exclusion³ entered into force. Previously, there were two separate regulations governing the education of those

² *Rozporządzenie Ministra Edukacji Narodowej z dnia 9 sierpnia 2017 r. w sprawie warunków organizowania kształcenia, wychowania i opieki dla dzieci i młodzieży niepełnosprawnych, niedostosowanych społecznie i zagrożonych niedostosowaniem społecznym (JoL /Dz.U./ of 24 August 2017, item 1578).*

³ *Rozporządzenie Ministra Edukacji Narodowej z dnia 24 lipca 2015 r. w sprawie warunków organizowania kształcenia, wychowania i opieki dla dzieci i młodzieży niepełnosprawnych, niedostosowanych społecznie i zagrożonych niedostosowaniem społecznym JoL /Dz. U./ of 07.08.2015, item 1113*

pupils: one in general or integration schools and the other in special schools – the 2015 Regulation introduces a common solution. It defines, among other things, ensuring special education and describes Individual Educational and Therapeutic Plans (IETP). Ośrodek Rozwoju Edukacji (Education Development Center, EDC) in Warsaw developed a document that contains both the legal bases of and practical advice for the development of IETPs⁴. In the Good Practices Bank of the Centre's Special Educational Needs Department, sample IETPs for pupils with various developmental problems are available⁵. They are very useful to mainstream school teachers who need methodical guidelines. Besides, presentation of different solutions is very valuable because, apart from the elements arising from the aforementioned Regulation, there are no standard models or forms of the IETPs. Each school may develop any form that is convenient, provided it complies with the criteria determined in the Regulation. It leaves a lot of freedom, but also increases the responsibility of a school and its teachers. Thus, it is important to understand the rules of developing IETPs, so as to be able to use them to the best of the needs of the teachers and specialists working with a disabled child at school. On 1 September 2017, provisions of the new Regulation of the Polish Minister of Education of 24 July 2015 on the terms of providing education and care for children and youth with disabilities, socially excluded or threatened by social exclusion entered into force. Those provisions discuss in detail the organisation of special education in various kinds of schools and institutions⁶.

⁴ J. Rafał-Łuniewska, *Zmiany warunków organizowania kształcenia specjalnego*, ORE Warszawa 2015: <https://www.ore.edu.pl/component/phocadownload/category/77-inne?download=3450:zmiany-warunkow-organizowania-ksztalcenia-specjalnego-w-edukacji-ogolnodostepnej>

⁵ Cf. *Bank dobrych praktyk*, Portal internetowy Ośrodka Rozwoju Edukacji MEN, [online] <https://www.ore.edu.pl/programy-i-projekty-69647/bank-dobrych-praktyk-82894/dobre-praktyki> [access: 10.06.2017].

⁶ *Rozporządzenie Ministra Edukacji Narodowej z dnia 9 sierpnia 2017 r. w sprawie warunków organizowania kształcenia, wychowania i opieki dla dzieci i młodzieży niepełnosprawnych, niedostosowanych społecznie i zagrożonych niedostosowaniem społecznym* (JoL /Dz.U./ of 24 August 2017, item 1578).

Developing IETP means planning support for a pupil eligible for special education. This is a difficult job for mainstream schools that do not have special educators. The competencies of mainstream school teachers are limited in this respect⁷, and they cannot be blamed for that. Despite the introduction of inclusion in Polish schools, there are no mandatory standards for teacher education in terms of special education. Dorota Podgórska-Jachnik writes that: *It is hard to make a school [mainstream school – M.W.] ready and open to receive a child with any kind of disability, based [only – M.W.] on additional specialist preparation of every teacher. This is simply impossible. Schools will try to bridge the gaps by shifting the burden of ensuring professionalism to the assistant teacher, counselling teacher and/or psychologist or school counsellor, and eventually, according to the assumption of the educational system reform that implements inclusion – to the entire school team responsible for special education*⁸.

The team responsible for a pupil with special educational needs includes all the teachers and specialists who work with the child, irrespective of the amount of time they spend with him. Each of them should, taking into account the specificity of a given subject, participate in developing the programme. When developing an IETP, its structure should be followed. The logic of developing an IETP covers three complementary levels:

Level I – diagnostic; its important elements are: through analysis of the decision on special education eligibility (diagnosis, recommendations, justification), multispecialist evaluation of child's

⁷ B. Jachimczak, *Special Pedagogue in a mainstream school – possibilities and limitations*, „Studia Edukacyjne” No. 7, pp. 233–239 Poznań 2008; Jachimczak B. *Przygotowanie nauczycieli wychowania przedszkolnego do realizacji wybranych zadań z zakresu pomocy psychologiczno-pedagogicznej*, „Studia Edukacyjne”, Poznań 2012, No. 21, p. 163–176; Plichta P. *Przygotowanie nauczycieli do edukacji włączającej – kontekst europejski*, [in:] D. Podgórska-Jachnik (ed.), *Dobre praktyki pedagogiczne szansą innowacyjnej edukacji*, Wyd. Wyższej Szkoły Pedagogicznej, Łódź 2012 s. 101–114, and other.

⁸ D. Podgórska-Jachnik, *Uwarunkowania i perspektywy edukacji włączającej osób z uszkodzonym słuchem*, [in:] E. Twardowska, M. Kowalska (ed.), *Edukacja niesłyszących*. Wyd. Polskiego Związku Głuchych w Łodzi, Łódź 2011, pp. 28–29.

functions (specialist tests at the preschool, school and counselling centre – psychological, logopedic and other, diagnosis by teachers, interview with parents), child's/pupil's special educational needs (identifying his needs).

Level II – planning; this is the main process of developing an IETP, which should cover, first of all: the therapeutic objectives – the principles of working with a child, the educational goals associated with the curriculum, i.e. determining the procedure for achieving the objectives, accommodating the environment to the educational requirements, the types of assistance and support.

Level III – practical; it covers specific actions undertaken to implement the plan, i.e.: support, classes (obligatory, additional, extra)⁹. The practical level also includes ongoing evaluation of the effects of work, the child's expected performance and evaluation of the plan¹⁰.

An EDC brochure describes the roles and duties of the school principal and the team of teachers working with a specific pupil, and his parents. It also mentions the term *functional diagnosis*, and explains its elements. This is important, because it is not possible to write a plan for a pupil with special educational needs based only on the label of a nosological diagnosis. Before writing an Individual Educational and Therapeutic Plan, it is very important that the respective teachers who teach or work with a child watch that child.

It is also worth noting another term arising from the Regulation: “multispecialist evaluation of pupil's/child's functions” (MEPF). In my opinion, this is the most important foundation of an Individual Educational and Therapeutic Plan. The evaluation covers: on the one hand, all the specialist medical certificates, possible medical histories, hospital discharge reports, opinions of specialists who take care of the child, decision on special education eligibility, and

⁹ Podniesienie efektywności kształcenia uczniów ze specjalnymi potrzebami edukacyjnymi, Materiały szkoleniowe Ministerstwa Edukacji Narodowej, Part II, Warszawa, 2010, po. 6–27.

¹⁰ J. Łuniewska-Rafał, *Zmiany warunków kształcenia specjalnego*, Ośrodek Rozwoju Edukacji, Warszawa 2015, p. 4.

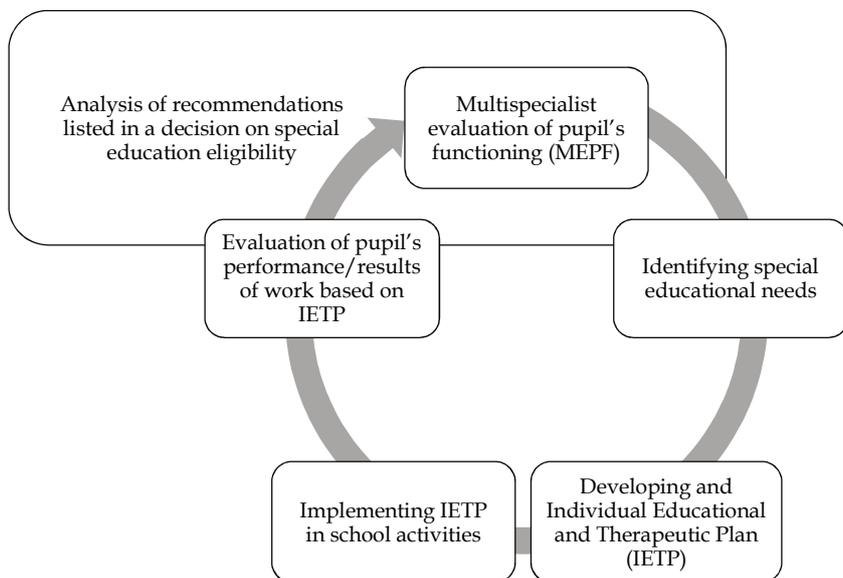


Fig. 1. The process of accommodating school education to pupil's special needs, taking into account the development of the MEPF and IETP (source: own elaboration, using I. Skibska, M. Warchał, 2011, p. 378¹¹)

on the other hand: teachers' and parents' observations and functional diagnosis performed at school according to the actual needs. I would like to emphasise in particular the second element. If we combine all those sources of information: medical diagnoses, opinions of school counsellors, psychologists and other specialists, with the opinion of teachers and parents – only then do we get a full picture of a child that will make it possible to develop the best IETP for him. It should be noted that a multispecialist evaluation of pupil's functions (MEPF) based on the abovementioned Regulation of the

¹¹ I. Skibska, M. Warchał (2011), *Edukacja inkluzyjna dziecka niepełnosprawnego w szkole ogólnodostępnej a integracja społeczna*, [in:] K. Denek et al. (ed.), *Edukacja Jutra w kontekście wyzwań współczesności*, Sosnowiec, Oficyna Wydawnicza „Humanitas”, pp. 369–386.

Polish Ministry of Education of 9 August 2017, the team of teachers who work with a specific child perform at least twice a year¹². Ideally, the first evaluation at the beginning of a year should be the input diagnosis for the IETP and the second should serve to evaluate the effects of work and possibly revise the IETP for the next school year/stage. This way, a certain logical cycle is created that reflects the procedural character of accommodating education to pupil's special needs.

The MEPF form¹³ contains a table with detailed questions and comments, so that each team may prepare the best evaluation of a pupil. Team meetings may be accompanied by a child's parent or legal guardian, and the school is obliged to notify them of the date of the team meeting. Teachers frequently make the mistake of not reading the decision on special education eligibility before a team meeting. I believe that every school should have a system – a set of procedures to be performed between the submission of such decision by a parent and the first team meeting. It is a good practice to familiarise parents with the proposed methods of work with a child both concerning the respective school subjects

and the type and quantity of special classes, e.g. speech therapy, specifying the number of hours and the schedule of those classes.

If we diligently perform the multispecialist evaluation of pupil's functions and in every subsequent MEPF properly evaluate our pupil, then developing the right IETP for a specific pupil and evaluating his performance should not be problematic.

Developing an Individual Educational and Therapeutic Plan

Because the main goal of the IETP is to help a child that requires special care and educational support, the plan should first of all be

¹² Rozporządzenie Ministra Edukacji Narodowej z dnia 9 sierpnia 2017 r. w sprawie warunków organizowania kształcenia..., ibidem.

¹³ R. Cybulska (2017), *Uczeń ze specjalnymi potrzebami edukacyjnymi w systemie edukacji w świetle nowych przepisów prawa oświatowego*, Warszawa, ORE.

practical, i.e. it should translate to specific therapeutic activities. In the process of developing IETPs, the standard forms developed by specialists help clearly and logically describe the most important elements of the plan.

As has already been mentioned, there may be different IETP forms. Because there is no standard form, it is worth looking at some of the available alternatives, which I can recommend to other teachers from my own educational experience. In my opinion, the model developed by Romana Cybulska and Barbara Łaska¹⁴ is worth recommending, as well as the IETP form proposed by Monika Gołubiew-Konieczna¹⁵. In the latter case, the author emphasises the importance of identifying child's/pupil's strengths and weaknesses when watching and diagnosing him. It is enough to find just one area, one activity that a child/pupil can do well – his strength, to serve as the foundation for our therapeutic work.

