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BEATA JACHIMCZAK



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Contents

Preface	5
ARTICLES	
ADAM MIKRUT	
'Reasonable accommodation' in the education of children and youth with disabilities – as based on the convention on the rights of persons with disabilities. Part 2	11
NAVA BAR	
The work process for the promotion of students with special needs integrated in the kindergartens of regular education: the case of Israel	31
IZABELA KAISER	
Leisure time of intellectually disabled children in the opinion of their parents	47
DIANA AKSAMIT	
Existential experiences of single mothers raising children with severe intellectual disability and their psychological, social and pedagogical determinants	63
KAROLINA KALISZEWSKA	
The process of adaptation to the role of a parent of a child with Down syndrome as a stress management strategy	79

ALEKSANDRA MACH	
From being a teenage mother to adult life according to a woman with intellectual disability	99
IWONA CHRZANOWSKA	
Special gerontology (geragogics) as the area of research and reflection for special pedagogics: Selected issues	117
IWONA MYŚLIWCZYK	
The analysis of the statements of nursing home workers on the perception and experience of adulthood by their charges	143
ANNA GUTOWSKA	
The Microworld of Differentness of Adults with Intellectual Disability: A Research Report	159
BEATA TYLEWSKA-NOWAK	
The life plans and dreams of residents of social care homes for people with intellectual disabilities	179
MAGDALENA HINC-WIRKUS	
‘Time Comprehension and Management Training’ in Everyday Activities for Persons with Moderate Intellectual Disabilities	195
TERESA WEJNER-JAWORSKA	
Dyslexia in adults and depression – in the perspective of a narrative of a participant of pedagogical therapy	223
IRENA RAMIK-MAŻEWSKA	
The work of people with deeper intellectual disability as a source of emancipation in the context of personal fulfilment	245
CONFERENCE REPORT	
BEATA TYLEWSKA-NOWAK, MARZENA BUCHNAT	
Report from the 14th Scientific conference. from the series. Discourses of Special Education “Disability versus changes – changes versus disability”	265
REVIEW	
JUSTYNA SOCHA	
Review of Barbara Winczura’s book entitled “Emocje dzieci i młodzieży z trudnościami w rozwoju i zachowaniu”, Oficyna Wydawnicza “Impuls”, Kraków 2017	273



Preface

We are proud to present you with the new volume of *Interdisciplinary Contexts of Special Pedagogy*, which covers reflections on issues ranging from the support provided to disabled people during their school education to the early and late adulthood. Such an arrangement seems reasonable taking into account the fact that in every phase of development, especially the juvenescence, school is a place where people try to find their identity based on their own reflections and the opinions of important persons from their environment. It is a significant place where they get information that enable them to assess their own intellectual and social abilities as well as professional predisposition influencing their further education and self-development¹. This volume starts with an article by A. Mikrut, which offers the continuation of the reflections started in the previous issue concerning the provisions of the Convention on the Rights of Persons with Disabilities ratified in 2012 in the context of the obligation to provide all disabled persons with the access to 'reasonable accommodation'. The author continues to analyse the support provided to students with special education needs *in the area of education law as well as practical examples of its application*². He

¹ Furmańska E., 'Samoocena i samoakceptacja we wczesnej adolescencji', *Edukacja i Dialog*, 2001, no. 1.

² All fragments of the text written in italics (selected by the editor) are quotations from abstracts prepared by the authors.

points out that *he managed to identify in the analysed area numerous solutions that comply with the spirit of 'reasonable accommodation'*. An article by N. Bar from Israel is, to a certain extent, a continuation of the analysis concerning the education system for disabled children. It contains a description of the work processes applied simultaneously in Israeli preschools. The first process is intended for students with special needs in mainstream preschools in the context of the early development support. The second one involves the work with a child which aims to prevent the necessity of referring them to special education. These processes reflect the change in the education law and in the educational practice within the Israeli system of education, which have become focused on the support for children with special education needs and their inclusion into mainstream preschools. I hope that the Reader will treat this article as an occasion to compare special and inclusive education systems in Poland and Israel. This part of the issue is closed by an article by I. Kaiser discussing the opinions of the parents of students with mild and moderate intellectual disability on the ways and importance of spending free time by their children. I hope that the results presented here will provoke reflection both among teachers as well as parents and therapists, who sometimes forget that the life of a disabled child is not only 'school and therapy'.

The second part of the theoretical and academic reflections is related to adults. The first three texts refer to the situation of parents in the context of upbringing a disabled child. On the one hand, one can conclude that a family bringing up a disabled child performs the same activities as all families, yet, on the other hand, its situation is specific, as it must face permanent stress and crisis. Its typical character is related to mechanisms that shape and affect it as well as tasks that it must perform. There is no difference between these tasks and the ones faced by all families. However, the consequences of the dissimilarity of a family with a disabled child analysed in the same contexts, that is, the systemic and relational approach, make it possible to formulate certain assumptions in the area of priorities. Disability of a child implies changes in the life of a family. It trans-

forms the patterns it follows and may lead to the increase of tensions and conflicts between family members. It therefore seems necessary to summon the internal adaptation abilities of a family, which involves mainly the transformation of the behavioural patterns of individual members as well as the change of the hierarchy of values or roles in the family in order to ensure effective adaptation to the experienced change³. D. Aksamit presents in its article *the accounts of mothers bringing up their adult children with profound intellectual disability, who represent motherhood that differs from the general model role of a mother and the model role of a woman*. K. Kaliszewska offers a theoretical analysis of the process of adapting to the role of a parent of a child with the Down syndrome. Referring to source literature, she shows how difficult, multi-stage and stress-inducing the process is both for the mother and for the father.

A. Mach presents a completely different look at parenthood. She refers to a case study concerning early motherhood and the growing up of an intellectually disabled woman.

The adulthood and the old age of disabled people is another area that is analysed in this issue. This part opens with an article by I. Chrzanowska, in which she makes *an attempt to analyse certain issues in the area of gerontology related to disabled people. The problems are analysed in the context of social ageing observed in Poland and in the world, particularly Europe. The selected areas of reflection are combined with the belief that it is necessary to conduct academic research that could fill the gap in the achievements of Polish special needs education in the area of research conducted to date on the issue of the broadly defined life situation of senior disabled persons*. Other texts presented in this issue prove that the adulthood appears in the research on special needs education much more frequently than the old age. I. Myśliwczyk presents study results based on the analysis of the narratives of nursing home workers. As she point out, the study *has revealed the*

³ See B. Jachimczak, 'Dydaktyczne i pozadydaktyczne uwarunkowania efektów nauczania indywidualnego dzieci przewlekle chorych'. *Impuls*, Cracow 2011, p. 60-61.

'subjective truth' about the functioning of intellectually disabled adults. The analysis of the narratives revealed workers' actions that can support, initiate and shape the lives of adults at the institution or impair their functioning to such an extent that they become passive, reserved and isolated. A. Gutowska tackled the issue of experiencing otherness by intellectually disabled adults. In her qualitative study results, she presented separate categories of otherness based on interviews with 14 intellectually disabled adults, participants of the District Mutual Aid House and their carers (parents and workers of the District Mutual Aid House). The article by B. Tylewska-Nowak is mainly devoted to the future plans and dreams of the residents of nursing homes for intellectually disabled persons.

The following two articles discuss the examples of therapeutic practice for adults. The first one – by M. Hinc-Wirkus – is a description of a case that involves the application of 'orientation and time management training' in a daily routine of a person with moderate intellectual disability. The second one – by T. Wejner – presents the issue of dyslexia and its influence on the occurrence of a depressive disorder in a young man, discussing the role of educational therapy.

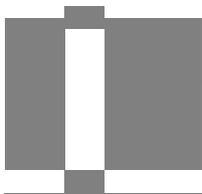
The entire reflection on the adulthood of a disabled person, their possibilities and limitations closes with an article by I. Ramik-Mażewska presenting work as a source of emancipation.

I am very grateful to the Authors for their research involvement and contribution to the dissemination of study and theoretical analysis results, and I hope that their work will inspire you for further research on the adulthood and old age of disabled persons. I also encourage all Readers to share their own research results in our magazine.

dr hab. prof. UAM Beata Jachimczak
Volume Editor



ARTICLES



‘Reasonable accommodation’ in the education of children and youth with disabilities – as based on the convention on the rights of persons with disabilities

Part 2

ABSTRACT: Adam Mikrut, *‘Reasonable accommodation’ in the education of children and youth with disabilities – as based on the convention on the rights of persons with disabilities*. Part 2. Interdisciplinary Contexts of Special Pedagogy, No. 17, Poznań 2017. Pp. 11-29. Adam Mickiewicz University Press. ISSN 2300-391X

The authorities of the Republic of Poland, by ratifying the Convention on the Rights of Persons with Disabilities, have undertaken the responsibility to implement such changes in the national legal order and in social policies that aim at ensuring full and equal enjoyment of all rights and freedoms by people with disabilities and preventing their discrimination in different aspects of life. One of the ways to fulfil this commitment is the ‘reasonable accommodation’. According to Article 2 of the Convention the term means ‘(...) necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden’ and its purpose is to reduce physical, technical or social barriers hindering or restricting the various roles and tasks of those affected by disorders in the structure or functions of the body.

The author of this article explored manifestations of such activities in the field of education laws and their practical application. He determined that in the analysed area, many solutions are in line with the spirit of the ‘reasonable accommodation’.

KEY WORDS: Convention on the Rights of Persons with Disabilities, reasonable accommodation, right to education

Introductory remarks

In the first part of this paper, published in the previous issue of *Interdisciplinary Contexts of Special Pedagogy*, the author explained the meaning of the term 'reasonable accommodation' used in the Convention on the Rights of Persons with Disabilities adopted on 13 December 2006 by the United Nations General Assembly (Resolution 61/106).¹ Let us remind that reasonable accommodation involves – as defined in Article 2 of the Convention –

'(...) necessary and appropriate modifications and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms'.²

He searched, and will search in this part of the text as well, for the elements of such reasonable accommodation in legal and organisational solutions concerning the exercise of disabled persons' right to education. It should be pointed out – which was already discussed in the previous part – that the paper was written after the Polish President signed the Education Act of 14 December 2016,³ which – pursuant to Article 1 of the Act on the Provisions Implementing the Education Act of 14 December 2016⁴ – comes into force, will enter into force, with a few exceptions (Article 18 and Article 47, and Chapter 6), on 1 September 2017. This means that solutions consistent with the idea of reasonable accommodation were sought after mainly with respect to the provisions of the current version of the Act on the Education System and the ministerial regulations

¹ *Convention on the Rights of Persons with Disabilities*, Journal of Laws of 2012, item 1169.

² *Convention on the Rights of Persons with Disabilities*, Journal of Laws of 2012, item 1169, Article 2.

³ *Education Law Act of 14 December 2016*, Dz. U. (Journal of Laws) of 2017, item 59.

⁴ *Implementing Provisions – Education Law Act of 14 December 2016*, Dz. U. (Journal of Laws) of 2017, item 60.

associated with this Act.Regulation.⁵ Solutions that involve reasonable accommodation discussed in the first part of this paper included, among other things: the adjustment of the preschool and school curriculum to the individual needs of children and students in the form of the so-called individual educational and therapeutic programme as well as the control of school performance. Below, the reader will find other numerous examples of the reasonable accommodation, incorporated in the Polish education law and its practical applications.

Elements of ‘reasonable accommodation’ in Polish education law – other examples and solutions

Aspects of ‘reasonable accommodation’ are also visible in the principles concerning lower secondary school final exams, secondary school final exams (Matura) and exams confirming vocational qualifications, defined in Chapter 3b of the Act on the Education System. The provisions of Article 44zw(1), (2) and (3) stipulate, respectively, that students with a special needs certificate issued due to moderate or severe intellectual disability do not have to take the lower secondary school final exam. A student with a relevant certificate issued due to multiple disabilities, none of which is an intellectual disability, can also be released from the obligation to take the exam or a part of it.⁶ A student holding a special needs certificate issued due to mild intellectual disability, who is taking a modern language exam and who continued to learn this language in lower secondary school in accordance with the requirements defined in the general education core curriculum, the analysed article provides for the release from the obligation to take this exam at the advanced

⁵ *Education System Act of 7 September 1991*, Dz. U. (Journal of Laws) of 2016, item 1943, 1954, 1985 and 2169 and of 2017, item 60, legislation in force as at 2 March 2017; www.prawo.vulcan.edu.pl 2 March 2017.

⁶ Article 44zw(1) of the Act states that students with multiple disabilities, including moderate or severe intellectual disability, do not take this exam.

level; however, they can take the exam at the request of their parents. Modern language is also the kind of educational course in relation to which the education law provides for the possibility of exemption from certain obligations related to the secondary school final exam. This situation is provided for in Article 44zzg(1). It says that a deaf student is relieved of the obligation to take the oral part of the exam. However, Section 2 of the above-mentioned article stipulates – which seems particularly important – that a speech-impaired student is released from the entire secondary school final exam.