The two IETPs seem different, but they both comply with the recommendations of the Regulation of the Ministry of Education of 9 August 2007. We can see some common elements in the two of them. They are: document information (name of the child, date of issuing the document, validity period, author of the document). The other common elements, provided for by the abovementioned Regulation, are: integrated activities of teachers and specialists who work with a child; forms and duration of psychological and educational assistance provided to a child or student, and the number of hours of the respective forms of assistance; scope of cooperation between teachers and specialists and the parents of a child or student in performing the tasks identified in the decision on special

¹⁴ R. Cybulska, B. Łaska, Ośrodek Rozwoju Edukacji, Wydział Specjalnych Potrzeb Edukacyjnych, aktualności, access: 08.11.2017, <https://www.ore.edu.pl/onas/wydzialy/specjalnych-potrzeb-edukacyjnych/7878-ksza%C5%82cienie-specjalne-%E2%80%93-propozycje-arkuszy>

¹⁵ Monika Gołubiew-Konieczna, director of the counseling centre, director of the Psychological and Educational Counseling Centre no. 7 in Gdańsk, psychologist, intellectual disability teacher, author of numerous publications on working with pupils with special educational needs.

education eligibility by the preschool, school or institution (other recommendations, specialist devices, other assistance); if need be, the scope of cooperation with psychological and educational counselling centres; regular multispecialist evaluation of child's/pupil's functions, taking into account the effectiveness of the psychological and educational assistance provided to a pupil (as has already been mentioned – at least once per school year).

The form developed by Romana Cybulska and Barbara Łaska may be recommended in particular to those who like to put information into tables. I know many such teachers. They claim that tables are easier to put information in order and easier to use. Division into rows and columns prevents dispersion of data and makes us sure that we will not forget anything. Opponents of this approach say that tables are limiting – they impose a certain style and predetermined actions, it is stereotypical and hinders inventiveness. Thus, the second IETP form, developed by Monika Gołubiew-Konieczna, gives more freedom, but it does not contain detailed examples of specific content that could be used in the respective parts of the IETP. Educational counsellors at the Regional Centres for Teacher Education (RCTE) and the Internet offer numerous IETP forms (unfortunately, not all of them are correct). I believe that every team of teachers can choose something for themselves. Of course, neither of the two examples presented by me in this article is fixed. They may be modified or adapted to create an individual plan. The important thing is to remember to include all the elements required by the Regulation. My suggestion is to choose one unified model for a given school, accepted by the teachers of that school. It is not a good practice to create many different forms, however, it is a very good idea to create a model tailored to the specific school. IETP is a working tool and as such, it needs to be accepted by the persons who are going to use it in their everyday work. Thus, it is worth discussing the structure of the IETP and making it the subject of a self-learning debate of the Teacher Board, and modifying it, if need be. It should be a normal process of improving the working methods of the school personnel.

The basic document that makes it possible to adjust the IETP to pupil's needs is a decision of special education eligibility issued by a public psychological and educational counselling centre. Such decision has a specific validity period and it is usually issued for a given part of education – and the IETP should cover the same period. The decision contains elements that are necessary to plan pupil support and specific accommodation and rehabilitation activities to be undertaken by the school: the diagnosis, recommendations and their justification. Only those activities planned by the school that are compliant with the recommendations listed in a decision will be financed by the school's governing authority. So, the decision both sets the direction of and serves as a framework for accommodation and rehabilitation activities.

The diagnosis contained in a decision informs about child's problems as well as his developmental possibilities and potential. This should be reflected in his Individual Educational and Therapeutic Plan. It sometimes happens, however, that schools complain about improper decisions. Another obstacle may be the teachers' inability to read and interpret them. This is an area for mutual care, and good cooperation between the school and the counselling centre makes it possible to improve the language of communication. One way to achieve it is to use the International Classification of Functioning, Disability and Health (ICF) in developing a decision. The Ministry of Education has developed new forms of decisions based on the new classification, and more specifically – on its version for children and youth ICF-CY (International Classification of Functioning, Disability and Health – Children and Youth)¹⁶. On 7 September 2017, the Ministry published a new regulation on opinions and decisions that includes their new forms and new principles for issuing them¹⁷. This regulation enables the chair of a team

¹⁶ Ibid.

¹⁷ Rozporządzenie Ministra Edukacji Narodowej z dnia 7 września 2017 r. w sprawie orzeczeń i opinii wydawanych przez zespoły orzekające działające w publicznych poradniach psychologiczno – pedagogicznych (Dz. U. 2017, poz. 1743)

issuing a decision to ask a school principal/ institution director for an opinion that is necessary for that decision. The form prepared by a school/institution is fully based on the ICF and pupil's strengths¹⁸.

A correct IETP provides information, among other things, on: the curriculum appropriate for our pupil, the somatic diseases he has been diagnosed with, the number and type of suggested specialist activities, the pupil's functioning in a group, his social competencies, the degree of his mental and physical competencies, his performance with respect to his age, and his potential, i.e. possibilities for development and strengths. In case of questions, the counselling centre may be contacted and asked to interpret or supplement the diagnostic picture, and this should be done in order to avoid mistakes that will have a negative effect on the pupil.

The recommendations provided in a decision specify the pupil support vision developed by a counseling centre. They concern in particular: the suggested form of teaching that will be the most beneficial for a child, the forms of stimulation, rehabilitation activities, therapy, enhancement, developing the child's potential and strengths, and other psychological and educational assistance; the conditions of providing for educational needs¹⁹. The type of disability, determined through specialist diagnosis, determines the level of adaptation optimal for a given pupil and the resulting scope of rehabilitation²⁰. This serves as direct input for profiling individual rehabilitation activities for a specific child. The Regulation lists some possible forms of individual rehabilitation, e.g.: teaching spatial orientation and mobility, teaching Braille language or alternative communication methods (blind pupils), teaching sign language or alternative communication methods (deaf or aphasic pupils), or

¹⁸ Pursunat to §7.1 Rozporządzenia Ministerstwa Edukacji Narodowej z dnia 7 września 2017 r. w sprawie orzeczeń i opinii wydawanych, *ibid*.

¹⁹ Dudzińska A., Niedźwiedzka A. (2016), *Najczęstsze pytania dotyczące kształcenia specjalnego informator dla rodziców*, [online] <http://niegrzecznedzieci.org.pl/wp-content/uploads/2016/01/WszystkoJasne-Raport-Najcze%CC%A8stsze-Pytania-Do%CC%A8ce-Kszta%C5%82cienia-Specjalnego.pdf> [access: 20.05.2017], p. 11.

²⁰ *Ibid*, p. 67.

teaching social skills, including communication (pupils with autism, including the Asperger syndrome)²¹, but these may also be rehabilitation activities focusing on other competencies. It is recommended to teach cognitive processes to pupils with intellectual disabilities. If need be, a counseling centre may also recommend, apart from rehabilitation activities, also specialist activities that constitute an element of psychological and educational pupil support in the Polish educational system. All the recommendations of a counseling centre should be justified – this is another mandatory part of a decision, useful for teachers developing an IETP.

Although a decision on special education eligibility is the basic document to develop an IETP, it is not about copying the content of one document to another, but about activating a process of heuristic search for strategic solutions. Thus, I suggest that before developing an IETP, each teacher participating in its development or each team ask themselves the following four important and simple questions concerning a pupil:

- a. What is the pupil's (key) problem?
- b. Whys does he have this problem?
- c. How can the pupil be helped?
- d. Why do we choose this particular method?

If IETP is preceded by careful observation and good diagnosis of a child, answering those questions should not be problematic. If a teacher consults his answers with the opinion of other teachers, specialists and parents, he will be solid foundations for an IETP.

A frequent mistake made when developing an IETP is being too detailed about specific tasks, which hinders the flexibility of action. If the plan is to be practical, it should be rather concise, so that a teacher may keep it "in his head" and follow its assumptions at all times when working with a pupil. This means providing relatively general, though specific, given the individual nature of the plan, directives and methods, and their accommodations, that are easy to

²¹ Rozporządzenie Ministra Edukacji Narodowej z dnia 9 sierpnia 2017 r. w sprawie warunków organizowania kształcenia..., *ibid.*

remember and implement every day, in every class, in every situation. This should also translate to the identification of goals, which should be neither too general, nor too distant, nor such that evade interim evaluation (MEPF). It is better to plan smaller steps that can be controlled rather than too big ones that make it impossible to capture the dynamics of changes. The goals formulated for an IETP should be verified from such angle, so that they are easier to evaluate later on.

Finally, it should be noted once again that a good IETP is not a document for the persons who control a school/institution that rests in a colourful binder but rather a tool for everyday educational work. It helps adapt the teaching process and prepare appropriate materials, and it helps a child/pupil with disabilities be successful. Let him be very successful and let us make him happy. It is worth remembering those simple rules for working with a special educational needs pupil when developing all kinds of documentation that concern him. The child should not be forgotten about in the complex documentation process.

Conclusion

The process from a decision to IETP presented in this article is not simple, although it may seem so. A decision developed by a public psychological and educational counseling centre and delivered to a school means that the school has to develop an MEPF and IETP. The most important aspect for working with a pupil is to develop an IETP in such a way that it may serve as a signpost for the teachers and specialists who work with the pupil. The legislation I quoted says that the team of teachers working with a pupil eligible for special education should meet at least twice and that the parents should be informed of the dates of such meetings. The role of parents in developing an IETP should be analysed. Cooperation with parents may be the key to success. Teachers of subjects that are taught for only one hour in a week must participate in the work of

multiple teams. Especially in smaller schools, team meetings require appropriate logistics. They also generate unwillingness and fatigue of teachers, who must devote a lot of their extra time to such meetings. The effort contributed to developing a sound working plan, and in particular a relevant functional diagnosis, should – thanks to joint and informed actions – ensure optimal development of a pupil, despite his limitations. It is possible, although various tasks concerning special educational needs on the border between a counseling centre – a school/preschool, without proper organisation and support, still cause many unnecessary tensions and misunderstandings.

I hope that after reading this article, the road to IETP will be somewhat easier than before. It will determine certain possibilities to reorganise work in schools/preschools so that supporting children with disabilities in mainstream school will be much more practical, expedient and relevant.

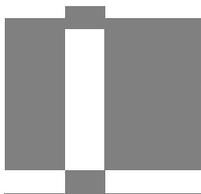
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Wykaz aktów prawnych

- Rozporządzenie Ministra Edukacji Narodowej z dnia 24 lipca 2015 r. w sprawie warunków organizowania kształcenia, wychowania i opieki dla dzieci i młodzieży niepełnosprawnych, niedostosowanych społecznie i zagrożonych niedostosowaniem społecznym Dz. U. z dnia 07.08.2015 poz. 1113,
- Rozporządzenie Ministra Edukacji Narodowej z dnia 9 sierpnia 2017 r. w sprawie warunków organizowania kształcenia, wychowania i opieki dla dzieci i młodzieży niepełnosprawnych, niedostosowanych społecznie i zagrożonych niedostosowaniem społecznym (Dz.U. z dnia 24 sierpnia 2017 r. poz. 1578).
- Rozporządzenie Ministra Edukacji Narodowej z dnia 7 września 2017 r. w sprawie orzeczeń i opinii wydawanych przez zespoły orzekające działające w publicznych poradniach psychologiczno - pedagogicznych (Dz. U. 2017, poz. 1743)



Tendencies in issuing decisions on the need for individual teaching in the Malopolska voivodship

ABSTRACT: Izabella Gałuszka, *Tendencies in issuing decisions on the need for individual teaching in the Malopolska voivodship*, Interdisciplinary Contexts of Special Pedagogy, No. 22, Poznań 2018. Pp. 355-374. Adam Mickiewicz University Press. ISSN 2300-391X. DOI: <https://doi.org/10.14746/ikps.2018.22.20>

The article is devoted to individual teaching as a form of education provided to pupils whose health condition makes it impossible or very difficult to attend school. The decision is issued by public psychological and pedagogical counselling centres at every stage of education from pre-school to upper secondary school. Due to the duration of research and collected data, the theoretical part refers not only to the acts and regulations of 2017, but also to the regulations no longer in force. The purpose of the dissertation is to try to answer the following questions: What is individual teaching? On what basis can this form of education be obtained? What are the possible consequences of individual teaching? In the research part, the author analyses data obtained from the resources of selected psychological and pedagogical counselling centres in the Malopolskie Voivodship. The analysis was compiled with the use of data of the Statistical Office in Krakow concerning the school year 2014/2015 and then discussed.

KEY WORDS: education, special educational needs, acts of educational law, individual teaching, some groups of pupils with SEN

*The purpose of education is to enable each individual to
to take possession of its individual potential*

John Dewey

Introduction

2017 was a time of many systemic changes concerning the education of children and youth. Individual teaching of children and young people in the school year 2017/2018 is organized on the basis of: the Act of 14 December 2016 – Educational Law, valid from 1 September 2017¹, the Regulation of the Minister of National Education of 28 August 2017 amending the Regulation on individual compulsory one-year pre-school preparation of children and individual teaching of children and youth² and the Regulation of the Minister of National Education of 7 September 2017 on decisions and opinions issued by adjudicating panels operating in public psychological and pedagogical counselling centres³. Regardless of the changes in the provisions of the educational law, the research presented below is to draw attention to the procedures and frequency of issuing opinions on the need for individual teaching.

The basic determinant of education, as stressed by J. Bałachowicz⁴, is the realization of teaching focused on the child, leading to the maximization of his or her personality potential and development of his or her subjectivity. Such optimisation of development is possible only if appropriate educational conditions, based on the principle of individualisation of education, are ensured. This individualisation manifests itself, first of all, in adjusting the teaching and educational strategies used in everyday work to the needs and possibilities of the student. Individual teaching offers the possibility of selecting methods of achieving goals, adjusting the pace of classes, methods and forms of acquiring knowledge and skills to the varied possibilities and preferences of the student.

¹ Journal of Laws of 2017, item 59.

² Journal of Laws of 2017, item 1656.

³ Journal of Laws of 2017, item 1743.

⁴ J. Bałachowicz, *Indywidualizacja jako postulat i konieczność współczesnej edukacji początkowej*, [in:] *Dziecko-uczeń a wczesna edukacja*, ed. I. Adamek, Z. Zbróg, Wydawnictwo LIBRON, Krakow, 2011, pp. 11–30.

Individual teaching is a form of special education that requires specific organisation of learning and working methods. Its aim is to provide children with developmental disorders with the opportunity to pursue compulsory schooling. M. Pilch⁵ points out that a student pursuing compulsory schooling cannot be required to make the effort of attending school if his or her disability or illness constitutes a real obstacle to this end, while overcoming this obstacle would impose a significant burden on the student. According to the Act on the Education System of 7 September 1991⁶ “individual compulsory one-year pre-school preparation or individual teaching shall cover children and young people whose state of health prevents or significantly impedes them from attending kindergarten or school. In the new Act of 14 December 2016 – Education Law⁷ with effect from 1 September 2017, the types of establishments in which children and young people may be subject to individual teaching have been extended to include other forms of pre-school education, as well as pre-school establishments in primary schools.

In order for a child to be covered by individual teaching, it is necessary to obtain: a decision on the need for individual one-year pre-school preparation of children attending kindergarten or other forms of pre-school education, or in the case of pupils a decision on the need for individual teaching of children and youth whose health condition makes school attendance impossible or significantly more difficult. The decision is issued by a public psychological and pedagogical counselling centre or a public specialist counselling centre. In accordance with the Regulation of the Minister of National Education of 18 September 2008 on decisions and opinions issued by adjudicating panels operating in public psychological and pedagogical

⁵ M. Pilch, *Ustawa o systemie oświaty. Komentarz*, Wydawnictwo Wolters Kluwer, Warsaw 2006.

⁶ *Announcement of the Speaker of the Sejm of the Republic of Poland of 31 October 2016 on the consolidated text of the Act on the Education System*, Journal of Laws of 2016, item 1943, Art. 71b, Section 1a.

⁷ Journal of Laws of 2017, item 59, 949, Art. 127, Section 2.

ical counselling centres⁸, the decision may be issued only at the request of the parent or legal guardian of the child. The application should be accompanied by a certificate on the child's state of health, in which the doctor specifies:

- the period, however, not shorter than 30 days, during which the child's state of health makes attending kindergarten or school impossible or significantly impedes their attendance;
- the diagnosis of the disease or other reason why the child's state of health makes attending kindergarten or school impossible or significantly hinders attending kindergarten or school;
- the extent to which a child whose state of health significantly hinders attending a kindergarten may participate in classes in which the core curriculum of pre-school education is implemented, organised with a group or individually in a separate room in the kindergarten;
- the extent to which a pupil whose state of health makes it significantly more difficult to attend school can participate in compulsory educational activities organised with a class at school or individually in a separate room at school⁹.

Currently, the new Regulation of the Minister of National Education of 7 September 2017 on decisions and opinions issued by adjudicating panels operating in public psychological and pedagogical counselling centres¹⁰, has changed the terminology: the decision on the need for individual compulsory one-year pre-school preparation and decision on the need for individual teaching. A certificate on the child's or pupil's state of health attached by the applicant may be issued by a specialist doctor or a general practitioner on the basis of medical documentation of specialist treatment. In the certificate, the doctor shall specify the following:

- the anticipated period, however, not shorter than 30 days, during which the state of health of the child or pupil prevents or significantly impedes attending kindergarten or school;

⁸ Journal of Laws of 2008, No 173, item 1072.

⁹ Journal of Laws of 2008, No 173, item 1072.

¹⁰ Journal of Laws of 2017, item 1743.

- the diagnosis of the disease or other health problem with an alphanumeric indication in accordance with the current International Statistical Classification of Diseases and Health Problems (ICD),
- restrictions on the child's or pupil's functioning resulting from the disease or other health problem, which prevent or significantly impede attending kindergarten or school¹¹.

The decision on the need for individual compulsory one-year pre-school preparation and individual teaching shall be issued for a period not longer than one school year. In such decisions, the panel shall specify the following:

- limitations in the functioning of the child and the pupil resulting from the course of the disease or therapeutic process;
- the period during which there is a need for individual, one-year compulsory pre-school preparation and individual teaching;
- the recommended conditions and forms of support to meet the individual's developmental and educational needs and the psychophysical abilities of the child and the pupil, including conditions for the development of its potential and strengths;
- actions recommended to promote the child's integration in the pre-school and school environment and to facilitate the child's return to kindergarten and the pupil's return to school;
- the recommended developmental and therapeutic goals, depending on the needs, to be implemented during the individual one-year compulsory pre-school preparation and individual teaching within the framework of psychological and pedagogical assistance provided (to the child and) to the pupil and, depending on the needs, to his/her parents by the kindergarten, school and counselling centre, together with an indication of recommended forms of psychological and pedagogical assistance;
- in the case of a student of a school providing vocational education – also the possibility of further education in the pro-

¹¹ Journal of Laws of 2017, item 1743, § 6.

fession, including the conditions for practical vocational training¹².

Until September 2017 the manner and mode of organizing individual teaching of children and youth was specified in the Regulation of the Minister of National Education of 28 August 2014 on individual compulsory one-year pre-school preparation of children and individual teaching of children and youth¹³. According to the cited document, teaching was organized for a definite period of time, in a way ensuring the implementation of the recommendations specified in the decision. Classes were conducted by one or several teachers who had individual and direct contact with the student. They took place in the child's place of residence, usually in the family home. They could also be organised in a kindergarten, in another form of pre-school education or in a school, if the decision indicated such a possibility, as well as in an institution, if it had a separate room in which the classes could be conducted.

Children and pupils who had been granted the decision on individual compulsory one-year pre-school preparation or individual teaching before 7 September 2017, when the Regulation on decisions and opinions issued by adjudicating panels operating at public psychological and pedagogical counselling centres entered into force¹⁴, may continue to benefit from this form of schooling. Following this date, decisions are issued on the basis of the new Regulation of the Minister of National Education of 9 August 2017 on individual compulsory one-year pre-school preparation of children and individual teaching of children and youth¹⁵. Pursuant to this act, individual pre-school preparation and individual teaching classes are conducted in the place of residence of the child or pupil, in particular in the family home and in special institutions: youth education centres, youth sociotherapy centres, special education and training centres, special education centres for children and young people

¹² Journal of Laws of 2017, item 1743, § 14, 15.

¹³ Journal of Laws of 2014, item 1157.

¹⁴ Journal of Laws of 2017, item 1743.

¹⁵ Journal of Laws of 2017, item 1616.

requiring special organisation of schooling, methods of work and education, as well as remedial centres enabling children and young people with profound intellectual disabilities, as well as children and young people with multiple disabilities, of which one of the disabilities is intellectual disability, the realization of compulsory schooling and compulsory education, respectively¹⁶. Classes may also take place at a foster family, in a family orphanage, in a care and educational institution or in a regional care and therapy centre, as referred to in the Act of 9 June 2011 on Family Support and the System of Alternate Care¹⁷.

Current legislation does not allow for individual pre-school preparation or individual teaching on the premises of a kindergarten or school. Compulsory educational classes conducted as part of individual teaching result from the framework curriculum of a given type and type of school and are adapted to the developmental, educational and psychophysical needs of the student, as specified in the decision on the need for individual compulsory one-year pre-school preparation or teaching¹⁸.

Controversies around individual teaching

The school should not fulfil the objectives of an anonymous society, but should meet the aims, desires and aspirations of specific participants of the educational process. It should be an institution that creates opportunities for self-fulfilment, unrestricted development of personality, as well as enabling the achievement of individual life goals. In a school defined in this way, as emphasized by T. Lewowicki¹⁹, a uniform definition of objectives and tasks ceases to be in force, and the scope of freedom in creating the educational

¹⁶ Act of 14 December 2016 – Educational Law, Art. 2, Section 7.

¹⁷ Journal of Laws of 2017, item 697 and 1292.

¹⁸ Journal of Laws of 2017, item 1616.

¹⁹ T. Lewowicki, *Przemiany oświaty. Szkice o ideach i praktyce edukacyjnej*, Wydawnictwo Akademickie Żak, Warsaw 1997.

model and the individual's own participation in education are determined by the general social norms and the principle: do not act to the detriment of others.

Individual teaching conducted at home or at school allows to adapt the ways of learning and activating the student to his/her abilities and predispositions. A student covered by this type of edu-

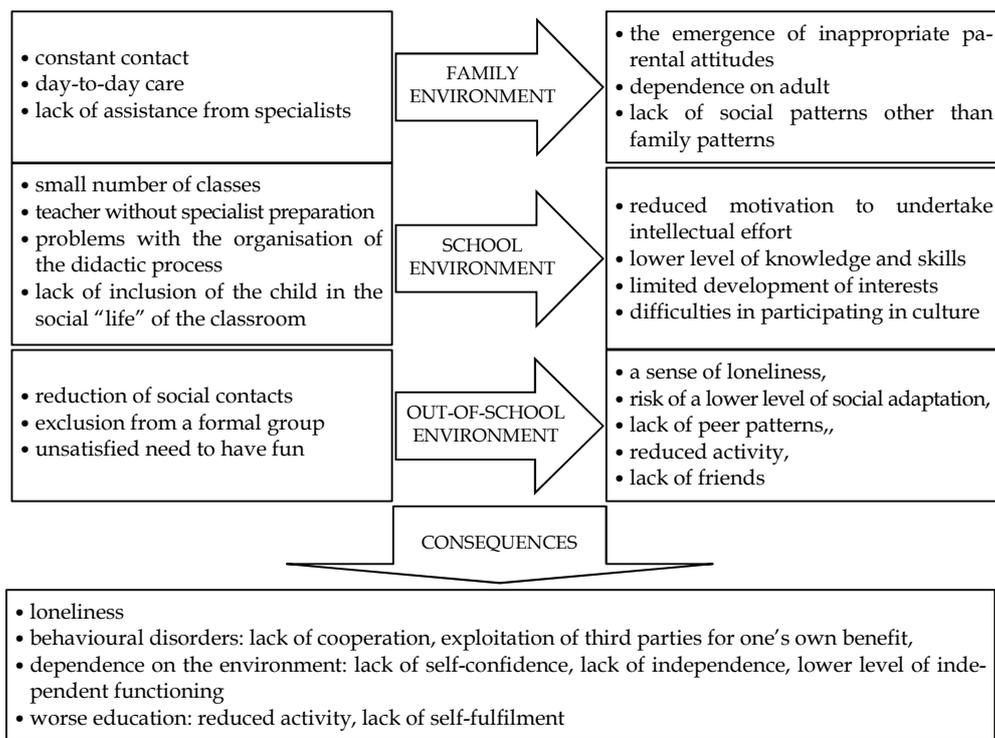


Diagram 1. Possible consequences of individual teaching for the child

Source: own elaboration, based on. B. Jachimczak²⁰.