Students and school leavers holding a special needs certificate can, due to their disability, take the above-mentioned lower secondary school final exam and secondary school final exam on conditions and in the form adjusted to the type of disability, as stipulated in Article 44zzr(1) of the Act. The manner of adjusting these forms was specified in Section 8 of the analysed article. Pursuant to this provision, it involved the preparation of separate examination sheets suitable for the type of disability of the person taking the exam, '(...) yet, no separate examination sheets are prepared for school leavers holding a special needs certificate issued due to mild intellectual disability'. The adjustment of the conditions of organising the lower secondary school final exam and the secondary school final exam involves, as defined in Section 10 of this article:

- '1) Minimising the limitations resulting from the disability (...);
- 2) Providing (...) a workplace suitable (...) for educational needs and psychophysical abilities;
- 3) Using appropriate specialist equipment and teaching resources;
- 4) Sufficient time extension (...);
- 5) Specifying the principles of evaluating solutions to tasks (...), taking into account educational needs and psychophysical abilities (of the person taking the exam – author's note);
- 6) Ensuring the presence and support during the exam (...) of an intervention teacher for a student or a school leaver to support them in reading and writing, or a specialist relevant for a given type of disability (...) if it is necessary for the proper communication with a stu-

dent or a school leaver, or support in the use of specialist equipment and teaching resources’.

It is worth mentioning that, pursuant to the provision of Article 44zzza(10) of the Act, the minister responsible for education specifies also, by virtue of a regulation, detailed conditions and manner of organising the discussed exams outside school if it is necessary due to the health condition or disability of the person taking the exam.

Elements of reasonable accommodation are also present in fragments of the Act that refer to an exam confirming vocational qualifications. Article 44zzzf(1) states that a student or a school leaver that holds a relevant special needs certificate issued due to their disability may take such an exam in conditions and in a form adjusted to the type of the disability. The adjustment of the form of the exam involves, pursuant to Section 7 of the discussed article, the preparation of separate exam sheets for a blind or visually impaired student, student, school leaver or a graduate. As regards the conditions in which such a person is taking the exam, they are analogous to the ones described above in relation to the lower secondary school final exam and the secondary school final exam, which is stipulated in points 1-5 of Section 8. Similar conditions – pursuant to Article 44zzzh(1) – are also ensured on the basis of a relevant medical certificate to blind, visually-impaired, deaf, hearing-impaired, physically disabled, including aphasia, mildly intellectually disabled or autistic (including those with the Asperger syndrome) persons who take the discussed exam after completing a qualifying vocational course or vocational training for adults, or job training for adults if the programme of such training met the requirements specified in the core curriculum for vocational education; or when conditions for the approval of external examination confirming vocational qualifications are met. Due to the health condition or disability of the person taking the exam confirming vocational qualifications, it can be organised outside a school, a facility or an employer’s premises or at the premises of the entity organising the qualification course under a relevant regulation of the minister issued in accordance with Article 44zzzv(8) of the Act.

The above-discussed adjustments of the manners and conditions of taking the lower secondary school final exam, the secondary school final exam or the vocational qualifications exam by disabled persons are to be implemented by the Central Examination Commission established under Article 9a(1) of the Act and by Regional Examination Commissions established by a relevant minister under Article 9c(1). The former is responsible for – as stipulated in Article 9a(2)(10)(a) of the Act – announcing detailed communications in this respect in *Biuletyn Informacji Publicznej* every year. Regional commissions use them as the basis for the organisation of these exam.

Reasonable accommodation is also reflected in certain regulations included in chapter 2 of the Education System Act entitled ‘Preschool education, schooling obligation and education obligation’. Pursuant to these regulations – Article 14(1) – in our country, preschool education obligation applies to children from the beginning of the school year in the calendar year in which they are 3 and lasts by the end of the calendar year in which they are 7. Children holding a special needs certificate – in accordance with Section 1a of the quoted article – may be subject to compulsory preschool education even if they are more than 7, but not longer than by the end of the calendar year in which they are 9. In such a case, the age at which such a child begins compulsory preschool education is ‘shifted’. Section 3a of the analysed article states that the obligation ‘(...) starts at the beginning of the calendar year preceding the school year in which the child begins to fulfil the schooling obligation’. Under Article 14a(4) of the Act, the legislator imposed on the commune (Polish *gmina*) the obligation to provide 5- and 6-year old disabled children subject to preschool compulsory education, but also those who are still subject to this obligation although they are seven years old, with free-of-charge transport and care during the travel to the nearest preschool or any other form of preschool education (day care facility), or to return the costs of the transport of the child and the carer if the transport is organised by parents.

The fact that a child holds a special education needs certificate may also – under Article 16a(1) of the Act – form the basis for the

postponement of the fulfilment of the schooling obligation, which, according to our education law, as specified in Article 15(2), '(...) starts at the beginning of the calendar year in which a child is 7 and lasts by the end of the lower secondary school, but not longer than by the age of 18', and the schooling obligation lasts – as stated in Article 15(1) – by the time the child is 18. The postponement cannot last longer than by the end of the school year in the calendar year in which the child is nine. It is worth mentioning here that, pursuant to the Regulation of the Minister of National Education of 24 July 2015,⁷ the education of disabled students may be continued by the end of the school year in which the student is, respectively: 1) 18, for primary school, 2) 21 – for lower secondary school and 3) 24 – for upper secondary school. The commune is obliged – as stipulated in Article 17(3a) of the Act – to provide a disabled student with a free-of-charge means of transport and relevant care during the travel to the nearest primary school and lower secondary school, and in the case of students with moderate or profound physical or intellectual disability – also to the upper secondary school, but not longer than by the age of 21, or to return the costs of transport and care if the service is provided by the parents.

Pursuant to Article 22(2) of the Act, the minister of education specifies, among other things, curriculum frameworks and core curricula by virtue of a regulation. Elements of reasonable accommodation are therefore also visible in ministerial documents issued in relation to it. It is expressed, among other things, in Article 2(1)(3) and (4) of the Regulation of the Minister of National Education of 7 February 2012 on Curriculum Frameworks in State Schools,⁸ which states that the curriculum defines, *inter alia*, the minimum number of hours and weekly number of hours of special therapy

⁷ *Regulation of the Minister of the National Education of 24 July 2015 on the conditions of organising the education and care for children and youth with disability, social maladjustment and at risk of social maladjustment* Dz. U. (Journal of Laws) of 2015, item 1113, Article 4.

⁸ *The Regulation of the Minister of National Education of 7 February 2012 on framework curricula in state schools*, Dz. U. (Journal of Laws) of 2012, item 204.

classes for disabled students at a given education level. In Appendix 1 to this Regulation⁹, it is stated that both in early school education and in grades 4-6 of the primary school, the minimum number of special therapy hours at an ordinary classroom setting is 190 hours per student, whereas the weekly number of special therapy hours per student in a school year is 2 hours. In Appendix 2¹⁰, on the other hand, it is stipulated that the minimum number of rehabilitation hours in grades 1-3 and grades 4-6 '(...) in the case of students with moderate or severe intellectual disability, including multiple disabilities if one of the disabilities is moderate or severe intellectual disability', attending a mainstream school is also 190 hours, while the weekly number of hours in each school year is also 2 hours per student. The same number of hours of rehabilitation classes in situations analogous to the above-mentioned ones are also stipulated in Appendix 3¹¹ concerning the curriculum in a three-year lower secondary school, including a special lower secondary school, Appendix 5¹² concerning the curriculum in a three-year lower secondary school for students with more severe intellectual disability (moderate or profound) and Appendix 6¹³ concerning a curriculum in

⁹ *Framework curriculum for primary school, including a special primary school, excluding a special primary school for children with moderate and profound intellectual disability*, Appendix 1 to the Regulation of the Minister of National Education of 7 February 2012 (item 204).

¹⁰ *Framework curriculum for special primary school for children with moderate and profound intellectual disability*, Appendix 2 to the Regulation of the Minister of National Education of 7 February 2012 (item 204).

¹¹ *Framework curriculum for lower secondary school, including a special lower secondary school, excluding a special lower secondary school for children with moderate and profound intellectual disability*, Appendix 3 to the Regulation of the Minister of National Education of 7 February 2012 (item 204).

¹² *Framework curriculum for special lower secondary school for children with moderate and profound intellectual disability*, Appendix 5 to the Regulation of the Minister of National Education of 7 February 2012 (item 204).

¹³ *Framework curriculum for basic vocational school, including special basic vocational school for students with disability, social maladjustment and at risk of social maladjustment*. Appendix 6 to the Regulation of the Minister of National Education of 7 February 2012 (item 204).

a three-year basic vocational school, including a special one. More diverse is the minimum number of hours of rehabilitation classes per disabled student in regular classroom settings of a three-year general secondary school (180 hours)¹⁴ and a four-year technical school (240 hours)¹⁵. In both cases, the weekly number of rehabilitation hours per one student in each school year is still 2 hours.

Concluding the issue of curricula and reasonable accommodation elements included in them, two important regulations are worth mentioning. Firstly – which we have already mentioned writing about the possible period of education of disabled children at individual education levels – pursuant to Article 5(1) of the analysed Regulation, for this category of students '(...) the period of education can be extended at every education level by one year, increasing the number of hours of obligatory education classes proportionally'. Pursuant to Article 5(2), a decision on the extension of education is made by the teachers' board. Secondly – notes no. 1 in Appendices 2 and 5 quoted above state that students with moderate and severe intellectual disability, including students with multiple disabilities if they include moderate or severe intellectual disability, attending a mainstream primary school or a mainstream lower secondary school, follow curricula designed especially for them rather than those intended for other students of the above-mentioned schools. In other words – they are not covered by curricula mentioned in Appendices 1 and 3.

Reasonable accommodation is reflected – in our opinion – by the approach to the issue of core curriculum. They are specified – as stipulated in Article 22(2)(2) and (2a) of the Act – by the minister of national education by virtue of a relevant Regulation. Generally, disabled students with normal intellectual ability as well as those

¹⁴ *Framework curriculum for general secondary school, including a special general secondary school for children with normal intellectual ability...*, Appendix 7 to the Regulation of the Minister of National Education of 7 February 2012 (item 204).

¹⁵ *Framework curriculum for secondary technical school, including a special general secondary school for children with normal intellectual ability...*, Appendix 8 to the Regulation of the Minister of National Education of 7 February 2012 (item 204).

with mild intellectual disability are covered by the same general education core curriculum for primary school, lower secondary school, basic vocational school, general secondary school, secondary technical school and post-secondary school as well as appropriate vocational education core curriculum as their able-bodied peers. However, the situation is different – which reflects the reasonable accommodation – in the case of children with moderate or severe intellectual disability. Pursuant to the Regulation of the Minister of Education of 27 August 2012, they are covered by a separate general education core curriculum in primary school and lower secondary school, specified in Appendix 3.¹⁶

Solutions concerning preschool education and education curricula for specific general educational classes and curricula for specific jobs seem to be less clear. They are selected in accordance with Article 22a of the Act, yet, the provisions included in it do not apply, among other things to disabled students, as defined in Section 8. Based on our previous reflections, we already know that an individual education and therapeutic programme developed for a given child or student with special education needs should contain information on the manner and scope of the proper adjustment of preschool education and the requirements from educational classes covered by the curriculum followed by the student. Suggestions included in the document published at the website of an education office imply that disabled students of mainstream schools,¹⁷ who are covered by the same curriculum as students with no intellectual disability follow a core curriculum applicable in given classroom settings, but properly adjusted to their needs and psychophysical abilities.¹⁸ We also know – which has been mentioned above – that

¹⁶ *Regulation of the Minister of Education of 27 August 2012 on preschool and general education core curriculum in different types of schools*, Dz. U. (Journal of Laws) of 2012, item 977.

¹⁷ The quoted document refers precisely to students with mild intellectual disability.

¹⁸ *Uczeń z orzeczeniem o potrzebie kształcenia specjalnego dla uczniów z upośledzeniem umysłowym w stopniu lekkim, pozostający w szkole ogólnodostępnej*, www.ko.rzeszow.pl/zalaczniki/dokumenty/0205200701.doc [accessed on: 17 III 2017].

separate core curricula for different types of schools were developed exclusively for students with more severe intellectual disability. Therefore, it seems that in respect to those who attend mainstream primary or lower secondary school, curricula developed for this category of students (put forward by the ministry or developed independently) should be adjusted individually.¹⁹

The title reasonable accommodation is, in our opinion, particularly visible in the statutory regulation concerning school handbooks and educational materials. They were specified in Article 22ab of the Act. Section 2(4) states that it is possible to include more than one handbook or educational material for a given education range in grades 1-3 or to given educational classes in higher grades into the set of handbooks and educational materials used in all classroom setting of a given school with respect to disabled students subject to special education in primary and secondary school, whereby – as specified in Section 3 – the team of teachers suggesting such a solution to the principal must take into account the educational needs and psychophysical abilities of these students. Due to the fact that such special education may take place in mainstream schools, the provisions cited here should be treated as ones that apply also to the principles of creating sets of school handbooks for children with disability attending these schools. At the level of primary school – as defined in Article 22ac(1) of the Act – they have a right, like their able-bodied peers, to use handbooks, educational materials or exercise materials free of charge in cases where they are intended for use during obligatory general education classes listed in the framework curriculum. If a school has got unused handbooks and educational materials adjusted to the educational needs and psychophysical abilities of disabled students, purchased from designated subsidy, they can be handed over to the principal of another school, as stated in Article 22ak(6) of the Act. This possibility pro-

¹⁹ See e.g.: *Program wychowania i nauczania dzieci i młodzieży upośledzonych umysłowo w stopniu umiarkowanym i znacznym*, Ministry of National Education (MEN), Warsaw 1997.

vides a chance to use to these resources by disable children that start attending a mainstream school during a school year, therefore they were not taken into account when a request for designated subsidy was formulated.