²⁰ B. Jachimczak, *Dydaktyczne i pozadydaktyczne uwarunkowania efektów nauczania indywidualnego dzieci przewlekle chorych*, Oficyna Wydawnicza Impuls, Krakow 2011, p. 10.

cation, as emphasised by K. Rzedzicka²¹, is in a seemingly comfortable position, because he/she usually learns in the home environment, has his/her own teacher who is entirely engaged in working with one pupil, and whose attention and time is focused on one pupil, unlike in a typical school classroom. However, the biggest disadvantage of this type of schooling is that it contributes to the social isolation of the pupils. It also deprives them of the possibility of establishing social relations typical of school age with people from outside the family, especially with their peers.

B. Jachimczak²² listed the negative consequences for children in individual teaching, taking into account the child's functioning in the closest environment: family, school and out-of-school (Diagram 1).

The consequences of individual teaching, as indicated in diagram 1, affect the child not only in terms of functioning at school. Long-lasting, prolonged individual teaching can have a negative impact on the child's future life, both personal and professional. Limitation of social contacts, as well as difficulties in establishing them, may result in incorrect social development and lack of proper interpersonal relations. Furthermore, the reduction of educational requirements of individual teaching leads to a lower level of education and acquired skills. Methodologically limited classes reduce the possibility of comprehensive psychomotor development. J. Wyczesany²³ stresses that individual teaching is one of the most difficult forms of education for both children and young people. It lacks many valuable features of teaching and upbringing present in school institutions: generally accessible, inclusive or special institu-

²¹ K. Rzedzicka, *Kontrowersje wokół przejścia od nauczania indywidualnego do nauczania w zespole klasowym uczniów z mózgowym porażeniem dziecięcym*, [in:] *Nowatorskie i alternatywne metody w teorii i praktyce pedagogiki specjalnej*, ed. W. Dykcik, B. Szychowiak, Wydawnictwo Naukowe UAM, Poznań, 2001, pp. 117–123.

²² B. Jachimczak, *Dydaktyczne i pozadydaktyczne uwarunkowania efektów nauczania indywidualnego dzieci przewlekle chorych*, Oficyna Wydawnicza Impuls, Krakow 2011, p. 10.

²³ J. Wyczesany, *Pedagogika upośledzonych umysłowo: wybrane zagadnienia*, Oficyna Wydawnicza Impuls, Krakow 2005.

tions. Contact with peers and other teachers, which undoubtedly enhances students' knowledge and experience, should be particularly stressed.

Referring individual teaching to children with various disabilities, J. Wyczesany²⁴ distinguished three models of organisation of individual education, as well as the resulting heterogeneous consequences for the child's development (Diagram 2).

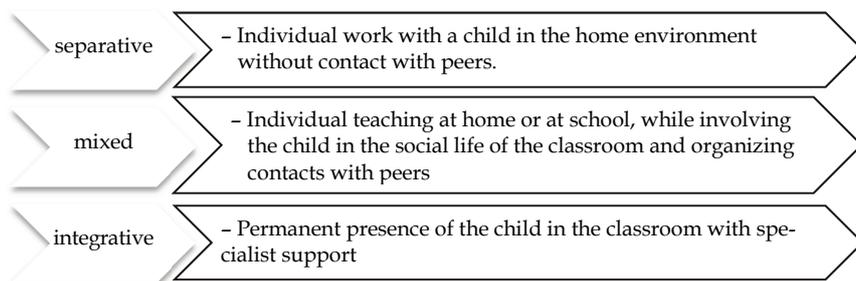


Diagram 2. Models of individual teaching

Source: own compilation, based on J. Wyczesany²⁵, B. Jachimczak²⁶.

The regulation of the Ministry of Education of 28 August 2014 on individual compulsory one-year pre-school preparation and

²⁴ J. Wyczesany, *Oligofrenopedagogika: wybrane zagadnienia pedagogiki upośledzonych umysłowo*, Oficyna Wydawnicza Impuls, Krakow, 1998; J. Wyczesany, *Problemy edukacji dzieci i młodzieży niepełnosprawnej w systemie nauczania indywidualnego* [in:] *Nowatorskie i alternatywne metody w teorii i praktyce pedagogik specjalnej*, ed. W. Dykcik, B. Szychowiak, Wydawnictwo Naukowe UAM, Poznań 2001.

²⁵ J. Wyczesany, *Oligofrenopedagogika: wybrane zagadnienia pedagogiki upośledzonych umysłowo*, Oficyna Wydawnicza Impuls, Krakow 1998; J. Wyczesany, *Problemy edukacji dzieci i młodzieży niepełnosprawnej w systemie nauczania indywidualnego*, [in:] *Nowatorskie i alternatywne metody w teorii i praktyce pedagogik specjalnej*, ed. W. Dykcik, B. Szychowiak, Wydawnictwo Naukowe UAM, Poznań 2001.

²⁶ B. Jachimczak, *Dydaktyczne i pozadydaktyczne uwarunkowania efektów nauczania indywidualnego dzieci przewlekle chorych*, Oficyna Wydawnicza Impuls, Krakow 2011.

individual teaching of children and young people²⁷ enabled individual teaching based on a separative, mixed or integrative model. The Information and Promotion Department of the Ministry of National Education stressed that the condition of organising education according to a specific model²⁸ was the indication of such a possibility in the decision issued by a psychological and pedagogical counselling centre, on the basis of a certificate of the supervising doctor. Following the introduction of the new Regulation of the Minister of National Education of 9 August 2017 on individual compulsory one-year pre-school preparation of children and individual teaching of children and young people²⁹, children and pupils do not have the opportunity of individual teaching at school. Therefore, only two of the models mentioned above can be implemented: separative and mixed, with teaching organised at home. The legislator provides for other solutions for the integrative model³⁰, which, however, do not apply to a child with a decision on individual compulsory one-year pre-school preparation and a pupil with individual teaching, and as such are not the subject of this article.

The integrative model, when the child can be with a school group and attend individual classes, is the most beneficial for the child and has the least negative consequences. On the other hand, the least beneficial model for the child's emotional, social and cognitive development is the separative model, when the student, while staying at home, is deprived of contacts with a peer group and loses the opportunity to broaden his/her knowledge and interests. The mixed model works well if the student is not able to participate in classroom activities due to his/her health condition. In view of the

²⁷ Journal of Laws of 2014, item 1157.

²⁸ <https://men.gov.pl/ministerstwo/informacje/czy-uczniowie-objeci-indywidualnym-nauczaniem-moga-brac-udzial-w-zajeciach-dla-klas-odpowiedz-na-watpliwosci.html>

²⁹ Journal of Laws of 2017, item 1616.

³⁰ Cf. Regulation of the Minister of National Education of 9 August 2017 on the rules of organisation and provision of psychological and pedagogical assistance in public kindergartens, schools and institutions, Journal of Laws of 2017, item. 1591.

numerous negative consequences of individual teaching, it is necessary to consider the frequency and direction of indications of the need for individual teaching.

Assumptions of own research

The main aim of the research was to determine the trends concerning the decisions on individual teaching, taking into account: the number of decisions issued for all students from a given district, the number of children covered by individual teaching at particular stages of education and the most frequent reasons for issuing such decisions. The obtained data was collected by means of a diagnostic survey, using a document analysis technique and supplemented by interviews with the directors of these institutions.

The research was conducted in five selected public psychological and pedagogical counselling centres, in three districts in the Małopolskie Voivodship:

- wadowicki: Psychological and Pedagogical Counselling Centre in Wadowice and Andrychów,
- myślenicki: Psychological and Pedagogical Counselling Centre in Myślenice and Dobczyce,
- krakowski, the city of Krakow: Psychological and Pedagogical Counselling Centre No 2 in Krakow.

The sampling was purposeful in view of the number of pupils covered by the centres in a given region. In the districts of Wadowice and Myślenice, data was collected in all public counselling centres, while in the case of the city of Krakow as a district, only one of the four counselling centres authorised to issue decisions on individual teaching was selected. The data for the school year 2015/2016 made available by the counselling centres, in order to illustrate the number of decisions on individual teaching issued in relation to the number of pupils at a given educational stage, was compared with the data of the Statistical Office in Krakow concerning education for the year 2014/2015³¹.

³¹ <http://krakow.stat.gov.pl/statystyczne-vademecum-samorzadowca>

Tendencies in the frequency and indications of decisions on the need for individual teaching – results of own research

The first aspect of individual teaching that has been analysed is the frequency of granting the decisions on the need for such form of education against the background of the total population of students attending educational institutions in the analysed districts (Table 1).

Comparing the quantitative data obtained in the analysed psychological and pedagogical centres with the data of the Statistical Office in Krakow, it can be stated that in the districts of Wadowice (0.94%) and Myślenice (0.81%), nearly 1% of children among all pupils are covered by individual teaching. In the city of Krakow, the analysed percentage of children is 0.45%, however, it should be noted that data from only one psychological and pedagogical counselling centre was analysed from among four centres authorised to issue such decisions.

With regard to the number of decisions issued in individual centres and when comparing them with the stage of education, it can be noted that both in the district of Wadowice (1.6%) and Myślenice (1.07%) the decision on individual teaching is most often granted to students of lower secondary schools. On the other hand, in the city of Krakow, such a decision is most often granted to students of upper secondary schools (1.18%).

The next part of the study focused on the determination of the number of decisions on the need for individual teaching, taking into account the stage of education (Table 2).

When analysing the data taking into account the stage of education, it was observed that the majority of decisions on the need for individual teaching were granted to lower secondary school students (36.1%). Taking into account the three years of teaching at this level of education, it can be assumed that on average there were about 58 students in individual teaching per year of schooling. Also primary school pupils constituted a relatively high percentage

Table 1. Number of decisions on the need for individual teaching in comparison with the number of pupils in primary, lower secondary and upper secondary schools

EDUCATIONAL STAGE	PSYCHOLOGICAL AND PEDAGOGICAL COUNSELLING CENTRE											
	Wadowicki district			Myslenicki district			The city of Krakow			In total		
	IT		N	IT		N	IT		N	IT		N
	Number	%	Number	Number	%	Number	Number	%	Number	Number	%	Number
Kindergarten	10	0.65	10 595	6	0.87	8968	4	0.23	16 610	20	0.51	36 173
	59			72			35			186		
Primary school												
Lower secondary school	85		5287	48		4478	41		7588	174		17 353
Upper secondary school	51		5911	25		5170	48		4069	124		15 150
TOTAL	205		21 793	151		18 616	128		28 267	484		68 676

Source: Own compilation based on data from the Statistical Office in Krakow* and data from own research.

Key:

IT – individual teaching

N – total number of students at a given educational level (data from the statistical office)

* <http://krakow.stat.gov.pl/statystyczne-vademecum-samorzadowca>

Table 2. Number of decisions on the need for individual teaching for children and youth in selected public psychological and pedagogical counselling centres in the Małopolskie Voivodship

PSYCHOLOGICAL AND PEDAGOGICAL COUNSELLING CENTRE		EDUCATIONAL STAGE								TOTAL	
		Kindergarten	Primary school	Lower secondary school	Upper secondary school			Total			
					General secondary school	Technical secondary school	Vocational school				
Wadowicki district	Wadowice	5	37	51	27	12	2	41	134	205	
	Andrychów	5	22	34	1	8	1	10	71		
Myslenicki district	Myslenice	3	49	36	13	5	3	21	109	151	
	Dobczyce	3	23	12	3	1	0	4	42		
Krakowski district	Kraków	4	35	41	45	1	2	48	128	128	
TOTAL		20	166	174	124			25.6%	484		
Average number of students per year		approx. 20 persons	approx. 27 persons	approx. 58 persons	approx. 39 persons						

Source: Own compilation.

Table 3. Indications for issuing the decisions on the need for individual teaching in selected public psychological and pedagogical counselling centres in the Malopolskie Voivodship

Psychological and pedagogical counselling centre		Indication for the need for individual teaching											
		Psychological problems		Chronic diseases		After surgery		After an accident		Cancer diseases		Pregnancy	
		N	%	N	%	N	%	N	%	N	%	N	%
Wadowicki district	Wadowice	69	51.5	28	20.9	10	7.5	18	13.4	7	5.2	2	1.5
	Andrychów	33	46.5	20	28.2	7	9.6	2	2.8	3	4.2	6	8.5
Myslenicki district	Myslenice	36	33	38	34.9	10	9.2	15	13.8	9	8.3	1	0.9
	Dobczyce	24	57.1	10	23.9	5	11.9	3	7.1	0	0	0	0
Krakowski district	Krakow	74	57.8	20	15.6	15	11.7	8	6.3	5	3.9	6	4.7
Total		236	48.7	116	24	47	9.7	46	9.5	24	4.9	15	3.1

Source: Own compilation.