Pursuant to Article 22ae(1)(1)(3), schools are equipped with handbooks and materials by local government units at the request of public administration. The above-mentioned local government units receive adequate designated subsidy granted by the voivode under Section 3 of the analysed article. The subsequent Section 5 specifies detailed amounts per student by grades. As far as activities that can be identified as reasonable accommodation are concerned, regulations contained in Section 5a of Article 22ae are particularly important. It states values of indicators by which the amounts are multiplied for disabled students. These indicators have been specified as follows:

- 1) Not lower than 2 and not higher than 3 – in the case of students with intellectual disability, deaf, hearing-impaired, with autism, blind and visually-impaired, subject to points 2 and 3, holding a special needs certificate, provided that the students will use handbooks, educational materials and exercise materials adjusted to the education needs and psychophysical abilities of these students;
- 2) Not lower than 5 and not higher than 10 – in the case of visually-impaired students holding a special needs certificate, provided that the students will use handbooks, educational materials and exercise materials adjusted to the education needs and psychophysical abilities of these students, in large print;
- 3) Not lower than 10 and not higher than 25 – in the case of blind students holding a special needs certificate, provided that the students will use handbooks, educational materials and exercise materials adjusted to the education needs and psychophysical abilities of these students, printed in Braille'.²⁰

²⁰ Current regulations regarding the amount of designated subsidy for the purchase of handbooks for disabled students were signed on 16 March 2017, <https://men.gov.pl/strony/wskazniki-kwoty-dotacji-celowej-na-zakup-podrecznikow-dla-uczniowniepelnosprawnych-nowe-rozporzadzenia-podpisane> [accessed on: 20 III 2017].

One should mention at this point that, pursuant to Section 11 of the interpreted article of the Act, designated subsidy may be the source of financing for printing and producing handbooks as well as educational and exercise materials as well as purchasing devices used for these purposes. As opposed to children with special education needs, it can also be used to cover the costs of appropriate equipment and software required for the use of electronic handbooks and materials.

Handbooks are admitted for school purposes under terms specified in Article 22a of the Act by the minister of national education after obtaining a positive opinion of experts. Once the handbooks meet specified requirements, they are entered on relevant lists – which has been stipulated in Article 22a of the Act – at the website of the ministry.²¹ One should point out that the contents of the handbooks must comply with the current core curriculum, therefore those that become outdated can be used by teachers and students as auxiliary materials. At the same time, one should remember that disabled students who, in accordance with education legislation, follow the same core curriculum as their able-bodied peers may use current handbooks for mainstream schools.²² In practice, as Monika Gułubiew-Konieczna writes, students with mild intellectual disability attending mainstream schools use the same handbooks as their able-bodied peers.²³

Justification of funding to cover the costs of reasonable accommodation as part of education including disabled students

Education of disabled students requires greater funding than in the case of mainstream education. It results from the need for a spe-

²¹ <https://podreczniki.men.gov.pl/> [accessed on: 20 III 2017].

²² <https://men.gov.pl/zwiekszenie-szans/ksztalcenie-specjalne/informacja-o-podrecznikach-do-ksztalcenia-specjalnego.html> [accessed on: 20 III 2017].

²³ M. Gołubiew-Konieczna, *Edukacja uczniów z niepełnosprawnością intelektualną w świetle aktualnych przepisów prawa oświatowego*, Wydawnictwo Edukacyjne Akapit, Toruń 2006, p. 22.

cial organisation of the education process, taking into account technical conditions, methods and teaching resources relevant for the needs and abilities of such students, as well as establishing close and necessary social relations between the participants, including the cooperation with the family environment.²⁴ Analysing data concerning the way the part of the general education subsidy for local government units is divided in individual years, publicised by means of regulations of the minister of education, one can easily conclude that the provided weights reflect the evident care of the public authorities about the satisfaction of the development and education needs as well as the development of psychophysical abilities of students provided with special education, irrespective of where it is put into practice – in the conditions of segregation or non-segregation. As stated in an appendix to the above-mentioned regulation applicable also for 2017, these weights – reflecting, in fact, the multiplier of the outlays for the fulfilment of school tasks towards individual groups of students – may be as follows:

- P = 1.40 – for students with mild intellectual disability;
- P = 2.90 – for blind, visually-impaired students and students with physical disability, including aphasia;
- P = 3.60 – for deaf and hearing-impaired students and with moderate and severe intellectual disability;
- P = 9.50 – for children and youth with severe intellectual disability who fulfil their schooling obligation or education obligation by participating in rehabilitation and education classes organised by primary, lowers secondary and upper secondary schools as well as psychological and pedagogical counselling centres, for students with multiple disabilities and autism, including the Asperger syndrome.²⁵

²⁴ *Jak organizować edukację uczniów ze specjalnymi potrzebami edukacyjnymi?*, Ministry of National Education (MEN), Warsaw 2010, p. 90.

²⁵ Algorytm podziału części oświatowej subwencji ogólnej dla jednostek samorządu terytorialnego na rok 2017, *An appendix to the Regulation of the Minister of National Education on the manner of dividing the part of the general education subsidy for local*

At this point, there arises the question about the legitimacy of such preferences in the division of a given pool of money for the financing of education, namely whether it complies with the principle of social fairness. The author of this text has already made an attempt to answer such a question in a different place.²⁶ To this end, he referred, among other things, to the question teasingly posed by the authors of a characteristically entitled text: 'Integration as an Ethical Problem (Integracja problemem etycznym) ()', published in the collective work: *Integration of Children with Special Needs. Selected Ethical Issues (Integracja dzieci o specjalnych potrzebach. Wybrane zagadnienia etyczne)*. G. Fairbairn and S. Fairbairn wondered if it would not be better to increase the outlays on education for able-bodied students, following the principle that the most effective way to support 'weaker' members of the society is to help '(...) those that are well endowed, so that they could support less endowed ones'.²⁷ From this point of view, it is hard to call the above-mentioned method of dividing education resources fair, as many disabled people, especially those with more severe intellectual disability, will always be only participants in the division rather than the production of tangible goods. However, one cannot ignore the argumentation in favour of increased financing for special education based on the principle of social fairness understood – as stated by T. Sienkiewicz – as '(...) availability of services, creating equal opportunities

government units, <https://men.gov.pl/ministerstwo/informacje/podzial-czesci-oswiatowej-subwencji-ogolnej-w-2017-roku.html> [accessed on: 23 III 2017].

²⁶ See: A. Mikrut, 'O wątpliwościach moralnych wokół argumentowania i urzeczywistniania idei edukacji integracyjnej', *Wychowanie na co Dzień* 2015 no. 3, p. 24-29; A. Mikrut, 'Reflection of Inclusive Education in Ethic', [in:] *Reflection of Inclusive Education of the 21st Century in Correlative Scientific Fields (How to Turn Risks into Chances)*, ed. V. Lechta, B. Kudláčová, International Academic Publishers, Frankfurt am Main; Peter Lang; Veda. Publishing House of the Slovak Academy of Sciences Bratislava, Bratislava 2013, p. 54-60.

²⁷ G. Fairbairn, S. Fairbairn, 'Intergracja problemem etycznym', [in] *Integracja dzieci o specjalnych potrzebach. Wybrane zagadnienia etyczne*, ed. G Fairbairn, S. Fairbairn, Centrum Metodyczne Pomocy Psychologiczno-Pedagogicznej MEN, Warsaw 2000, p. 16 (translation: A. Fus, W. Tabisz).

and protecting weaker individuals'.²⁸ Following this way of thinking, social fairness is therefore expressed, among other things, by facilitating '(...) the access to various goods and services, including the discussed education, to persons with low internal and environmental resources (weak, ill, disables, lost or helpless in the face of the challenges of modern world and socially excluded)'.²⁹ Taking into account the fact that disabled persons are characterised – to a lesser or greater extent – by limitations concerning these resources, one can easily conclude that any actions to reduce these limitations should not be treated as favouring certain persons at the expense of others, but as a reasonably understood social fairness. It is the lack of such actions that should be considered unfair, as such a situation would widen the gap between educational opportunities of able-bodied persons and those with various kinds of body functions and/or structure disorders. After all, there are no doubts as to the fact that the former will naturally be in a privileged position in this respect.³⁰

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²⁸ After: B. Szczupał, *Prawa osób niepełnosprawnych w aspekcie realizacji zasad sprawiedliwości społecznej*, [in:] *Rozwój i funkcjonowanie osób niepełnosprawnych. Konteksty edukacyjne i prawne*, ed. Z. Gajdzica, *Impuls*, Kraków 2005, p. 182.

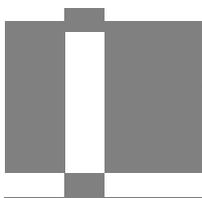
²⁹ A. Mikrut, 'Reflection of Inclusive Education in Ethic', [in:] *Reflection of Inclusive Education of the 21st Century in Correlative Scientific Fields (How to Turn Risks into Chances)*, ed. V. Lechta, B. Kudláčová, International Academic Publishers, Frankfurt am Main; Peter Lang; Veda. Publishing House of the Slovak Academy of Sciences Bratislava, Bratislava 2013, p. 55-56.

³⁰ A. Mikrut, 'O wątpliwościach moralnych wokół argumentowania i urzeczywistniania idei edukacji integracyjnej', *Wychowanie na co dzień*, 2015, no. 3, p. 27.

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The work process for the promotion of students with special needs integrated in the kindergartens of regular education: the case of Israel

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The Special Education Law in Israel was legislated on July 12, 1988. The law determined precedence and advance preference for the placement of special needs students in the regular educational system over the special education system. In the spirit of the law, methodical and painstaking processes that arrange the work with special needs students in the educational system were determined. This article presents two work processes implemented in parallel in the regular kindergartens. The first work process is with students who have functional difficulties, before their definition and as prevention of their definition as students with special needs. The second process is the work process with the special needs students who are integrated in the regular kindergartens, intended to prevent their referral to frameworks of special education. These processes reflect the development that occurred in the importance ascribed in the educational system in Israel to careful and adjusted work with students who have difficulties and special needs and are integrated in the kindergartens of regular education. Alongside the described development, the article presents the challenges and the questions that the implementation of the processes poses.

KEY WORDS: kindergarten; students with functional difficulties; students with special needs; work process

Special Education in Israel

The Israeli educational system was founded in the In the late 1980s, in a gradual process of implementation of the assimilation of the approach that emphasizes the rights of the students with special needs and their integration in one educational system with their peers members of the same age group¹. As part of this approach, special attention has been given to the development of a continuum of educational frameworks based on the principle of the least restrictive environment (LRE)². The continuum of frameworks is intended to provide an appropriate solution to the needs of the diverse population of students with special needs³. The assumption is that this population is diverse in terms of the severity of disabilities and in terms of the student's needs; therefore as the framework is more separate, the services given there to the student will be more comprehensive⁴. The continuum of educational frameworks for students with special needs ranges in Israel from special education kindergartens from age three⁵ and special education schools till age twenty-one; special classes in the regular schools; and inclusion in regular kindergartens and in regular classes in schools of regular

¹ G. Avissar, *Inclusion and accessibility: Curriculum planning and implementation for students with disabilities*, Mofet Institute, Tel Aviv, 2010; N. Bar, A. Kizel, On the continuum from mainstreaming to inclusion: The development of the approaches towards students with special needs and their expression in the educational frameworks in Israel, *Interdisciplinary contexts of Special Pedagogy*, 2016, 11. pp. 161-188; M. Marom, K. Bar-Simon Tov, A. Kron, P. Koren, *Inclusion of special needs children in the regular educational system: A review of the literature*, The Center for the Research of Social Policy in Israel Press, Jerusalem, 2006.

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⁵ The students with severe disabilities are referred to special education kindergartens from age three by the medical services in the community.

education. The inclusion framework operates according to the model of full inclusion, in which students with different functioning levels study in a shared scholastic space, having full partnership with the peer group. The guiding principle in the placement of the student with special needs into one of the frameworks is the placement into an environment that will limit the student's development the least according to the LRE principle⁶. In addition, the placement of the student with special needs into one of the frameworks is realized only after it has been found that the support and services given to the student in the framework in which he learned, based on the severity of the disability, do not allow to provide him with effective education⁷.

A significant step in the development of special education in Israel was the legislation of the Special Education Law on July 12, 1988⁸. The Law determined precedence and advance preference of the regular educational system over the special education system, assuming that a student with special needs who will be integrated, as much as possible, in regular education will be ready for full integration in society outside of the areas of the educational system⁹. An example can be found in the statement published in the Circular of the general director of the Ministry of Education on June 2013:

“One of the touchstones of the educational system in Israel is its ability and willingness to provide an appropriate educational-scholastic solution for the special needs of students who find it difficult to adjust in scholastic or social terms to the norms accepted in the regular education framework, and to avoid, to the extent possible, their referral to the special education frameworks”¹⁰.

⁶ P. Klein, V., Sobelman-Rozental, *Together and alone: Integrating children with special needs into regular educational frameworks in the Early Childhood*. Reches Publishers, Even Yehuda, 2000.

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¹⁰ Circular of the Director General: *The mainstreaming program in the regular education frameworks for dealing with students with special needs who learn in the regular*

In the spirit of the Special Education Law and the perception on which the law relies, methodical and painstaking processes that arrange the work with special needs students in the educational system were determined.

The Work Processes with Students with Functional Difficulties in the Kindergarten

The composition of the population in the kindergarten is heterogeneous (for the most part) and contains children whose characteristics, abilities, and difficulties are varied. In every kindergarten there are usually a few children who have difficulties. Their difficulties can arise from various sources (biological, environmental) and can be expressed in varying degrees of severity, ranging from temporary and transient difficulties to persistent difficulties. Some of them constitute a basis for deficiencies that will appear in a later stage¹¹. Studies indicate that there is a connection between developmental problems in early childhood and subsequent behavioral problems and social difficulties¹². Two structured and systematic processes are held in parallel in the kindergarten in Israel for the treatment of students with difficulties aged three to six – the work process with students who have functional difficulties and the work process with the special needs students who are integrated in the

classes and in the special education classes. Ministry of Education, Jerusalem, June 1, 2003, 10(b).

¹¹ “Mabatim” (Looks), *Guidance booklet for assessment and observation in kindergartens for the in-depth Familiarity of children.* Ministry of Education, Jerusalem 2016.

¹² M. H. Cantell, T. P. Ahonen, M. M. Smyth, *Clumsiness in adolescence: Educational, motor, and social outcomes of motordelay detected at 5 years.* Adapted Physical Activity Quarterly, 1994, 11, pp. 115-129; A. J. Reynolds, J. A. Temple, D. L. Robertson, E. A. Mann, *Long-term effects of an early childhood intervention on educational achievement and juvenile arrest: A 15-year follow-up of low-income children in public schools.* JAMA, 2001, 285(18), pp. 2339-2346.

regular kindergartens, in order to prevent their referral to the framework of special education. The processes reflect the efforts invested in the identification and support of students with functional difficulties, out of the understanding that the period of childhood is critical in the child's development¹³. Many studies emphasize the importance of the first years in the child's life as a significant period of development, in which he develops the basis for various skills, shaping his personality and especially his cognitive development¹⁴. Moreover, studies indicate that early identification and intervention in cases of developmental delays and developmental difficulties may affect the development and learning of children in the early childhood¹⁵, especially in the first and two years after completion of the intervention program¹⁶. They may reduce future problems in skills and functioning in various areas such as cognitive functioning, social skills, and academic achievement¹⁷. Gitanjali, Scott-Little, and Clifford (2000) emphasize that early identification and adjusted interventions at this age, for those who need it, may

¹³ L. M. Anderson, C. Shinn, M. T. Fullilove, S. C. Scrimshaw, J. E. Fielding, J. Normand, V. G. Carande-Keulis, *The effectiveness of early childhood development programs*. American Journal of Preventive Medicine, 2003, 24(3), pp. 32-46; P. Klein, V. Sobelman-Rozental, *Together and alone*.

¹⁴ S. W. Bijou, *Development in the preschool years: A functional analysis*, American Psychologist, Aug 1975, 30(8), pp. 829-837; L. A. Karoly, M. R. Kilburn, J. S. Cannon, *Early childhood interventions: Proven results, future promise*, Rand Corporation, California 2005.

¹⁵ M. B. Bruder, *Early childhood intervention: A promise to children and families for their future*, Exceptional Children, 2010, 76(3), 339-355; M. J. Guralnik, *Effectiveness of early intervention for vulnerable children: A developmental perspective*. American Journal on Mental Retardation, 1998, 102(4), pp. 319-345.

¹⁶ J. Leak, G. J. Duncan, W. Li, K. Magnuson, H. Schindler, H. Yoshikawa, *Is timing everything? How early childhood education program impacts vary by starting age, program duration and time since the end of the program*. Presented at the association for policy analysis and management meetings, Boston, MA, November 4-6, 2010.

¹⁷ G. Camilli, S. Vargas, S. Ryan, W. S. Barnett, *Metaanalysis of the effects of early education interventions on cognitive and social development*. Teachers College Record, 2010, 112(3), pp. 579-620.

enable the prevention of the emergence of social-emotional difficulties, the prevention of the creation of gaps in relation to peers; the prevention or reduction of the severity of difficulties in functioning; the realization of abilities that are not expressed spontaneously¹⁸ and the increase, for some of the students, of the chances of remaining in the regular education.

The starting point of the work processes with students who have difficulties is the view of every student as an individual, and it is expressed in the identification of the student's difficulties and the response to his special needs through the construction and implementation of a personal educational intervention program. In the implementation of the work process with students who have functional difficulties, all the educational staff in the kindergarten is partners, under the leadership of the kindergarten teacher, with the support of the kindergarten psychologist, and with a regular dialogue with the student's parents. The process begins with a functional assessment conducted by the kindergarten teacher for all the kindergarten students aged three to four, at the beginning of the school year. The assessment is performed according to the program of the Ministry of Education called 'Mabatim' (Looks)¹⁹, with each student in an individual manner. The goal of the assessment is to identify the students' difficulties in the different areas of performance - cognitive, lingual, motor, sensory, social, and emotional. On the basis of the assessment performed, students with functional difficulties who need support adjusted to their needs are identified. The initial identification of each student's abilities is essential in any individual work plan²⁰. Based on the assessment, personal interven-

¹⁸ S. Gitanjali, C. Scott-Little, R. M. Clifford, *Readiness for school: A survey of state policies and definitions*. *Early Childhood Research and Practice*, 2000, 2(2), pp. 1-18; M. J. Guralnik, *Effectiveness of early intervention for vulnerable children: A developmental perspective*. *American Journal on Mental Retardation*, 1998, 102(4). pp. 319-345.

¹⁹ "Mabatim" (Looks), *Guidance booklet for assessment and observation in kindergartens*.

²⁰ S. Bagnato, *Authentic assessment for early childhood intervention best practices*, Guilford Press, New York 2007.

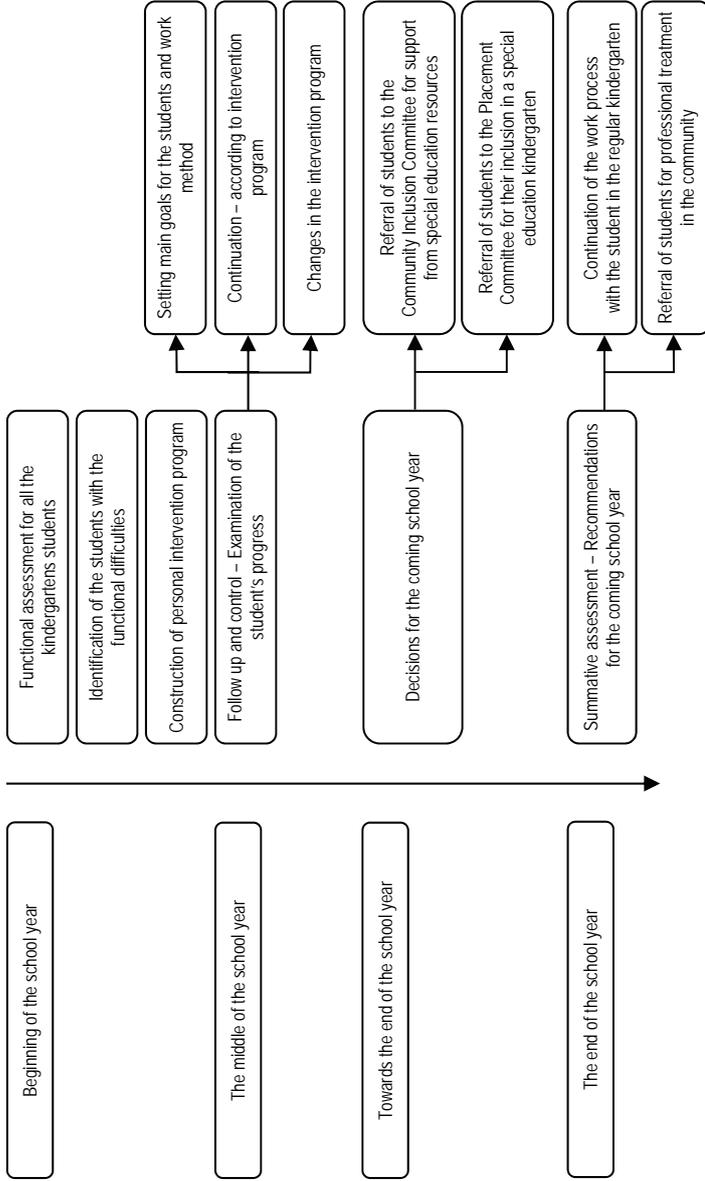
tion programs are built by the kindergarten teacher for the students with functional difficulties. Main goals are defined and the ways of work of the educational staff with the students are determined in the individual, group, or full kindergarten class setting. The intervention program includes various kinds of interventions, for example: using visual means for a student who has difficulty in the understanding of the language; supporting the student who has difficulty in moving from activity to activity; choosing a suitable composition for group work, and more. In addition to the interventions provided by the kindergarten teacher, in cases where additional intervention is needed, the children will be referred to the diagnostic-therapeutic systems in the community. A significant component of the intervention program is its activation in the child's natural environment²¹.

In the middle of the year, processes of follow up and control are conducted for the examination of the student's progress according to the intervention program, and changes are made as necessary, so as to provide an adjusted solution to the student and to promote the student in the kindergarten framework. In this stage, decision is made about the students, in the Community Inclusion Committee, subject to their parents' consent and with their participation in the meeting²². The committee will determine the entitlement of the student in the coming school year for support in the kindergarten framework from the resources of special education including support from special education staff members. The Community Inclusion Committee operates according to the Special Education Law, under the leadership of the Ministry of Education kindergartens

²¹ M. B. Bruder, *Early childhood intervention*; R. M. Vilaseca, M. J. Del Rio, *Language acquisition by children with Down syndrome: A naturalistic approach to assisting language acquisition*. Child Language Teaching and Therapy, 2004, 20, p. 163-180.

²² *The Special Education Law 5762-2002 (Amendment No. 7)*, State of Israel, 2002; Circular of the Director General: *The implementation of the Special Education Law: Institutional mainstreaming committee, placement committee sitting for appeals against the mainstreaming committee, placement committee, and appeals committee*, Ministry of Education, Jerusalem, January 1, 2014, 15(a).

Table 1. The work processes with students with functional difficulties in the kindergarten led by the homeroom kindergarten teacher



supervisor. The Committee decisions are based on an acceptable assessment performed for the student by an educational psychologist or developmental doctor who defines the student as a student with special needs. The Inclusion Committee discusses only students for whom the regular educational framework has realized all of its possible educational interventions with them²³.

Towards the end of the year, a number of decisions are taken, with the involvement of the parents, about the kindergarten students for whom a personal intervention program was prepared during the year. One decision is made by the Community Inclusion Committee that convenes and determines which students will be entitled to support from the resources of special education in the coming school year in the regular kindergarten²⁴. A second decision is made about a very few students, who have especially prominent difficulties, about their referral to the Placement Committee for their inclusion in a special education kindergarten in the coming school year. Such a decision will be made only after the examination that all educational interventions with the students in the regular education framework were realized completely²⁵. At the end of the school year, a summative assessment is performed for the students, in accordance with the goals set for them in the intervention program. In this stage, recommendations are given for the continuation of work with the students in the regular kindergarten in the coming school year, as well as recommendations for the referral of students for treatment from different professional factors in the community, such as paramedical therapists. Table 1 describes the presented work processes with students with functional difficulties in the kindergarten led by the homeroom kindergarten teacher.

²³ Circular of the Director General: *The implementation of the Special Education Law*, January 1, 2014, 15(a).

²⁴ Circular of the Director General: *The implementation of the Special Education Law*, January 1, 2014, 15(a).

²⁵ Circular of the Director General: *The implementation of the Special Education Law*, January 1, 2014, 15(a).