(34.3%) of pupils covered by this form of education. However, taking into account the six-year learning system, there were on average 27 such pupils per year of schooling. On the other hand, the number of young people covered by this type of education in upper secondary schools (25.6%) was slightly smaller when compared to the education stages described earlier, but taking into account the duration of this stage of education (3-4 years), there were on average 39 students per one year of schooling. The smallest number of children covered by individual education were children granted with the decision on individual compulsory one-year pre-school preparation who constituted 4.1%, i.e. 20 children per year.

Taking into account the number of decisions issued at different stages of education, the reasons and indications according to which doctors direct children to individual teaching seem quite interesting (Table 3).

When analysing the data presented in Table 3, it can be seen that almost every second decision on the need for individual teaching regards students who have been diagnosed with various types of mental disorders by a doctor (48.7%). On the other hand, almost every fourth indication refers to a chronic disease which makes it impossible or significantly hinders attending kindergarten or school (24%). Only every tenth decision is related to surgery or an accident (9.7%), and every twentieth to cancer (4.9%) or pregnancy (3.1%).

Summary

Individual teaching is a form of special education that allows children whose health makes it impossible or very difficult to attend kindergarten or school to fulfil compulsory education. Due to its specificity, it allows to fully adjust education to the psychophysical possibilities of the student and his/her preferences in acquiring knowledge and skills. Most often, individual teaching takes place in the student's home, significantly limiting his/her contacts with peers, thus disrupting the individual's development. In justified

cases it may be a positive measure – it allows for a flexible adaptation of the individual teaching model to a given student, his/her current state of health, mental condition at a specific moment of life, allows for better functioning. Unfortunately, it often becomes a “convenient” solution for schools struggling with “difficult students”. Such social isolation has a negative impact on the individual and social development of young people, the basic condition of which is, as emphasized by W. Dykcik³², to enable the participation in social life in different scopes, situations and contexts.

Analysing the collected data from selected psychological and pedagogical counselling centres in the Małopolskie Voivodship, it can be stated that the decision on the need for individual teaching is granted to nearly 1% of all students, most often at the lower secondary school level. The most common reason and indication for granting such a decision are mental disorders and chronic diseases. It may be concluded that the decisions, granted in accordance with the current regulation, will be issued for the longest possible period, i.e. for one school year.

When analysing the relation between the specific educational stage and the reason for granting the decision, it may be assumed that the large number of decisions granted to lower secondary school students may be caused by late diagnosis, symptoms appearing only in the period of adolescence, or the type of deficits which make learning difficult only at a later stage of school education.

With regard to the empirical data collected, it is worth asking about the legitimacy of issuing such a large number of decisions on individual teaching and the quality of this form of education. The new regulations and the proposed solutions are intended to limit this form of education to a minimum. Will this succeed?

³² W. Dykcik, *Poszukiwanie nowatorskich i alternatywnych koncepcji indywidualnej rehabilitacji oraz społecznej integracji osób niepełnosprawnych – aktualnym wyzwaniem praktyki edukacyjnej*, [in:] *Nowatorskie i alternatywne metody w teorii i praktyce pedagogik specjalnej*, ed. W. Dykcik, B. Szychowiak, Wydawnictwo Naukowe UAM, Poznań 2001.

It must be stressed that individual teaching should be one of the ultimate means of compulsory schooling. Exploiting this form of education is highly unfavourable from the point of view of the development of young people. It is worth considering why so many children use this form of education. The decisions on the need for individual teaching should be verified in order not to become a form of eliminating problems and difficulties resulting from working with students with special educational needs.

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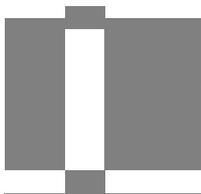
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From diagnosis to accompanying in mourning – support for families with a child with a lethal defect

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This article characterizes the interactions and institutions in which parents can receive support after their child has been diagnosed with a lethal defect. First of all, parents need information and emotional support when making decisions regarding their child. The primary source is the hospital staff and the perinatal hospice – if the parents decide to contact them. If the child is born alive and discharged home parents need support during its treatment (which often means palliative care) and rehabilitation, even social rehabilitation. Home-based hospices for children have a lot to offer in this area. At every stage of the child's illness it is important to contact other parents of children with a lethal defect. They can help to eliminate the feeling of isolation, give practical advice regarding the situation and, above all, provide hope that some children live despite fatal diagnosis.

KEY WORDS: child with a lethal defect, prenatal pedagogy, social support

The article attempts to outline the sources of support for parents of a child with a lethal defect. It describes persons and institutions that already during the period of pregnancy can provide parents with reliable information about various aspects of the disease, help

to plan birth, improve access to health care services and, above all, surround the family with emotional support.

This topic was inspired by blogs run by parents of children with a lethal defect (Edwards, Patau and Miller-Dieker Syndromes). The author of one of the blogs observed that when talking about terminally ill children whose health condition is far from promising any improvement, people tend to use statements such as: “a hopeless case”, “it won’t help him/her anyway”, “it’s a waste of time and money”, “only persistent therapy can help”, “a hospice is the only solution for such children”, “he/she’s just taking the place of children who have a chance to recover”. This leads to a feeling of loneliness, deprives parents of the strength to face the disease and hope for a better future. One such statement can complicate their already dramatic situation. At the same time, the blogs show that parents of children with lethal diseases are not always left to their own devices, because, as they wrote in their virtual diaries, they received support from people and institutions, even if at first they did not realize that such possibilities existed.

The specific situation of parents after the diagnosis of a lethal defect in the child

The term “lethal defect” which appears in the title is used to denote severe developmental abnormalities with uncertain or poor prognosis. A lethal defect can lead to: 1) miscarriage of a dead foetus, 2) premature birth of a dead child, 3) death of a child immediately after birth or in early infancy regardless of the treatment applied. Despite the progress in medicine and the possibility of using the most modern achievements of biotechnology and pharmacology in treatment, there is no possibility of causal treatment of lethal defects¹.

¹ J. Krzeszowiak, R. Śmigiel, *Rola i zadania położnej jako członka zespołu sprawującego opiekę nad ciężarną pacjentką z rozpoznaną wadą letalną u płodu*, „Pielęgniarstwo i Zdrowie Publiczne” 2016, 6, 1, p. 58.

Every year, more than 600 children with a lethal defect are born in Poland². The number of foetuses with lethal defects is even higher, especially if the mother is older³. Thanks to the development of prenatal diagnostics techniques which are divided into two main groups: invasive (ultrasonography and examination of the pregnant woman's blood serum) and non-invasive, which involve the collection of the prenatal child's cells in order to determine its karyotype and possible DNA analysis (such as genetic amniocentesis, CVS test, cordocentesis and fetoscopy)⁴, some lethal defects can be diagnosed from the end of the first trimester of pregnancy.

It is extremely difficult for parents to learn that an expected child has a disease that will lead to his or her premature death, perhaps still in the prenatal period. As Dorota Kornas-Biela observes, this kind of information evokes panic, sadness, regret, disbelief, denial, emotional lability in parents. A sense of shame, guilt and injustice and many other extremely negative experiences may also appear⁵. As Renata Kleszcz-Szczyrba puts it, the diagnosis of a lethal defect entails a multiple loss. The first one is the irreversible loss of the child's health, the second is the loss of the parents' plans and hopes, which were associated with the child⁶.

² The number of live-born children with a lethal defect was estimated based on the assumption that 3% of live-born children have WRWZAC and 7% of this group are children with a lethal defect; T. Dangel, *Wady letalne u płodów i noworodków: opieka paliatywna jako alternatywa wobec eugenicznej aborcji, eugenicznego dzieciobójstwa i uporczywej terapii*; <http://www.hospicjum.waw.pl/phocadownload/Etyka/WadyLetalneUPlodowINoworodkow.pdf> [access: 2.05.2017].

³ For example, the risk of the fetal Edwards Syndrome is 1:2484 for a 20-year-old woman, 1:1456 for a 30-year-old and 1:157 for a 40-year-old.; H. Kypros, P. Nicolaidis, P. Węgrzyn, *Badanie ultrasonograficzne między 11+0–13+6 tygodniem ciąży*, Fetal Medicine Foundation, London 2004, p. 22.

⁴ J. Skrzypczak, J. Kornacki, *Ciąża o przebiegu niepowikłanym*, [in:] *Położnictwo. Podręcznik dla położnych i pielęgniarek*, red. G.H. Bębrowicz, Warsaw 2005, pp. 72–74.

⁵ D. Kornas-Biela, *Niepomyślna diagnoza prenatalna: dylemat rodziców, wyzwanie dla profesjonalistów*, http://www.mp.pl/etyka/poczatki_zycia/39622,niepomysl-na-diagnoza-prenatalna-dylemat-rodzicow-wyzwanie-dla-profesjonalistow [access: 2.05.2017].

⁶ R. Kleszcz-Szczyrba, *Witraże w ciemności czyli o przedwczesnej śmierci dziecka. Książka niosąca światło*, Księgarnia św. Jacka, Katowice 2015, p. 78.

If parents receive the diagnosis during the prenatal period, this will involve an additional burden for them as they will have to decide between the following options: termination of pregnancy, which is permitted by law in this situation vs. continuation of pregnancy. If the child is born alive, parents will be confronted with decisions such as: 1) resuscitation of the child vs. no resuscitation; 2) intensive therapy vs. palliative care provided at home, in a hospital ward or in a residential facility; 3) surgical correction of the defect vs. no surgical treatment; 4) death in hospital vs. death at home⁷.

When confronted with a multitude of problems, parents need comprehensive support. During pregnancy, the main focus is on multi-faceted information about the disease, showing understanding to the parents and preparing them to make decisions related to the child. If the child is born alive and discharged home, there is also the need to support parents in their care, treatment, rehabilitation and taking measures to prevent social exclusion of the family.

Support provided by the staff of health care institutions

A pregnant woman, regardless of whether she is insured or not, has the right to health care during pregnancy, childbirth and confinement, which is regulated by relevant regulations, in particular the Regulation of the Minister of Health of 20 September 2012 *on the status of medical procedures for the provision of health care services in the field of perinatal care provided to a woman during physiological pregnancy, physiological birth, confinement and care of a new-born child*. On the other hand, under the Regulation of the Minister of Health of 6 November 2013 *on guaranteed services from the scope of health programmes*, a pregnant woman may also benefit from the "Prenatal tests programme" provided that she meets at least one of the criteria set out

⁷ T. Dangel, *Decyzje dotyczące dzieci z nieuleczalnymi chorobami prowadzącymi do przedwczesnej śmierci w perinatologii*, pp. 3-6, http://www.ptb.org.pl/pdf/dangel_neonatalna.pdf [access: 20.09.2015].

in the programme⁸. When the pregnancy and childbirth are complicated or when there is a obstetric failure, the procedure regarding the woman is specified in the Regulation of the Minister of Health of 9 November 2015 *on standards of medical procedure in the provision of health services in the field of obstetrics and gynaecology in the field of perinatal obstetrics and gynaecology care provided to a woman during pregnancy, childbirth, confinement, in cases of specific complications and care for a woman in the situation of obstetric failures*.

Under optimal conditions, a wide range of medical specialists are involved in the diagnosis of a child's lethal defect and decision-making processes after diagnosis: obstetricians dealing with the pregnancy and prenatal diagnosis, clinical geneticists, foetal echocardiography specialists, paediatric surgeons, neonatologists and palliative medicine specialists who are involved in the care of the child after its birth.⁹ The task of these people is to diagnose the disease properly and to provide parents with as complete information as possible. This should include knowledge about the symptoms of the disease, prognosis, perspectives of treatment and rehabilitation of the child. In addition, parents should be consulted about their procreation plans¹⁰.