The Work Processes with Students with Special Needs in the Kindergarten

Two models are applied in Israel for the inclusion of students from kindergartens that are defined as having special needs by the Community Inclusion Committee (called in Israel 'inclusion students'). The common model is the inclusion of students with mild disabilities in the regular kindergartens and the support of them by the special education kindergarten teacher, two to three hours per week, in an individualized manner or in small learning groups, inside or outside of the kindergarten class. The main teaching of these students continues to be held by the kindergarten teacher who was not trained for special education. For the most part, the special education kindergarten teacher works with the student outside of the homeroom class. The aspiration is to work with the student in his natural environment, in the space of the kindergarten, with members of the age group, and also to enable the modeling for the kindergarten teacher of adjusted work with the student who has special needs. The second model, which is not common for budgetary reasons, is the 'inclusive kindergartens' in which a number of students with special needs, generally up to eight, study along with 'regular' students. In these kindergartens there are two teachers: the homeroom kindergarten teacher and the special education kindergarten teacher. The teaching curriculum is determined by both teachers. Some of the kindergarten activities are together with all the children and in some of the activities the students with special needs learn separately with the special education kindergarten teacher. The goal is to integrate the students with the special needs in all the kindergarten class activities²⁶. A few students, integrated into the kindergarten that operates according to both models, receive treatment totaling one weekly hour from an occupational therapist, speech therapist, or therapist in the emotional area. Studies indicate that there is a direct connection between the emotional-

²⁶ P. Klein, V. Sobelman-Rozental, *Together and alone*.

social functioning and the child's effective adaptation, his sense of well-being, scholastic success, and the development of a proper relationship between the teacher and the student in the future²⁷. These studies highlight the importance of emotional treatment for the kindergarten students who need it.

The work process with the special needs students, in each of the models, is conducted in parallel to the process led by the kindergarten teacher with the students with functional difficulties. The work of the special education kindergarten teacher is based on the collection of comprehensive data on every student at the start of the year; a conversation for acquaintanceship with the parents; observations of the student in the kindergarten at different times and during different activities that enable expression of the varied behavior of the students in daily routines according to their abilities and difficulties²⁸; and a personal examination for the student in the different areas of functioning. All these lead to the construction of an individual educational program, as required under the Special Education Law²⁹, with the participation of the kindergarten teacher, the kindergarten psychologist, and the student's parents. During the construction of an individual educational program the goals of the work with the student are determined. The special education kindergarten teacher holds a continuous relationship with the kindergarten teacher and with the paramedical therapists from the community, if there are, for the creation of continuity with the treatment held outside of the kindergarten space. In the middle of the year, formative assessment is held to examine the progress of the special needs student³⁰. For the few who are intended to go to the school in

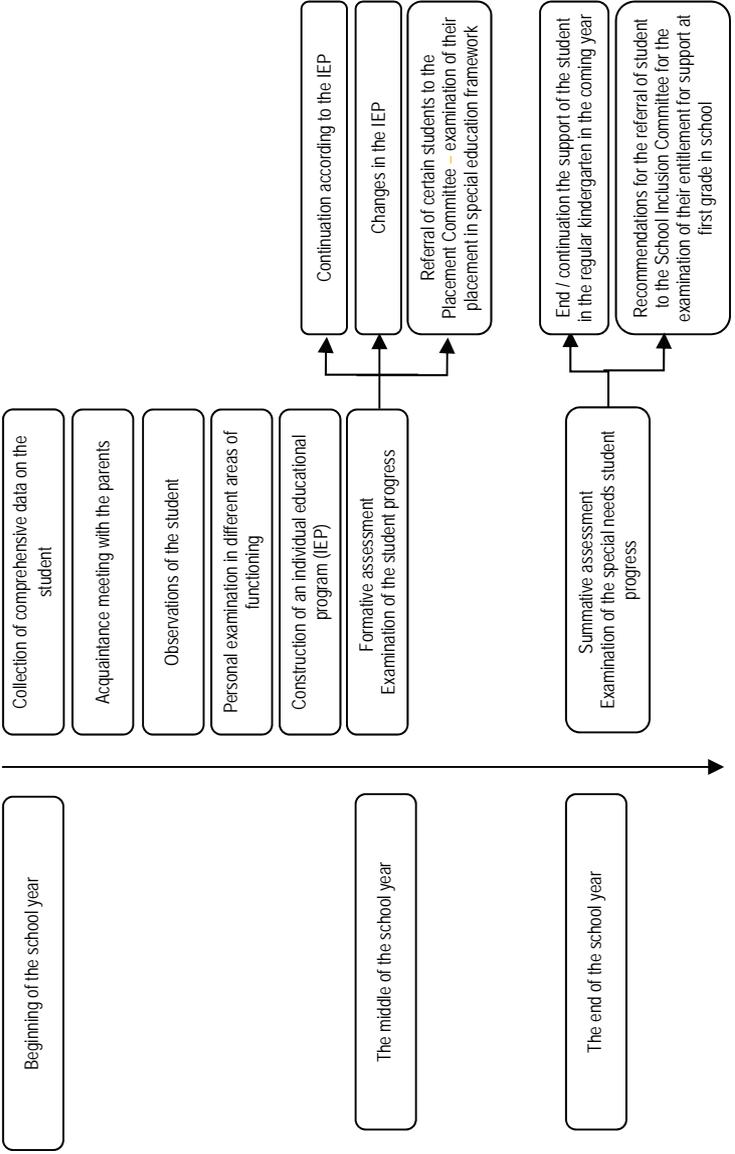
²⁷ C. Blair, *school readiness integrating cognition and emotion in a neurobiological conceptualization of children's functioning at school entry*. *American Psychologist*, February 2002, 57(2), pp. 111-127; P. A. Graziano, R. D. Reavis, S. P. Keane, S. D. Calkins, *The role of emotion regulation in children's early academic success*. *Journal of School Psychology*, 2007, 45, pp. 3-19.

²⁸ S. Bagnato, *Authentic assessment for early childhood intervention*.

²⁹ *The Special Education Law 5762-2002 (Amendment No. 7)*, State of Israel, 2002.

³⁰ Circular of the Director General: *The implementation of the Special Education Law*, January 1, 2014, 15(a).

Table 2. The work processes with students with special needs in the kindergarten



the coming school year, decisions are made about their referral to the Placement Committee for the examination of the possibility of their placement in the special education class in the regular school or their placement in the special education school³¹. At the end of the year, a process of summative assessment is held for the examination of the student's progress. Accordingly, recommendations for the continuation are made, to end or to continue the support of the student from the resources of special education in the coming school year in the kindergarten³². For those who are intended to go to school, there are recommendations for the absorbing schools for the referral of certain students to the School Inclusion Committee at the start of the first grade to obtain entitlement for support from the resources of special education in the school. Throughout the entire process described, the student's progress is painstakingly examined, with a dynamic view of the program built for him, and necessary changes are introduced in it according to the need, and with the parents' involvement in their child's progress and the decisions made on his matter. Table 2 describes the presented work processes with students with special needs in the kindergarten.

Summary – Developments, Challenges and questions

The described process reflects the development that occurred in the importance ascribed in the educational system in Israel to careful and adjusted work with students who have difficulties and special needs and are integrated in the kindergartens of regular education. The determination that the student will not be entitled to support from the special education services unless it is proved that all interventions with him in the framework of regular education were realized indicates the caution adopted by the educational system in

³¹ Circular of the Director General: *The implementation of the Special Education Law*, January 1, 2014, 15(a).

³² Circular of the Director General: *The implementation of the Special Education Law*, January 1, 2014, 15(a).

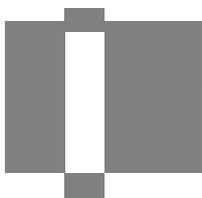
the definition of the child as having special needs. It also indicates the transfer of the responsibility to the kindergarten teacher for the early stage identification of students with difficulties, the construction of adjustment programs for them, and the implementation of these programs. The emphasis placed today on the involvement of the entire staff and the parents in the implementation of the personal programs creates shared responsibility and focuses the work of all on the adjusted goals determined for work with the student. Alongside these perceptual developments, the kindergarten staff copes with a number of challenges. The limited special education resources make it difficult to provide appropriate support for students with special needs who are integrated in the kindergartens, and the special education kindergarten teacher finds herself working a limited number of weekly hours with her special needs students. Moreover, support from the special education kindergarten teacher is given to students with the lowest functioning in the kindergarten, thus delaying the advancement of other students who have difficulties. In addition, the main support provided to the students is of the type of teaching, while there are students who need support in other or additional areas, such as the motor and emotional-social areas, for whom there is mostly no answer, so the gap in development of some of the students may increase. Likewise, alongside the perceptual developments and methodical processes implemented in the kindergartens of regular education in Israel, a number of questions are addressed. Does the kindergarten teacher perceive herself as responsible for the special needs student integrated in the kindergarten? Does the kindergarten teacher have the knowledge and instruments for the advancement of the special need students and, are they sufficient for the prevention of the students' referral to the framework of special education?

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Leisure time of intellectually disabled children in the opinion of their parents

ABSTRACT: Izabela Kaiser, *Leisure time of intellectually disabled children in the opinion of their parents*. Interdisciplinary Contexts of Special Pedagogy, No. 17, Poznań 2017. Pp. 47-62. Adam Mickiewicz University Press. ISSN 2300-391X

Objective of the study: The study aims at diagnosing the opinions of parents of children with minor and moderate intellectual disabilities on the forms and significance of leisure time behaviour.

Materials and methods: The study was conducted in 2017 among the parents of students of the Maria Montessori Special Primary School at the 102nd Special School Complex in Poznań. The author's own research questionnaire was used, containing questions about forms of spending free time, the amount of free time available and the participation of children in extracurricular classes and out-of-school activities, as perceived by parents.

Results: The majority of parent respondents, regardless of the degree of their children's disability, stated that their children had a lot of free time, at least two hours per day on weekdays and over six hours per day during the weekend. In the perception of most parents, during summer and winter holidays their children have whole days free. The respondents notice both active and passive forms of leisure activities pursued by their sons and daughters. The parents confirmed the participation of their children in numerous extracurricular classes and out-of-school activities.

The study revealed that parents, siblings, or other family members were most often partners of leisure for intellectually disabled children. All the respondents declare that they know what their children are doing in their leisure time and who they spend it with.

KEY WORDS: family, leisure time, free time, intellectual disability

Introduction

In contemporary civilisation, leisure time is one of the highest-rated values that influences one's personality and is decisive for one's quality of life. Its volume is treated as an important determinant of social well-being, cultural development, even the level of health in specific countries or social groups.

The volume of leisure time rising day to day forces not only the individual, but also the entire society to gain interest in new areas of human activity that will encompass this expanding volume¹. Rational management of leisure time, after all, influences the broad development of one's personality, the improvement of physical fitness, relieves conditions of emotional tension, serves the restoration of one's physical and psychological power.

Issues related to the filling and appropriate utilisation of free time are becoming a key social problem. In the modern family, coping more often than not with financial and organisation problems, the rational solution to the issue of leisure time is not easy. In many family circles, it can be observed that this issue does not enjoy any interest. Not all parents understand the profits stemming from correct usage of leisure time and the role it plays in the development of a child's personality. A. Jegier² indicates with fear the ever-often observed social phenomena referred to as the „managed child syndrome” or the „child neglected through wealth”.

Activities undertaken during leisure time, in particular their developmental and revalidation-relevant aspects, should be analysed in detail within the framework of oligophrenopaedagogy. The understanding that the development of intellectually-disabled persons must be comprehensive is becoming ever more common. One thus cannot speak of social adaptation of such individuals with consid-

¹ K. Czajkowski, *Wychowanie do rekreacji*, Wydawnictwa Szkolne i Pedagogiczne, Warszawa 1979.

² A. Jegier, *Wprowadzenie*, [in:] *Czas wolny małych dzieci w świecie realnym i wirtualnym*, ed. by A. Jegier, Difin SA, Warszawa 2016.

eration for one of the most basic levels of the revalidation process, which is rational consumption of leisure time.

Within the context of issues indicated as such, it seems significant for the obtaining of the opinion of parents concerning the leisure time of their intellectually disabled child seems to be of importance.

Leisure time of an intellectually-disabled child

The leisure time of a child differs from the leisure time of an adult. It must differ, as the socio-economic situation of a child and of an adult is different. Activities undertaken during leisure time of a young individual are subject, and should be subject, to control of parents or educators due to the fact that the child is characterised by lack of psychological maturity and limited experience³.

Within special education, it is accepted that the leisure time of intellectually-disabled persons is that time of day, which following the consideration of time spent learning at school or one's professional duties, regular regeneration of the body and special rehabilitation activities, with the addition of necessary duties around the house, remains for their sole disposal and thus may be a period of individual choices concerning the types and areas of activities related to relaxation, entertainment and the satisfaction of personal interests⁴. One needs to remember that the volume of leisure time that

³ K. Czajkowski, *Wychowanie do rekreacji*, WSiP, Warszawa 1979.

⁴ H. Borzyszkowska, *Zajęcia pozalekcyjne i poza szkolne oraz czas wolny dzieci upośledzonych umysłowo*, [in:] *Upośledzenie umysłowe, pedagogika*, ed. by K. Kirejczyk, PWN, Warszawa 1981, chapter 14; L. Ploch, *Jak organizować czas wolny dzieci i młodzieży upośledzonych umysłowo*, WSiP, Warszawa, 1992; M. Parchomiuk, *Sposoby spędzania czasu wolnego przez młodzież upośledzona umysłowo w stopniu lekkim i sprawną umysłowo*, „Wychowanie Na co Dzień” 2000, no. 4/5 pp. 13-16; T. Żółkowska, *Aktywność pozadydaktyczna uczniów z lekkim stopniem upośledzenia umysłowego a poziom opieki rodziców nad ich czasem wolnym*, „Zeszyty Naukowe. Prace Instytutu Pedagogiki i Psychologii” 1995, no. 21, pp. 115-128; J. Zimny, *Czas wolny wyzwaniem rodziny w kształtowaniu osobowości osób niepełnosprawnych*, [in:] *Rodzina w oczach społeczeństwa*,

children with limited intellectual abilities have is reduced as a result of participation in various additional activities spanning revalidation, such as speech therapy, rehabilitation, physical corrective exercises or reeducation. In addition, due to impairments in mental development, the lack of life experiences, social immaturity, these children are more dependent on their parents or caretakers. As a consequence, they are not at full liberty to design their leisure time as they please.

With respect to the intellectually disabled, L. Ploch⁵ notes four aspects of leisure time:

- the educational and psychological aspect; well-organised leisure time may aid in intellectual, moral, societal and physical development, simplifies social relations and experiences, creates opportunities to get to know and understand the surrounding world; awakens the need of cooperation with others, enriches the individual intellectually;
- the care aspect, meaning, support of comprehensive development of an individual, providing support in terms of security, health, prevention of difficulties and failures and the improvement of one's environment of life;
- the hygiene and health aspect; the mode of spending leisure time very clearly influences the psychological and physical relaxation of the body;
- the revalidation aspect, understood as creation of situations, in which persons with limited intellectual abilities must show initiative, activity and the ability to arrange their additional activities on their own.

L. Ploch further notes that „it may be inferred that the high significance of leisure time with respect to education, one's psychological condition, care and re-validation, is related to the interconnec-

ed. by J. Zimny, Katolicki Uniwersytet Lubelski Jana Pawła II w Lublinie, Stalowa Wola 2013, pp. 9-27.

⁵ L. Ploch, *Jak organizować czas wolny dzieci i młodzieży upośledzonych umysłowo*, WSiP, Warszawa 1992.

tion of the operative and cognitive side of the education process within free and unhindered co-activity with the motivation side of the intellectually disabled”⁶.

The role of the family in the shaping of forms of spending leisure time

The influence of the social environment on an individual occurs in course of the process of socialisation. It is understandable that this environment – depending on the prevailing norms, standards, value systems, customs, habits, attitudes or convictions – may exert a positive or negative influence on the life style of an individual.

The original, primary group that plays the basic role in socialisation is the family. As the natural environment, it has great possibilities, among others, spanning the analysed preparation of the child for rational usage of leisure time, e. g. by encouragement to physical activity, through personal attitude, transfer of sports skills, creation of conditions of participation in family entertainment, enabling the use of recreation and culture facilities. The family teaches one to make choices, shapes interests and habits in terms of recreation.

The key sense of the experience of leisure time lies primarily in the full freedom of its choice. One needs to remember, however, that such freedom cannot be bestowed upon a person that had not mastered the following of worthwhile efforts and habits. A child of 13-14 is of course characterised by a great ability to act alone, arrange its leisure time on its own, work on itself in a manner serving comprehensive development. Still, the formation of leisure time of an individual that is growing yet still immature is and must be greatly influenced by the convictions of the parents, their beliefs about advantageous modes of management of leisure time and the scope of liberty necessary for the child in terms of choices and ex-

⁶ L. Ploch, *Jak organizować czas wolny dzieci i młodzieży upośledzonych umysłowo*, WSiP, Warszawa 1992, p. 16.

cution of leisure-time activities. However, the participation of a caretaker in the education and control of activities during leisure time must take into consideration the will of the young generation seeking its own mode of entertainment⁷.

The role of the family in the education and the process of socialisation of an intellectually-disabled child is a particular one, as, as W. Dykcik notes, „the care for them is a unique grave problem due to the complexity and relevant duration of the illness, as well as the need for early diagnosis, facilitation and making the individual independent, under home conditions”⁸. The level of difficulty in the execution of tasks and functions to be fulfilled by the family with respect to an intellectually-disabled child also rises.

An important sphere of influence is the preparation to the rational consumption of leisure time, because the family environment is where from a very early age the ability to play, entertain and relax develops, where the first extra-biological needs and interests unfold; it is here where the intellectually disabled child is taught how to spend their leisure time.

The parents bear the duty of rational control of the organisation of leisure time. However, with respect to influences aimed in this way, it is necessary to adhere to the basic rules in force within oligophrenopaedagogy, such as:

- adapting the leisure time activities to the needs, interests as well as psychological and physical abilities of the child;
- the voluntariness of participation;
- motivation to undertake activities;
- the attractiveness of the proposed leisure time activities;
- comprehensive activation;
- gradation of difficulty levels and staging of the execution of tasks within the organised free time;

⁷ J. Gracz, T. Sankowski, *Psychologia w rekreacji i turystyce*, Akademia Wychowania Fizycznego w Poznaniu, Poznań 2001.

⁸ W. Dykcik, *Tendencje rozwoju pedagogiki specjalnej. Osiągnięcia naukowe i praktyka*, Wydawnictwo Naukowe Polskiego Towarzystwa Pedagogicznego, Poznań 2010, p. 162.

- the clarity of the methods and forms as well as the content developed for and used during leisure time activities;
- the continuity and systematicity of the provided care;
- assurance of hygiene and security.

Not every family can and may correctly prepare their children to manage their leisure time well. In this regard, L. Ploch⁹ distinguishes between three types of families:

- families that are consciously active, that create specific conditions to shape the abilities to arrange leisure time; the parents participate in the leisure time activities and are aware of their participation in the process of revalidation of a child with incomplete intellectual abilities;
- families that provide as much support as they can, leaving the initiative to facilities and institutions; their participation in the children's leisure-time activities is sporadic;
- passive families that do not attach importance to rational, cultivated and organised spending of leisure time.

The control of the mode of consumption of leisure time by intellectually disabled persons is a difficult and uniquely important issue. As the mentioned L. Ploch¹⁰ notes, it happens quite often that this time is neither organised nor supervised by adults. This creates great hazards for the security of children and youths, as well as for their physical and psycho-social health.

Assumptions of own research

Within the context of the aspects of leisure time delineated as such, it seems very important to get to know the opinions of parents on the leisure time behaviour of their intellectually-disabled child – as undertaken in empirical studies.

⁹ L. Ploch, *Jak organizować czas wolny dzieci i młodzieży upośledzonych umysłowo*, WSiP, Warszawa 1992.

¹⁰ L. Ploch, *Jak organizować czas wolny dzieci i młodzieży upośledzonych umysłowo*, WSiP, Warszawa 1992.

In order to obtain research material, the diagnostic survey method was implemented. During the conducted studies, the parent questionnaire technique was used, and it applied to the forms of leisure-time activities, the volumes of leisure time and the participation of children in activities outside of classes and of schools. The empirical data was collected in the year 2017 Maria Montessori Special Primary School at the 102nd Special School Complex in Poznań. The research group comprised 50 parents of minor-level intellectually disabled pupils – 52.6% (24 parents of girls and 26 of boys) as well as 45 parents of children with moderate-level intellectual disability – 47.3% (20 parents of girls and 25 of boys). The age of the children, to whom the study applied, lay between seven and 16 years. The decisive majority of these (83.1%) has siblings. The analysed parents represent a varied level of education. The most numerous groups are parents with higher (42.1%) and mid-level (29.5%) education.

Analysis of research results

The first analysed issue were the opinions of parents related to the leisure time budget of their children during school days, in the weekends as well as during winter and summer holidays.

The conducted research indicates that during the week, the majority of parents believe that children with moderate-level intellectual

Table 1. Volume of leisure time in the week in the views of parents (%)

Volume of leisure time	Opinions of parents of children with intellectual disability	
	at a minor level	at a moderate level
½ h-1 h	4.0	2.2
2-3 h	64.0	31.1
more than 3 h	32.0	66.7
has no leisure time	-	-
TOTAL	100.0	100.0

Source: own research

disabilities have more leisure time. It amounts to over three hours. Their peers with minor intellectual disabilities have at their disposal 2-3 hours of leisure time on school days. It can be supposed that this arises from their higher burden by homework. Pupils with minor intellectual disabilities do follow the basic curriculum of general education in force for public schools, which, among others, implies the necessity of heavy study also at home.

Positively should be evaluated that fact that no parents indicated their son/ daughter would have no leisure time at all. One needs to remember that an intellectually disabled child often participates in various additional revalidation courses, such as speech therapy, rehabilitation or re-education, which could imply excess limits of their time devoted to independent activity. And as A. Kusztełak and K. Łąg prove, from the point of view of correct development of each pupil, „there must exist a balance between work organisation and leisure”, and a false rhythm within these „causes the body to weaken, illness immunity to fall, tiredness to set on quickly, nerve-muscle coordination to worsen, muscle or joint pains to arise”¹¹.

A further period analysed within the context of parental evaluation of leisure time were weekends.

Table 2. Volume of leisure time in the weekends in the opinions of parents (%)

Volume of leisure time	Opinions of parents of children with intellectual disability	
	at a minor level	at a moderate level
1-2 h	-	-
3-4 h	10.0	8.9
5-6 h	20.0	17.8
more than 6 h	70.0	73.3
has no leisure time	-	-
TOTAL	100.0	100.0

Source: own research

¹¹ A. Kusztełak, K. Łąg, *Edukacja dla bezpieczeństwa. Interdyscyplinarne konteksty i dy-
lematy*, Wydawnictwa Naukowe Wyższej Szkoły Handlu i Usług, Poznań 2010, p. 65.

Table 3. Volumes of leisure time during holidays in the opinions of parents (%)

Volume of leisure time		Opinions of parents of children with intellectual disability	
		at a minor level	at a moderate level
summer holidays	1-2 h	-	-
	3-5 h	-	-
	6-8 h	24.0	37.8
	the entire day	76.0	62.2
	has no leisure time	-	-
	TOTAL	100.0	100.0
winter holidays	1-2 h	-	-
	3-5 h	16.0	-
	6-8 h	30.0	22.2
	the entire day	54.0	77.8
	has no leisure time	-	-
	TOTAL	100.0	100.0

Source: own research

The results presented in table 2 show that irrespective of the level of intellectual disability of the children – in the opinion of the majority of parents, in the weekend they have at their disposal a lot of leisure time – over six hours.

Summer and winter holidays are, in the views of parents, primarily a time without duties for children.

The conducted research shows that in view of the majority of parents of children with intellectual disabilities, irrespective of their level, during summer and winter holidays they have the entire day free. Accordingly, a grave problem arises, which is the summer rest of a **disabled child. They may leave for a camp or special** rehabilitation course, but these are just 2-3 weeks out of two months of summer holidays. The remainder of the time is left for the parents to arrange, for thoughtful actions for the benefit of the intellectually disabled child, to plan activities that will be interesting, safe as well as beneficial for them.

The need for appropriate, rational management of leisure time is stressed by W. Siwiński, when he proves that „it is an affair of the utmost importance, not only how much leisure time one has on average, but also how they utilise it, what forms are applied, do they compensate for the effort put into work and to what extent do they influence the development of the individual, their health, actions and work results”¹².

Taking the quoted opinion into consideration in the subsequent part of the study, the issue of forms of consumption of leisure time by intellectually-disabled children, was analysed.

The surveyed parents state that their children undertake motor activity. 98.9% of those analysed indicate active consumption of leisure time in the weekends and holidays, and 86.6% indicate that this is the case in the week as well. In the group of active forms of recreation during leisure time in the week, the weekends and holidays, no particular differences were recorded. The most popular have turned out to be walks (70%), swimming, (50%), cycling (50%) and dancing (30%). With respect to weekend and holiday forms, the parents additionally indicated long walking treks and trips outside of the usual place of residence, horse riding and running. Rollerblading or skating enjoy little popularity, as do football and cycling tours. The level of intellectual disability of the child did not cause differentiation of the active forms of leisure time indicated by the parents.

Despite the fact that the surveyed parents declared active modes of consumption of leisure time by their children, however, they also indicate passive relaxation. Among these forms of relaxation, no significant differences were recorded between activities in the week, the weekends and during holidays. The parents indicated decisively in most cases watching television (70%), painting and drawing (60%) and listening to music or radio shows (60%). Individual cases indicated sleeping, inactivity and boredom. In addition, during weekends and holidays, the children go to the cinema (20%) and play board games (20%). The fact that such forms of passive consumption of leisure time as surf-

¹² R. D. Tauber, W. Siwiński, *Pedagogika czasu wolnego*, Wyższa Szkoła Hotelarstwa i Gastronomii, Poznań 2002, p. 32.

ing the Internet and playing computer games as well as reading books and magazines were indicated by parents of children with moderate intellectual disabilities is quite an unexpected result.