What is important is not only the content of the information provided by the medical personnel, but also its form. Parents need someone who will understand their feelings and patiently listen to

⁸ 1) the mother's age over 35; 2) occurrence of chromosomal aberration in previous pregnancy; 3) finding the occurrence of structural chromosome aberrations in a pregnant woman or in the child's father; 4) finding a significantly higher risk of giving birth to a child afflicted with a monogenetically-conditioned or multifactorial disease; 5) confirmation during pregnancy of an abnormal result of ultrasound examination and/or biochemical tests indicating an increased risk of chromosomal aberration or fetal defects (Order No 66/2007 / DSOZ, appendix No 5).

⁹ J. Krzeszowiak, R. Śmigiel, *Rola i zadania położnej jako członka zespołu sprawującego opiekę nad ciężarną pacjentką z rozpoznaną wadą letalną u płodu*, „Pielęgniarstwo i Zdrowie Publiczne” 2016, 6, 1, p. 57.

¹⁰ A. Libera, *Psychologiczny aspekt poronień*, [in:] *Psychologia w położnictwie i ginekologii*, ed. M. Makara-Studzińska, G. Iwanowicz-Palus, Wyd. Lekarskie PZWL, Warsaw 2009.

them. It is inappropriate to use specific medical terms referring to the child in the presence of the parents, which function in medical nomenclature, but are non-personalistic. When talking with parents whose child is alive, the aspects that constitute the basis for building rational hope (far from presenting an illusion of curing the child) should be highlighted. Finally, as Jadwiga Łuczak-Wawrzyniak emphasizes, providing parents with information about the disease is not, or at least should not be a simple conversation, but an art in itself¹¹.

Once again, we had our daughter examined at the clinic in the University Hospital, scheduled for September. We were received by our wonderful Doctor. The same one who told us about our daughter's disease. Strange, I think of her as wonderful and yet she was the one who told me something which caused the greatest pain in my life. Also this time she was full of empathy and understanding. She examined our daughter with great care. I felt that although she didn't want us to be too optimistic, she let us know that according to her our daughter was doing quite well. She also said a few warm words about us: that we were wonderful parents, which made us to feel a little better¹².

Parents can also count on the support of a psychologist, including the one employed in the hospital. Unfortunately, research shows that most often parents do not know about such a possibility, which leads to the conclusion that the role of the psychologist should not be limited to waiting for parents to come to his/her office themselves, but rather to initiate contact and present the possibilities of psychological care¹³.

¹¹ J. Łuczak-Wawrzyniak, *Leczenie jest sztuką – na podstawie wybranych obszarów działalności szpitala ginekologiczno-położniczego*, „Ginekologia Polska” 2002, No 73(10), pp. 884–887.

¹² The quote, like the subsequent ones, comes from a blog devoted to a child with a lethal defect. In order to protect the identity of the authors of the blogs, the article does not provide their names and internet addresses. For the same purpose, the quoted excerpts of the entries have been slightly edited.

¹³ A. Kopeć et al., *Hospitalizacja dziecka w Oddziale Intensywnej Terapii Noworodka – doświadczenia rodziców*, “Current Problems of Psychiatry” 2016, No 17(1), p. 28.

However, the situation of parents after the child has been diagnosed with a lethal defect, very difficult from the psychological point of view, may prove that support provided by the hospital staff is insufficient. In addition to information, parents need support in the form of appreciative, instrumental and, above all, emotional and spiritual support¹⁴. This is possible provided they use several sources of support simultaneously.

Parents as the source of mutual support

When confronted with information about a child's lethal illness, the first and primary source of support, initially mainly emotional, should be the spouse/partner. However, this may be problematic due to the diversity of experiences and reactions of parents. According to D. Kornas-White, the woman, who is usually more involved in the situation and shows stronger emotional expression, often feels misunderstood by the child's father, abandoned and experiences a sense of underestimation on the part of the father of the gravity of the situation¹⁵. The attitude of the partner, different from one's own, may cause anger in a woman, she may interpret it as a manifestation of the man's small concern for the child or rejection of herself¹⁶.

A prerequisite for the mutual support of parents is a uniform position regarding the future of the pregnancy: whether they want to continue the pregnancy or, as permitted by law, decide to terminate it. There should be no question of an arbitrary suggestion of

¹⁴ Classification of forms of support by S. Kawula, *Wsparcie społeczne – kluczowy wymiar pedagogiki społecznej. Głos w dyskusji*, „Problemy Opiekuńczo-Wychowawcze” 1996, No 1.

¹⁵ D. Kornas-Biela, *Niepomyślna diagnoza prenatalna: dylemat rodziców, wyzwanie dla profesjonalistów*, http://www.mp.pl/etyka/poczatki_zycia/39622,niepomysl-na-diagnoza-prenatalna-dylemat-rodzicow-wyzwanie-dla-profesjonalistow [access: 2.05.2017].

¹⁶ J. Makselon, *Typologia i dynamika żałoby*, [in:] *Człowiek nieuleczalnie chory*, ed. B. Block, W. Otrębski, WNS KUL, Lublin 1997.

a solution, detached from emotional argumentation, without respect for the recognised worldview, because this may be the reason for blaming the partner for the decision at a later stage.

After the birth of the child, it is important to share the responsibilities associated with its presence, especially since apart from the duties considered standard in neonatal care, there are also those that are a consequence of the disease, such as feeding with the use of a probe or transcutaneous endoscopic gastrostomy (the so-called peg). There is also a psychological burden resulting from the awareness that the child's condition may deteriorate rapidly at any time and without any warning, because this is the specificity of lethal malformations. If other children are present in the family, they also need attention. Despite the presence of the sick sibling, their needs must be met. In these circumstances, the partner's support cannot be overestimated.

On Saturday our son had fever, diarrhea and nausea. I worked from morning until evening, so Dad stayed at home. He was alone with two sons, one of which required constant changing, dressing, feeding with carrots and rice and hydrating with electrolytes, while the other demanded continuous and active participation in fun and games. Dad was certainly not bored. Fortunately, he is the best Dad in the world and he is doing very well with the boys, so he emerged victorious from this battle.

Parents can support each other in the process of waiting for the child with a lethal defect and its upbringing, especially if they develop certain coping strategies. One of the most interesting things that have been observed when reading the blogs is treating the child's illness metaphorically as a journey, with the conviction that although it is difficult and leads along unknown routes, it will bring about positive changes.

From the first months of their lives we took our children on trips. This time the opposite happened, because it was our son who invited us on an expedition into the unknown. Although not with open arms and without a smile on our lips, we accepted this invitation. And here we

are on our journey together. This time, however, our journey has a much deeper dimension than usual. The non-material sphere that has always been present in our travels has come to the forefront. This time, we don't really know where we're going. At most, we know that this is a difficult road. I am convinced, however, that at the end of the road there is a place which will leave us speechless. Not only because of fatigue, but also due to admiration. I think that something positive has to come out of all this.

The support of the family by a perinatal hospice

A relatively new proposal to support parents of children with lethal defects is the offer of perinatal hospices, which are free of charge from prenatal recognition of the defect to the completion of the 28th day of the child's life¹⁷. The first institution of this type in Poland was established in Warsaw in June 2006, when an ultrasound clinic was opened at the Warsaw Hospice for Children Foundation¹⁸. At present, there are 16 such institutions in Poland, most often organised within the structure of children's hospices or clinical hospitals, offering perinatal hospice care. They are located in: Krakow (three), Wrocław (two), Warsaw, Tychy, Łódź, Białystok, Gdańsk, Poznań, Lublin, Opole, Rzeszów, Katowice and Bydgoszcz (one in each).

Currently there is no uniform model of functioning of perinatal hospices. The most comprehensive seems to be the concept of support developed by the perinatal hospice at the Warsaw Hospice for Children Foundation, which, thanks to the training provided to doctors and psychologists from other centres, is gradually being

¹⁷ More information on perinatal hospices can be found in the author's article *Hospicjum perinatalne – miejsce wsparcia dla rodziny z dzieckiem z wadą letalną*, „Problemy Opiekuńczo-Wychowawcze” 2016, No 8.

¹⁸ J. Szymkiewicz-Dangel, *Perinatalna opieka paliatywna – czy możliwa jest współpraca położników i neonatologów z hospicjami domowymi dla dzieci?*, „Opieka Paliatywna nad Dziećmi” 2007, Vol. 15, p. 27.

disseminated throughout the country¹⁹. This includes the following stages of support for a family with a child with a lethal defect:

- 1) Consultation with a doctor consultant of the ultrasound clinic at the hospice.
- 2) Further specialist consultations, mainly psychological and genetic; prenatal invasive tests and a meeting with other parents who decided to be supported by a perinatal hospice.
- 3) If the parents decide to terminate the pregnancy, the patient has the opportunity to seek psychological advice and join a support group. If the parents decide to continue the pregnancy, the hospice offers them perinatal palliative care including (depending on the diagnosis):
 - ultrasound scan/echogram control of the foetus at the hospice outpatient clinic,
 - maternity care in the pregnancy pathology clinic,
 - a meeting between the parents and an obstetrician organized by the hospice doctor in order to determine the perinatal procedure,
 - organisation of a meeting between the parents and a neonatologist to discuss the care of the new-born²⁰.

An important aspect of the support provided by a perinatal hospice is the work of the midwife. Her main task is to prepare the parents for childbirth and care at the time of pregnancy. The role of the midwife is also to make parents aware of the possibility of giving birth to a dead or dying child and how to prepare to say goodbye to the child (e.g. by preparing special clothes, filling in rituals according to the religion of the parents, taking pictures during and after the birth)²¹.

¹⁹ *Hospicja perinatalne – placówki poza systemem*, <http://info.wiara.pl/doc/3506371>. Hospicja-perinatalne-placowki-poz-systemem [access: 19.02.2017].

²⁰ D. Maksiewicz, T. Dangel, *II Ogólnopolska Konferencja Hospicjów Perinatalnych*, „Hospicjum” 2015, No 2(72), p. 13, file:///C:/Users/aneta/Downloads/informator-hospicjum-nr72-czerwiec-2015%20(1).pdf [access: 9.05.2017].

²¹ J. Krzeszowiak, R. Śmigiel, *Rola i zadania położnej jako członka zespołu sprawującego opiekę nad ciężarną pacjentką z rozpoznaną wadą letalną u płodu*, „Pielęgniarstwo i Zdrowie Publiczne” 2016, 6, 1, p. 57.

- 4) If the child is born alive, it is placed in a neonatal ward. There he or she receives palliative care aimed at providing comfort and protection against persistent therapy. At the same time, the parents maintain contact with the psychologist of the perinatal hospice.
- 5) If the child survives in the neonatal ward for several consecutive days and his/her condition allows for it, he/she may be referred by a neonatologist to a home hospice²². The family can then count on paediatric palliative care, which includes:
- healthcare services provided by doctors and nurses;
 - treatment of pain and other somatic symptoms in accordance with current guidelines and medical knowledge;
 - rehabilitation in the event that the hospice physician identifies existing medical indications for this purpose;
 - prevention of complications;
 - examinations commissioned by the family hospice doctor;
 - medication prescription;
 - renting the necessary medical equipment free of charge;
 - psychological care for the patient and his or her family, including support in mourning;
 - social support including, among other things, renovation and adaptation works carried out in the apartment, assistance in organizing and financing holiday trips and spiritual support, the key element of which is building hope, also through reference to religion, as well as assistance in accepting the fact of the illness and most often the death of a child²³.

According to the model propagated by the Warsaw hospice, in the event of a child's death, the hospice staff: a doctor and a nurse

²² Fundacja Warszawskie Hospicjum dla Dzieci, *Hospicjum perinatalne*, Warsaw 2016, p. 8, file:///C:/Users/aneta/Desktop/1037_hospicjum-perinatalne-materialy-informacyjne.pdf [access: 29.04.2017].

²³ A. Korzeniewska-Eksterowicz et al. (compilation), *Standardy prowadzenia pediatrycznej opieki paliatywnej Ogólnopolskiego Forum Pediatrycznej Opieki Paliatywnej*, pp. 2-3, <http://ofpop.pl/wp-content/themes/inove/img/standardy-ofpop-2016.pdf> [access: 29.04.2017].

(as well as a priest, if the parents wish him to be present), try to reach the patient's home as soon as possible. They show compassion for the parents, and by stressing that they took good care of their child, that they have done everything possible, they also provide appreciative support. There can also be a common prayer, which is an expression of spiritual support. Afterwards, the hospice staff assists the parents in formal matters: the doctor fills in the death certificate and the social worker handles official matters. In addition, the hospice staff accompany the parents in funerals and then invite them to join a support group in mourning²⁴.