From the pragmatic point of view, the analysis of the open question, in which the interviewees exposed their own suggestions of the forms of consumption of leisure time that they perceive as appropriate for their children, is significant. Among the active forms of spending leisure time, the interviewees most often indicated walks, games and playing on small football fields, sightseeing in cities and the surroundings, playing football, cycling, walking and cycling tours. It must be noted at the same time that in the view of parents, passive forms of leisure are also appropriate, such as controlled watching of television, playing computer games, reading books, manual activities (painting, drawing, moulding with clay), art-related activities, board games, logic games, listening to music, cinema or theatre visits. With respect to the youngest children, the parents also very often (80.2%) indicated free play as a beneficial form of spending free time used successfully to compensate for developmental deficiencies in intellectually disabled persons. The achieved result must be interpreted with great praise, because according to the basic provisions of paedagogy of play, such a form of activity is of paramount importance in the process of upbringing and education of disabled persons. Opinions of parents as to the appropriate leisure-time activities were not differentiated by the level of intellectual disability of their child.

Uniquely significant and valuable is the fact that in many statements, the parents stressed the importance of the consumption of leisure time together with the children, irrespective of the level of their intellectual disability. Accordingly, they indicated family trips, joint games or reading books or stories, playing with siblings. The achieved results permit a slightly more optimistic interpretation of the clearly negative conclusions of R. Pięta and B. Matacz¹³ that indicated only occasional contact between the child and parents dur-

¹³ R. Pięta, B. Matacz, *Czynniki środowiska rodzinnego wpływające na osobowość i edukację szkolną dzieci upośledzonych umysłowo*, <http://www.profesor.pl> education website [accessed on: 23.04.2017].

ing leisure time. The child – in view of the authors – spends the majority of its time playing independently, without the participation of otherwise busy parents.

A further issue from the analysed aspects of research was getting to know the opinions on the usage of sports and recreation facilities in the closest vicinity. The decisive majority of parents with minor-level intellectual disabilities (86%) indicated that their son/daughter uses sports facilities regularly. Children with moderate-level intellectual disabilities visit sports facilities less often (53.3%). The places named most often are playgrounds (90.2%), swimming pools (85.3%) and sports fields (60.9%). Individual statements indicated sports halls or stadia, indoor climbing facilities and ice rinks. Of particular note is the large group of parents with moderate-level intellectual disabilities (46.7%) who indicated that they do not use sports infrastructure at all. They indicated the causes for this to be primarily the lack of appropriate facilities in their vicinity, offers not suitable for the needs and abilities of their child, the lack of its independence, health problems, as well as financial hardships.

The analysed empirical study also applied to the opinions of parents about the role that is or should be played by the school in terms of the shaping of leisure time behaviour of children and youths. Thus, the issue of additional activities arranged by the school as well as the tasks of the school with respect to the arrangement of leisure time for their pupils, was taken on. The majority of the interviewed parents (68%) assured that their child participates in activities outside of classes. The most popular ones turned out to be forms such as interest clubs (Me and sounds, music, reading, art, culinary, dance), art classes, re-validation courses (improvement of speech impediments, coordination of the senses, improvement of school techniques, correction of posture flaws) as well as classes to equalise education chances. 32% of the interviewed parents conclude that their child does not participate in additional activities. The causes for forgoing these turn out to be: unsuitable hours (33.3%), lack of will to participate (33.3%) and the child's tiredness (16.6%). For parents of children with moderate-level intellectual disabilities, deci-

sive turned out to be the uninteresting offer of activities (40.0%) and the distance from the place of residence.

The analysed parents were almost unanimous (94.7%) in believing that the school should aid them in arranging leisure time for their children. They indicated, as the expected support services, intermediation in seeking information on the options of spending leisure time by disabled persons, preparation of family festivities, arrangement of activities at sports facilities or trips to interesting places. Many parents also indicated the need for the school to arrange the leisure time of their children during winter and summer holidays, in the form of trips lasting a few days, or day camps. Opinions of parents on the participation of the school in the arrangement of leisure time were not differentiated by the level of the child's intellectual disability.

An important component of leisure time are also activities outside of the school. Positively should be interpreted the fact that the decisive majority of parents with moderate intellectual disability (78.4%) declares the participation of their sons/ daughters in organised forms of spending leisure time outside of the school. Children with minor-level intellectual disability utilise such forms less frequently (51.6%). The forms indicated most often turn out to be sports (33.3%). In addition, the surveyed parents also indicated speech therapy (57.1%), rehabilitation (28.6%) and SI occupational therapy (23.8%), which, however (according to the assumed definition) are not leisure time activities.

The last issue of the analysed research aspects was the problem of oversight by a parent or caretaker over the way leisure time is spent. All surveyed parents declared that they know what the child is doing in their leisure time, and who they spend it with. It is a beneficial and expected situation, as the lack of such control might lead to the child spending its time in an unsuitable and irrational manner, giving in to the not always good influence of their peers or persons it might look to imitate. The leisure time of every child, and of a disabled child in particular, must to a very high degree be subject to specific rules and regulations set by adults. The partners in leisure time activities of children with diminished intellectual abilities are in most cases par-

ents (95.3%), siblings (71.4%) or other members of the family (66.7%). The results of the conducted research prove that the level of intellectual disability of the child is a factor differentiating the opinions of the parents on the participation of peers in leisure time activities. Parents of children with minor-level intellectual disabilities indicated decisively more often (56.7%) friends as participants in leisure time than parents of children with moderate-level intellectual disabilities – in this case it was just 4.8% of parents.

Conclusion

The results of the conducted empirical study confirm the high volume of leisure time at the disposal of intellectually-disabled children. In such a situation, broad activities of schools, **the family environment, social circles** as well as special educators themselves are necessary in order for leisure time to become an important component **of revalidation for a child with incomplete intellectual abilities**.

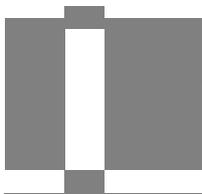
Any individual activities or group courses organised during leisure time can be of rehabilitative importance. If appropriate stimulation is ensured by the environment, the own activity of the intellectually disabled child, which is in many cases a passive individual, will be stimulated. Impeded thought processes, difficulties in adaptation, effectively block the skills and abilities exhibited by disabled children, and they can only be brought to the surface by appropriate activities. Well-organised and well-spent leisure time is just this sphere that can compensate for all other failures, give satisfaction and the joy of life, which may satisfy the need of creativity, belonging, expression and actin. Leisure time thus seems to be a field of unlimited rehabilitation possibilities, and it should thus **take place** among the top both in terms of scientific research, as well as (or maybe – primarily) in the practical activities for the benefit of intellectually-disabled children.

Leisure time appears to be the area of limitless rehabilitation opportunities, and therefore it should occupy a significant position

both in scientific research and (perhaps predominantly) in practical activities undertaken to help children with intellectual disabilities. Extensive activity of the school, family environment and special education teachers themselves is required to implement leisure time as a vital element in the process of revalidation of intellectually disabled children.

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Existential experiences of single mothers raising children with severe intellectual disability and their psychological, social and pedagogical determinants

ABSTRACT: Diana Aksamit, *Existential experiences of single mothers raising children with severe intellectual disability and their psychological, social and pedagogical determinants*. Interdisciplinary Contexts of Special Pedagogy, No. 17, Poznań 2017. Pp. 63-77. Adam Mickiewicz University Press. ISSN 2300-391X

Self-relations of mothers raising adult children with severe intellectual disability constitute a documentation of motherhood diverging from an established role model of a mother and a woman. The narratives show that this group of women struggle with many difficult experiences and emotions related to their own existence. The aim of this paper is to analyse existential experiences of interviewed mothers in terms of reflections on the meaning of life and future, as well as questions such as 'Why me?', often asked by the interlocutors. I will make an attempt to identify determinants of these experiences.

KEY WORDS: motherhood, existence, meaning of life, future, disability

*To love is not enough.
One must embrace this love with both hands, and carry it along through life.*

K. I. Gałczyński

Introduction

Both Polish and foreign scientific literature concerning families raising children with severe intellectual disability is quite extensive. It appears that most of the research focus on parents¹ and siblings².

¹ See. A. Twardowski, *The Situation of the Families with children with disabilities (Sytuacja rodzin dzieci niepełnosprawnych)*, [in:] I. Obuchowska (ed.), *A Children with Disability in a Family (Dziecko niepełnosprawne w rodzinie)*, Warszawa 1991, pp. 18–53; R. Butkevičienė, *Šeimų, auginančių vaikus su negalia, adaptacijos modelis*. "Tiltai" 2001, nr 4, s. 83-91; L. Woolfson, *Family well-being and disabled children: A psychosocial model of disability-related child behaviour problems*, 'British Journal of Health Psychology' 2004, 9 (1), pp. 1-13; L. Bakiera, *Ż. Stelter, Parenthood from the angle of parents of child without and with disability (Rodzicielstwo z perspektywy rodziców dziecka pełnosprawnego i niepełnosprawnego intelektualnie)*, 'Yearbooks of the Sociology of the Family. Interdisciplinary Sociology Studies' ('Roczniki Socjologii Rodziny. Studia Socjologiczne i Interdyscyplinarne') 2010, XX, pp. 131-151; H. Liberska, M. Matuszewska, *Models of Families with Children with Disability (Modele funkcjonowania rodziny z dzieckiem niepełnosprawnym)*, 'Polish Psychological Forum' ('Polskie Forum Psychologiczne') 2012, 17 (1), pp. 79-90; *Ż. Stelter, Roles of a Parent of a Child with Intellectual Disability (Pełnienie ról rodzicielskich wobec dziecka niepełnosprawnego intelektualnie)*, Warszawa 2013; *Ż. Stelter, The Ways of Parenting the Child with Intellectual Disability (Sposób realizacji roli rodzicielskiej wobec dziecka niepełnosprawnego intelektualnie)*, 'Polish Psychological Forum' ('Polskie Forum Psychologiczne') 2014, No. 1, pp. 87-109.

² A. Sidor, *Psychological and Social Aspects of the Ways of Functioning of Young Adults with the Siblings with Intellectual Disabilities (Psychospołeczne aspekty funkcjonowania młodzieży mającej rodzeństwo z niepełnosprawnością umysłową)*, Lublin 2005; E. Pisula, *Parents and Siblings of the Children with Development Disorders (Rodzice i rodzeństwo dzieci z zaburzeniami rozwoju)*, Warszawa 2007; A. Wojciechowska, A. Cierpka, *Family from the Perspective of Siblings of Persons with Intellectual Disability – Comparative Analysis (Rodzina w percepcji rodzeństwa osób z niepełnosprawnością intelektualną – analiza porównawcza)*, [in:] E. Pisula, D. Danielewicz (red.), *Family with a Child with Disability (Rodzina z dzieckiem z niepełnosprawnością)*, Gdańsk 2007, pp. 101-122; A. Cierpka, *Family from the Perspective of Siblings of Persons with Disability (Rodzina w percepcji rodzeństwa osób z niepełnosprawnością)*, [in:] H. Liberska (red.), *Family with a Child with Disability – perspectives and limits of development (Rodzina z dzieckiem niepełnosprawnym – możliwości i ograniczenia rozwoju)*, Warszawa 2011, pp. 235-256; A. Żyta, *A Life with Down Syndrome. Biographic Narratives of Adults with Down Syndrome, Their Parents, and Siblings (Życie z zespołem Downa. Narracje biograficzne rodziców, rodzeństwa i dorosłych osób z zespołem Downa)*, Kraków 2011.

One of the subjects of interest is the question of social assistance³. Discussed studies are but a sample of the wide range of research on this subject, and they mostly concern families raising children with mild, moderate and severe intellectual disability, with autism, Down syndrome, or sensory disability. Although the number of research and studies on severe intellectual disability is not that impressive. It is caused chiefly by the fact that this particular disability is a complex phenomenon, difficult in terms of early and precise diagnosis, as well as therapeutic work. For years, education, training, and even rehabilitation have not been, in common opinion, associated with severe disability. A long-term practice of placing persons with severe intellectual disability in group homes or care homes has transformed this field into a kind of a taboo. Families raising children or adult children with severe intellectual disability have been taken care of by social and medical sector. It caused many existential problems which mothers of now adult children still contend with, despite many upturns in the system of social assistance, and introducing the policy of inclusion in education. In this research paper I will describe and analyse chosen existential experiences of an examined group of women. I will also make an attempt to identify determinants of these experiences.