I quickly contacted the home hospice. When I asked for help, I was mostly thinking about the essentials – about the equipment I would need to take care of my daughter at home. The response from the hospice was immediate. The next day the doctor and the nurse came to the hospital to get to know us. I must admit that I did not expect that this meeting would help me so much, especially mentally. I felt strong and safe. After the meeting I became convinced that our decision to take my daughter home was the right one. The next day the nurse brought us: an oxygen concentrator and syringes and probes needed for feeding. Our home is now surrounded not only by medical help and professionalism, but also by peace, cordiality and a good word.

Support received from other parents with children with a lethal defect

When a child has a rare disease, it is usually difficult to find people in a similar life situation in our immediate environment. At the same time, contact with such people could reduce the sense of isolation, result in the exchange of information and experience, make us aware of what we have influence on and what cannot be

²⁴ *Szpital to nie jest dobre miejsce dla dzieci*. Rozmowa z Tomaszem Danglelem, „Hospicjum” 2011, No 1 (55), p. 26, file:///C:/Users/aneta/Downloads/informator-hospicjum-nr55-marzec-2011.pdf [access: 21.02.2017].

changed. Research confirms that parents of terminally ill new-borns appreciate the role of people with similar experiences when coping with the difficult situation²⁵.

As part of the hospice support, parents may establish contact with other families with a child with a lethal defect already during pregnancy. Holiday trips, organized and financed by the hospice, are also an opportunity to meet other families with a sick child. Face-to-face contacts are not only a valuable source of knowledge for parents about various aspects of the disease, but above allow to build hope, as parents find out that there are children who live despite fatal prognosis and who have mastered skills that are true milestones.

In June we got in touch with another family with a child with the Edwards Syndrome. Naturally, we decided to meet. Then another “summit meeting” took place. I found out that children with the same disease can develop very differently. The other girl can maintain an upright position and walk, though only on tiptoes, but it’s a huge success for her and her parents. Our Princess also looked at her “sister in disease”. In September we had a long-awaited trip to the Baltic Sea. A lot of iodine, an ideal period for improving the respiratory tract, but it was more important to get to know other sick children. And the most important thing was to get to know Małgosia – the oldest child with the Edwards Syndrome I know. I would like to use this opportunity and say hello to everyone.

The Internet cannot be overlooked when considering the issue of supporting parents of children with a lethal defect. It is a popular source of information about health and disease, including children with a lethal defect. Parents of such children can be contacted through virtual support groups existing on social networking sites (e.g. *Mali Giganci z zespołem Edwardsa*), discussion forums (including associations’ websites, e.g. the *Association for Children with Rare Genetic Diseases and Their Families “Wspólnie”*) or parent blogs.

²⁵ A. Kopeć et al., *Hospitalizacja dziecka w Oddziale Intensywnej Terapii Noworodka – doświadczenia rodziców*, „Current Problems of Psychiatry” 2016, no. 17(1), p. 28.

Internet groups, although they have their disadvantages, offer unique conditions that make it easier for their members to disclose personal experiences and develop supportive relationships. One of the most important are: the ability to communicate across spatial boundaries and at any time, the impression of anonymity and the lack of divisions resulting from age, gender, appearance or education²⁶. The written form, which is the basis of any on-line communication, also has its advantages. The process of writing down thoughts, emotions and experiences is beneficial from a therapeutic point of view, as it improves one's mood and well-being, observes Małgorzata Wysocka-Pleczyk²⁷. It is worth noting that contacts established in the network are sometimes carried out outside the Internet, including telephone calls or even personal meetings²⁸.

Conclusion

After the child has been diagnosed with a lethal defect, the family enters an extremely difficult psychosocial situation. Parents learn that their child will die prematurely as a result of the lack of treatment of the cause of the disease. Despite the tragic diagnosis, many of them decide to make every effort to ensure that the child's life, even if it is short, is good (in the sense that it is free from pain and persistent therapy, surrounded by loving people). However, parents may feel incompetent and overburdened in achieving this goal.

²⁶ More information on the features of the Internet conducive to communication can be found in the work of M. Grabowska, *Wartość dodana Internetu na przykładzie internetowych grup wsparcia*, [in:] *Wielka sieć. E-seje z socjologii Internetu*, ed. J. Kurczewski, Trio, Warsaw 2006, pp. 270-273.

²⁷ M. Wysocka-Pleczyk, *Grupy wsparcia online jako nowa forma pomocy w zmaganiu się z chorobą*, "Hygeia Public Health" 2012, 47(4), p. 394.

²⁸ The described tendency was observed by the author while researching the participants of the discussion on the forum devoted to children with the Edwards Syndrome; A. Jarzębińska, *Wsparcie społeczne w interakcjach rodziców dzieci z Zespołem Edwardsa – użytkowników forum internetowego*, Wyd. US, Szczecin 2017, pp. 142-144.

They require support in virtually all its forms and from many sources at the same time.

First of all, parents need the support of specialists in the field of medical sciences: obstetricians dealing with the pregnancy and prenatal diagnostics, geneticists, paediatric surgeons, neonatologists. By providing parents with knowledge about various aspects of the disease, they support them in making decisions related to the child. They provide medical care for pregnant women and the child. After the birth, the family can receive help in the form of a home hospice, which provides support in various forms, even after the death of the child. Other families with a sick child complement the sources of support for parents with a child with a lethal defect. Such interactions allow for the exchange of information, guidance, provide appreciative and emotional support and – which is essential – build hope that, despite the fatal prognosis, some children with a lethal defect live and acquire further developmental skills.

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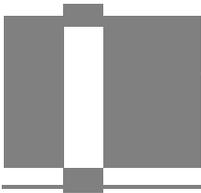
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CONFERENCE REPORT



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The 20th Congress of the Nationwide Alliance of Alzheimer's Organisations and The Scientific Conference: PUBLIC HEALTH – Problems of the elderly and their families

Report

On 1–3 June 2018, the 20th Congress of the Nationwide Alliance of Alzheimer's Organizations took place at the University of Zielona Góra, in the seat of the Rector's Office, at 9 Licealna Street in Zielona Góra. So far, the Congresses have been held cyclically and had a nationwide character. This year's Congress was held in Zielona Góra for the first time.

This does not mean, however, that Zielona Góra, the University of Zielona Góra or the Lubuskie Association for the Support of Carers and Persons Affected by Alzheimer's Disease were not known to the participants of the Congress. They have often visited Zielona Góra on the occasion of previous undertakings related to Alzheimer's disease, the problems of patients and their families.

As part of this year's Congress, the Scientific Conference "Public Health – the problems of the elderly and their families" was also held.

The organizers of the Conference and the Congress were: the University of Zielona Góra (Faculty of Pedagogy, Psychology and Sociology) and the Lubuskie Association for the Support of Carers and Persons Affected by Alzheimer's Disease¹.

¹ The Organizing Committee of the Congress and the Conference was composed of: secretaries: Dr. Agnieszka Nowicka, Jan Wyżykowski University in Pol-

This is yet another joint undertaking that meets social needs and tackles an important problem, not only for the sick, but also for their families and carers. The importance of the problem and the scale of the phenomenon leads to the conclusion that this is a growing social issue and there is a need to undertake assistance activities in the field of diagnosis of elderly people, the situation of sick people, support to those affected by the disease and systemic support for their careers and families.

The invitation to the Scientific Committee of the Congress and the Conference was accepted by people who are not indifferent to the difficult situation of people with disabilities, the sick, their families and who take action on their behalf in their work, but also experience the daily care of the elderly or persons affected by Alzheimer's disease. The Scientific Committee included: dr hab. Grażyna Miłkowska, prof. of UZ (University of Zielona Góra), President of the Lubuskie Association for the Support of Carers and Persons Affected by Alzheimer's Disease, Zielona Góra; dr Agnieszka Nowicka, Jan Wyżykowski University, Polkowice; dr Katarzyna Uzar-Szcześniak, Wrocław University; dr Jolanta Lipińska-Lokś, University of Zielona Góra.

The Honorary Patronage over the Conference was provided by: the Marshal of Lubuskie Voivodship Elżbieta, Anna Polak, the Mayor of Zielona Góra, Janusz Kubicki, the Rector of the University of Zielona Góra, Prof. dr hab. inż. Tadeusz Kuczyński. The Media Patronage was provided by Gazeta Lubuska.

The participants were greeted by: on behalf of the Marshal of Lubuskie Voivodship, Elżbieta Anna Polak: Mirosław Dulat – Deputy Director of the Health Department of the Marshal's Office in Zielona Góra, on behalf of the Mayor of Zielona Góra, Janusz Kubicki: Lidia Gryko – Deputy Head of the Department of Education and Social Affairs of the Municipal Office in Zielona Góra, on behalf of the Rector of the University of Zielona Góra Prof. dr hab. inż. Tadeusz Kuczyński: dr hab. M. Furmanek, prof. of UZ –

kowice (formerly an assistant professor at the University of Zielona Góra), Wioleta Baziuk, MA, day care centre „Senior – Wigor” in Zielona Góra, Lubuskie Association for the Support of Carers and Persons Affected by Alzheimer's Disease; PhD students at the Faculty of Pedagogy, Psychology and Sociology of the University of Zielona Góra: Krzysztof Łoziński MA, Sławomir Sobański MA, Astina Koch MA, Karolina Silna MA, Mateusz Kuźmik MA; Marta Nowicka MA, Jan Wyżykowski University in Polkowice (graduate of the University of Zielona Góra).

Dean of the Faculty of Pedagogy, Psychology and Sociology at the University of Zielona Góra and Dr. G. Miłkowska, Prof. of UZ – President of the Lubuskie Association for the Support of Carers and Persons Affected by Alzheimer's Disease.

The Conference was addressed to the academic, pedagogical and medical community, as well as the local community. Nearly 60 people took part in the conference, including:

- 1) representatives of organisations and associations from all over the country,
- 2) university teachers and doctoral students of the University of Zielona Góra dealing with the problems of the elderly,
- 3) carers and families of sick persons and persons with a potential interest in the subject matter,
- 4) employees of local government offices (ROPS, MOPS) and representatives of the National Health Fund.

During the Conference, all the objectives (common for the Conference and the 20th Congress) were implemented, namely:

- 1) promotion of the principles of health prevention in the field of dementia and the methods of their implementation,
- 2) getting to know the actions undertaken by Alzheimer Europe aimed at improving patients' access to diagnosis and treatment of all age-related diseases, in particular Alzheimer's disease,
- 3) presentation of initiatives undertaken in the Lubuskie Voivodship to improve the lives of people suffering from Alzheimer's disease and their carers,
- 4) promotion and sharing of experience concerning the measures and good practices in the field of systemic support for persons suffering from dementia and their families, and in particular those suffering from Alzheimer's dementia – developed in institutions all over Poland.

The conference was mostly educational in nature. Both the presentations made in the poster session and the conference presentations in the plenary session allowed to present important, current issues and enrich the awareness of the participants. The participants were presented with examples of good practices related to actions taken with and for the benefit of persons with Alzheimer's disease, which provided food for thought.

The following issues were presented in the poster session:

- Dr. Jolanta Lipińska-Lokś, University of Zielona Góra: *Old age as a phase in the human life cycle*,

- Marta Nowicka, MA, Jan Wyżykowski University, Polkowice: *Health problems of elderly people*,
- Krzysztof Łoziński, MA, PhD student at the Faculty of Pedagogy, Psychology and Sociology of the University of Zielona Góra: *Stereotypes and prejudices towards the elderly*,
- Astina Koch, MA, PhD student at the Faculty of Pedagogy, Psychology and Sociology of the University of Zielona Góra: *Alzheimer's disease – between theory and practice*,
- Mateusz Kuźmik, MA, PhD student at the Faculty of Pedagogy, Psychology and Sociology of the University of Zielona Góra: *The Clock Test*,
- Karolina Silna, MA, PhD student at the Faculty of Pedagogy, Psychology and Sociology of the University of Zielona Góra: *Alzheimer's disease – causes and related problems*,
- Sławomir Sobański, MA, PhD student at the Faculty of Pedagogy, Psychology and Sociology of the University of Zielona Góra: *Problems of carers of people suffering from Alzheimer's disease*

During the Conference, the participants also listened to many contributions to the plenary sessions:

- 1) Dr hab. Agnieszka Zembroń-Łacny, Prof. of UZ: *The neuroprotective influence of physical effort in Alzheimer's disease*,
- 2) Zygmunt Wierzyński, MA, President of Alzheimer Polska: *Presentation of the strategy of Alzheimer Polska – part 1*,
- 3) Substituting for Dr hab. Waldemar Sługocki, Prof. of UZ, Senator of the Republic of Poland – Dr Sławomir Kotylak: *Public health in the aspect of the elderly, the disabled and their carers*,
- 4) Dr hab. Grażyna Miłkowska, prof. of UZ – President of the Lubuskie Association for the Support for Carers and Persons Affected by Alzheimer's disease in Zielona Góra: *Old age – derived thoughts and personal reflections*, Inauguration of open lectures,
- 5) Krzysztof Łoziński, MA, PhD student at the Faculty of Pedagogy, Psychology and Sociology, UZ, Zielona Góra: *Alzheimer's disease from the perspective of demographic changes*,
- 6) Dr Edyta Długosz, Community Self-help Centre for people with Alzheimer's disease "Mefazja" in Lublin: *Problems of the elderly and their families, including Alzheimer's disease in particular*,
- 7) Dr Agnieszka Nowicka, Jan Wyżykowski University, Polkowice: *"The Carer's Syndrome as a consequence of long-term care for a person with Alzheimer's type dementia*,

- 8) Marta Nowicka, MA, Jan Wyżykowski University, Polkowice: *Alzheimer's disease as a source of physical, mental and social burden for family carers*,
- 9) Dr Katarzyna Uzar-Szcześniak, University of Wrocław, Wrocław: *Non-pharmacological methods of dementia therapy – types, effectiveness, practice*,
- 10) Ewa Duda, MA, KTOTO – Understanding Alzheimer's Disease Foundation, Osiny: *Alzheimer and Me – together we will understand. A project of a support network for the carers of people suffering from Alzheimer's disease and dementia syndromes*,
- 11) Barbara Stafiej, MA, Podkarpackie Association of Support for Persons with Alzheimer's Disease, Rzeszów: *The Conscious Carer Club as part of the "Generator of Innovation. Support Networks" Programme*.

On the second day of the Congress, on the day of the conference, in the afternoon, the participants visited the day care centre "Senior – Wigor" in Zielona Góra, where the conference entitled *The Exchange of Good Practices* was held. This part of the conference included practical presentations and workshops, illustrating the possibilities of working with people with Alzheimer's disease:

- Wioletta Baziuk, MA, day care centre "Senior – Wigor", Zielona Góra: *Support of the environment for people suffering from Alzheimer's disease and their families*,
- Agnieszka Żelwetro, MA, Alzheimer's Centre in Ścinawa, University of Humanities and Social Sciences in Wrocław: *About Reminiscence Theatre – how to show memories?*²,
- Dr Dorota Niewiedział, University of Zielona Góra: *Crisis in the family affected by Alzheimer's disease presented in systemic terms and methods to overcome it*³,

During this part of the Conference, representatives of Alzheimer Polska undertook: *"Work on the strategy of Alzheimer Polska's activity and development of recommendations for the Polish Alzheimer's Plan, part"*.

The third day of the Congress was very eventful, particularly for members of Alzheimer's organizations. Dorota Siwec, MA, Chief Specialist of

² The speech delivered by Agnieszka Żelwetro, MA, was prolonged as it aroused great interest of the participants and was followed by numerous questions.

³ Dr Dorota Niewiedział accepted the invitation of the organizers in the absence of J. Czarnecka, MA.

the Labour Law and Social Security Department, Warsaw, in her speech entitled *The situation of people suffering from Alzheimer's disease and the activities of the Ombudsman in this area*, ensured about the openness and favourable attitude of both the Ombudsman and herself.

Dr. Edyta Długosz, Vice President of Alzheimer Polska, recalled the *Assumptions of the Polish Alzheimer's Plan*. A plan which, although very important, natural and obvious, is still waiting for implementation.

The *Debate* with Piotr Bromber, MA, Director of the National Health Fund of the Lubuskie Voivodship Branch in Zielona Góra caused a lot of emotions. The issues raised by the participants of the Debate, who experience everyday life affected by Alzheimer's disease and act on behalf of other people suffering from Alzheimer's disease, concerned, among other things: the possibility and necessity of introducing screening tests to diagnose the problem of Alzheimer's disease at a relatively early stage: problems with a proper "place for people with Alzheimer's disease and their families in the system of help and support in Poland"; issues of raising public awareness of the disease, support for the affected people and their families. From the perspective of the National Health Fund, issues related to Alzheimer's disease, people affected by the disease and their families and carers are important, but at the same time difficult, as solutions are required at the decision-making level so that implementers of legal regulations are equipped with appropriate competences in the provision of services. Difficulties resulting from the lack of human resources, i.e. general practitioners, family doctors and specialists in geriatrics were also pointed out. It was suggested that the associations should continue to be involved and that real solutions should be sought. Perseverance and further dialogue were recommended.

An important part of the last day of the Congress was the speech delivered by Zygmunt Wierzyński, MA, President of Alzheimer Polska: *Presentation of recommendations for the Polish Alzheimer's Plan*. This included the conclusions and recommendations developed during the discussion at the Congress:

- "Work on the implementation of the Polish Alzheimer's Plan should be intensified. Seven years after its preparation and following numerous efforts of representatives of Alzheimer's organizations, as well as the Ombudsman and individual Members of Parliament, there is still no political will to adopt the plan for implementation. The participants of the Congress passed a resolution on forwarding

relevant motions to the Senior Policy Committee of the Sejm and Senate, as well as MPs and senators from particular districts,

- There is a need to integrate activities undertaken by organisations, foundations and associations working for the benefit of people with Alzheimer's disease and their carers with the activities of other entities, especially the Polish Alzheimer's Society,
- In view of the disturbing statistics, it is essential to raise public awareness of Alzheimer's disease – its causes, course and impact on the functioning of patients and their families. Social campaigns with the use of mass media should play an important role in these activities. Especially during the World Alzheimer's Month, which takes place every year in September around the world⁴.

The discussion ending the 20th Congress led to another conclusion, namely, that we should "keep up the good work" for people with Alzheimer's disease, because this is the only chance to achieve goals, improve the quality of life of the families and carers of the sick, and to relieve them and their loved ones from the suffering.

The organizers of the Congress and Conference were then thanked for their efforts, kind reception and substantive discussions, as well as a moment of rest (during coffee breaks, walks and meetings in the *Lubuskie Winemaking Centre in Zabór*).

The 20th Congress of the Nationwide Alliance of Alzheimer's Organisations ended with a warm good-bye to all the participants and the announcement of the next meeting.

In the opinion of the participants and organizers, the Congress and Conference were well realized.⁵ The assumed results were achieved and the task was implemented:

- there was a constructive exchange of experience, raising participants' awareness of the problems related to Alzheimer's disease and other dementias. Recommendations were developed to speed up the implementation of the Polish Alzheimer's Plan,
- this initiative has made the community (not only the local community) aware of: the problem of dignified ageing, the urgent need to im-

⁴ G. Miłkowska, Press release – 20th Nationwide Congress of Alzheimer's Organisations, Zielona Góra, 3.06.2018.

⁵ A public task co-financed with public funds received from the Marshal of the Lubuskie Voivodship and the Mayor of Zielona Góra.

prove the quality of life and living standards, to promote and ensure opportunities for active ageing, and to create conditions that enable carers of older people to reconcile work and family life (the need to care for parents or other dependants).

The obtained results are of great importance, as they are consistent with the area of health protection of the elderly, which is identified as one of the most important issues in the senior policy in Poland, as described in the Appendix to Resolution No. 238 of the Council of Ministers of 24 December 2013 (item 118): *Assumptions of Long-term Senior Policy in Poland for the years 2014–2020*.

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REPORT



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Review of the monograph “The Emotions of Children and Young People with Difficulties in Development and Behaviour” (scientific editor Barbara Winczura), Oficyna Wydawnicza „Impuls”, Krakow 2017

It is strange, but true – in Polish literature dedicated to people with developmental disorders there has not yet been a solid study referring to the emotions experienced by such people. What is more, there are not many books on this particular subject in world literature. This fact should make us wonder: why have there been so many books devoted to the quality of life, adaptation, self-acceptance, cognitive disorders, social integration ... and so little has been written about the emotions of children with disabilities? Is this just a marginal problem in the lives of these people? Or maybe we already know everything we need to know? Finally, is it possible that the tendency of looking at the life problems of people with disabilities through glasses in which one of the glasses can be described as cognitivism and the other as positive psychology makes us blind to the problems that are so obvious and so common that they are almost unnoticeable? These questions are of course rhetorical. Each of them provides a true answer. The lack of interest in the emotions of people with developmental dysfunctions results from one more reason – namely, the issue of emotional development and development disorders is extremely difficult when it comes to conducting research that would meet current scientific standards. Therefore, a relatively small number of researchers undertake studies in this area.

In the light of the above, the value of the monograph, edited by Barbara Winczura, devoted entirely to the issue of emotions experienced by chil-

dren and young people with disabilities, should be appreciated. We tend to write that new scientific books fill a gap in our knowledge to-date. In the case of the book under review, however, this is not just a standard generality. The study "The Emotions of Children and Young People..." provides us with knowledge that has not been available to date, for which there is a huge demand among the parents of children with disabilities, their teachers, special educators, psychologists and paediatricians. It is hard to imagine that it is possible to effectively support the development of children with disabilities without knowledge about their emotions. Emotions can help in the comprehensive development of all children, but they can also effectively hinder such development. In the case of children with disabilities, this assumption is also true. In this case, however, emotions usually perform a negative function when it comes to dysfunctional development. Therefore, in order to reduce the negative function of emotions, it is necessary to get to know the emotional psychological mechanisms, which may be disturbed, but may also have an impact on other developmental spheres of a disabled child. Professor Krystyna Ferenc described this problem thoroughly in the Introduction to the book under discussion, so there is no need for me to additionally justify the importance of the issues in question. I would just like to add that writing a book on a subject that is not well recognized required exceptional effort (searching for appropriate literature) and responsibility (pioneering works form a foundation on which the building of knowledge continues, so this foundation should be very solid).

The book "The Emotions of Children and Young People..." is a very solid scientific study. This is certainly the result of the selection of authors of particular chapters. Each of them is not only a "bookworm", who knows the problem of emotions experienced by people with disabilities from the theoretical point of view. When reading subsequent chapters it becomes obvious, that starting from the first author, Hanna Kubiak, to the last one, Sylwia Wrona, all the authors have practical experience in the field they write about. Furthermore, it is clear that they are not indifferent to the problems they deal with. They write with great commitment (while fulfilling scientific standards), and at the same time present a special attitude towards people with disabilities, which can be called a humanistic attitude - which is also a great value of the entire study. Moreover, each chapter is a good overview of theoretical knowledge (unfortunately not very broad, which only proves that research on emotions should be intensified) and the

results of empirical research, illuminating the emotional life of children and youth with developmental dysfunctions from different angles.

The reviewed book is a collective work. This does not mean, however, that it consists of loose and chaotically connected chapters. The contribution of the editor of the book should be highlighted, i.e. she has organised the whole in a very coherent way. The first part of the study is devoted to the characteristics of different states and mechanisms of emotions – depression, anxiety, shame and other emotions. This part begins with a discussion of the now significant concept of attachment, which may be of exceptional importance when it comes to explaining and understanding the difficulties associated with the emotional development of people with disabilities in the future. The second part of the book is devoted to the analysis of emotional experiences of children and young people with different types of disabilities: chronically ill, mentally disabled, blind and partially sighted, with hearing loss and autism. Of course, this is not a complete list of all possible developmental dysfunctions, but those that have been discussed should be considered as the most significant. The layout of the book is logical and fully understandable.

To sum up, the book is a very valuable supplement to the existing psycho-pedagogical literature: a) it fulfils the needs of pedagogical practice for knowledge about the emotional functioning of children and young people with developmental disorders, b) the presentation of the results of research and theoretical theses related to emotions experienced by such people was carried out at a high scientific level (I would like to emphasize the objectivity and reliability of the conducted analyses), c) the study was well thought through by the editor, both as regards the selection of the authors invited to cooperate, as well as the layout of the chapters. The book as a whole is distinguished by a high scientific level and a thorough elaboration of the difficult issue of emotions experienced by people with developmental disorders.

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