Theoretical framework

Women who, unaided, raise adult children with severe intellectual disability, especially children above the age of 24, who are often deprived of the opportunity to attend to rehabilitation centres due to their condition, shortage of places, or distance from dwelling

³ L. Gvaldaitė, *Šeimų savipagalbos veikla socialinio kapitalo perspektyvoje*, 'Acta paedagogica Vilnensia' 2010, Np. 22, s. 43-53; A. Naess, L.P. Grue, *Habilitering som koordinerende tiltak. Erfaringer fra tre brukergupper*, "Nova: Rapport" 2012, No. 4, s. 14-31; B. Kreiviniene, J. Perttula, *Subjective representations of families who have a child with severe disability on the place of social work help within the lawful social support system*, 'Special Education' 2011, No. 1, pp. 42-52.

place – these women lead a life filled with constant search and growing expectations toward themselves as mothers. The ways of dealing with reality in which examined women exist are reflected in major assumptions of philosophy and psychology of existentialism: ‘A human can always become more than they already are’⁴. Families constituted by these women and their children diverge from the established model and image of a family unit. Nonetheless, interlocutors indicate family as a *locus sensus*⁵ for their experiences of existence. As Kazimierz Popielski remarks, it is family, where ‘parents and their children, on their way of co-existence, can experience and discover a very natural and primal meaning and meaningfulness of life’.⁶

This is why experiences of mothers raising children with severe intellectual disability have been reflected upon and analysed using chosen questions of philosophy and psychology of existentialism, derived from existentialism of Søren Kierkegaard (19th century), Martin Heidegger, and Karl Jaspers (20th century)⁷. Major assumptions of existentialism concern existence of a human being, and a key to understanding it is their existential experience. Existential experiences of the examined group of women were analysed in various situations, breakthrough moments in their life, when they were, to the utmost, experiencing their personal existence inextricably interwoven with their children, in symbiosis between ‘me’ and ‘you’.

The fundamental existential questions most often revolve around issues regarding: identity, meaning of life, death, freedom, suffering, faith, and are conditioned by intra- and inter-psychical

⁴ P. Szczukiewicz, J. Olszewski, *Existential Attitude in Psychology and Psychotherapy – Opportunities and Limitations (Podejście egzystencjalne w psychologii i psychoterapii – możliwości i ograniczenia)*, ‘Psychology Horizons’ (‘Horyzonty psychologii’) 2014, Vol. IV, p. 105.

⁵ K. Popielski, *Family as Locus Sensus (Rodzina jako locus sensus)*, ‘Pelpin Studies’ (‘Studia Pelpińskie’) 2002, No. 33, pp. 511-523.

⁶ K. Popielski, *Family...*, *op. cit.*, p. 522.

⁷ P. Szczukiewicz, J. Olszewski, *Existential...*, *op. cit.*, p. 104.

factors. Existential experiences of examined mothers have been mostly related to reflections on the meaning of life and future, and questions such as 'Why me?', often asked by the interlocutors. They all fall into existential psychology paradigm of Karl Jaspers⁸, who claimed that we can talk about existential experiences of a human being in boundary situations of their life or in time of exceptional challenges they encounter: both conditions occur every day in the life of the examined mothers. Existential psychology is based upon a concept of four dimensions in which people exist: spiritual, social, psychological, and physical dimension. It appears that, for women raising children with severe intellectual disability the spiritual dimension of their life is the major one. Spiritual dimension is referred to as noetics (*Latin*: of or pertaining to the mind or intellect, originating in or apprehended by reason)⁹. Existentialists point out that thinking of problems related to human existence only in psychological or social dimension is flawed, as it does not allow to get through to the essence and complexity of the matter. Given the above, I examined and analysed existential experiences of interviewed women in terms of those four dimensions, with particular attention to the spiritual one.

Methodology of own research

Research material presented in this paper is based on thirteen interviews with women from all over Poland (the research is in progress). The aim of this research is theoretical, empirical and practical analysis of various motherhood experiences of women raising, by their own, young adults with severe intellectual disability. In this paper I focused on identification and analysis of existential experiences of the mothers, trying to answer the following research questions:

⁸ K. Jaspers, *Philosophy of Existence (Filozofia egzystencji)*, Warszawa 1990.

⁹ K. Popielski, *Noetical Dimension of Personality (Noetyczny wymiar osobowości)*, Lublin 1994, p. 49.

- What are the existential problems that examined women encounter?
- severe intellectual disability above the age of 24. Study subjects were recruited using a snowball sampling method, through social institutions, charity associations and non-profit organisations, as well as via internet blogs and websites. Primary technique used in this research was the in-depth interview technique. Respondents were asked to tell about some parts of their life or to tell the story of their whole life in terms of their experience of motherhood. Acquired information was analysed in terms of procedures used in grounded theory (GT) methodology¹⁰, with particular attention to main assumptions of existential psychology.

Analysis of own research outcomes

Experiences of single mothers raising adult children with severe intellectual disability

Aloneness of a mother and a severe intellectual disability of her child are connected on the basis of a deep emotional existential relationship. Other scientific research shows that women often see their own parenting from the angle of their children's achievements and evolvment.¹¹ This kind of motherhood is bound up with permanent care of an adult child, and is often called by some researchers a 'hipermotherhood'¹²: as the interviews indicate, it involves deep

¹⁰ B. G. Glaser, A. L. Strauss, *Discovering the Grounded Theory. Strategies of Quaitative Research (Odkrywanie teorii ugruntowanej. Strategie badania jakościowego)*. Kraków 2009.

¹¹ A. Maciarz, *Motherhood in the Perspective of Social Changes (Macierzyństwo w kontekście zmian społecznych)*, Warszawa 2004, p. 16.

¹² A. Pałęcka, H. Szczodry, *Hipermotherhood: The Mothers of Children with Intellectual Disability (Hipermacierzyństwo – na przykładzie matek osób z niepełnosprawnością intelektualną)*, [in:] A. Pałęcka, H. Szczodry, M. Warat (ed.), *Women in Polish Society (Kobiety w społeczeństwie polskim)*, Kraków 2010, pp. 17-42.

existential problems. The examined group of women consisted of mothers who lived through many events which have determined their existential experiences, and have shaped their reflections on the meaning of life and future, as well as formulating questions such as 'Why me?'

The 'Why me?' question in self-reflection of the examined mothers

Women varied in the ways of describing their motherhood. Some of them told their stories chronologically, describing events following in succession; others pointed out crucial moments in parenthood. Referring to the beginning of their motherhood, they often recalled the question 'Why me?'. In opinion of most of them, the beginning was the most difficult moment, filled with spiritual experiences. They felt that it was related to many difficulties which they must have encountered in spiritual and social aloneness.

Agnieszka¹³: The beginning was the hardest time – you have to come to terms with so many things... A lot of different questions was coming up somewhere inside of me: 'God, why me?'. Today I know that everything I lived through back then strengthened me as a human being; it showed me that I am strong, but it also left a mark.

Nela: I went through a crisis from the start. 'Why me?' I asked myself: this question was overpowering. I couldn't resign myself to this, I somehow understood it was time to forgot about myself. I don't know, I live with it for 30 years now, I think I'm strong.

Barbara: First, I didn't know how it would be, I was afraid it was the end of my life, that I would not handle it. I asked so many questions... But I managed, I think so.

The crisis which puts severe limitations on a life of a family as well as an individual, changes the ways of social and emotional

¹³ All names have been change to protect the identity of respondents.

existence.¹⁴ Looking back at it some years later, the mothers notice that these experiences revealed for them their existential potential. Asking themselves the question 'Why me?', the women tried to search for an answer in many different ways: submitting their children to medical tests, comparing themselves with other mothers, reviewing their own existential values. Some of them still have not found the answer. Deep analysis of every single word has shown that, despite the passage of time, the mothers have not fully come to terms with the state of affairs, and that this is a result of the 'silent self-blaming' for a child's disability. Mothers are often blamed by their immediate family, as a result of social prejudice. This applies to the group of examined women.

Nela: I was always living with the question 'Why me?'. 'Why did it happen to me?'. That's why I gnawed at any tests there were. I have never answered myself to this question, and it torments me to this day. I have waited for this answer, waited for too long.

Beata: I thought of the fact that it happened to me as something natural, and I assumed that it's something I had to come to terms with. I had these values inside of me that in a way shaped the answer for the question 'Why me?'

Aleksandra: I could have felt that many people thought it was my fault, cause you know – a mother is a mother. I often think that I actually am to blame, that somehow, I did something wrong, during my pregnancy, or afterwards...

Barbara: It's true, I sometimes compare myself to other mothers. Once in a while you think that other people have it easier in their life. But I don't want to complain, it could have really been worse.

As the above statements show, the question 'Why me?' was mostly asked in the first period of motherhood. It is worth mentioning that despite the passage of time, the question accompanies the

¹⁴ M. Sekułowicz, *The Problems of the Functioning of Mothers and Fathers of Children with Disabilities (Problemy funkcjonowania matek i ojców dzieci z niepełnosprawnościami)*, [in:] Z. Palak, A. Bujnowska, A. Pawlak (ed.), *Edukacyjne i rehabilitacyjne konteksty rozwoju osób z niepełnosprawnością w różnych okresach ich życia*, Lublin 2010, p. 47.

life of the mothers with varying degrees of emotional intensity. It can be assumed that the main cause of these existential experiences, such as asking the questions 'Why me?', was the mothers' powerlessness toward the situations that required many transformations and sacrifices of them. It was also related to a different idea of parenthood they had.

The sense of the meaning of life

Questions about the meaning of life are present in human existence for centuries. The answers to these questions are searched for in various life areas: family, work, dreams, life goals and achievements. These dilemmas were prevailing in mothers' narratives as well.

Nela: In the past, I didn't really wonder what I lived for, I didn't search for the meaning of what I was doing. But then, along with my son's disease, it came to me by itself, I began to think about it. It was more often back then... When my husband left us, for a long time I didn't feel as anything meant something, it was all so sudden... And you lose this sense.

Alicja: Sometimes I think: 'God, what do I live for?' But I know what for – for children, so they can feel they matter, because they are in the centre of my life, they give a meaning to my life...

Grażyna: I often wonder about my life, but I know she needs me and I should not let myself have these thoughts. Sometimes they would come to me, because I am alone in all this, well, maybe not totally, but you know what I mean. I lost my job, it was horrifying because i didn't know what to do, how would I provide for us, there are expenses.

Questions about the meaning of life came up along with the information about the child disability, and they tend to come back in critical moments in women's' life – at the time of divorce or job loss. Mothers point out that, with time, these dilemmas tend to change direction into the question of taking care of an adult child and the specificity of their severe intellectual disability. Living and

achievements of their children have become the meaning of their own existence.

Agnieszka: In this life of mine I just want to help her... I better have enough physical strength; psychologically – I don't even think about how I manage to live... If I don't manage, I will lose any sense of meaning. But as it is, this thought keeps me alive, the thought that I help, that I manage, that it matters.

Nela: There is no choice or hesitation... I dedicated my life to him and that's that.

Maria: It is not how I imagined my life would look like, is it? But without my daughter, I can't even talk about it cause I'll cry... I see the meaning of my life in her every achievement.

Main assumption of philosophy and psychology of existentialism state that the sense of meaning is experienced in relation to something or someone, and that to be able to recognise and accept the meaning of life one has to acknowledge it in their experiences and consciousness. In opinion of the examined women, the experiences they had to face, made their life meaningful without them thinking of it or searching for it. During the years, the motherhood which the respondents have been bestowed with, strengthened their firm conviction about the meaning of their life. It has been reflected in the process of shaping personal and social identity of examined women. As can be seen, there is an importance of a relationship within the paradigm of existentialism – a person is turned toward another human being; they fulfil themselves by being with other person, by living and experiencing their own selves in terms of relation toward other individual. It can be assumed that this kind of belief strengthened the mothers spiritually, psychologically, and physically.

Jolanta: What can I say? Life's hard. But you don't think about whether it does or doesn't matter... You act in such a way as to keep your child well. This is where the meaning is.

Agnieszka: I don't think in terms of the category of 'me' anymore, instead I think of 'us'. Because when she takes even a small step further, I feel I move forward too.

Zofia: What truly gives me hope is my strong belief that she needs me, and that if it wasn't for me, she would just stop living. It is sad after all, but it is actually my only goal.

The meaning of life is an aim of a constant striving within and for human existence, and it applies to mothers' lives. The sense of their own existence, their social and psychological identity are directly related to another human being. When talking about themselves, they usually relate to their own children. They are aware of the existential obstructions related to this attitude, but it is worth mentioning that as they have managed to live this way for years, they resigned themselves to the idea of sacrificing their lives for their children. However, it does not mean that they have come to terms with their sons' or daughters' disability or suffering.

Nela: The truth is, I don't have any life of mine anymore. When my son fell ill, I gave up thinking about myself. Different priorities. He became my whole life.

Maria: She needs my support, and it's obvious it's going to be this way for the rest of her life. I actually live for her. Do you know how she suffers sometimes? I would swap with her and suffer just so she could be happy.

Beata: Sometimes I feel like I'm going crazy, but she is what matters most, and this is just the way it has to be.

Therefore, in the attempt to answer the question about the determinant of the meaning of life which has been revealed in mothers' narratives, we can consider it a reality in which the mothers have come to live in, identifying the meaning of life in another person. It has been shaped by various experiences and life events, which the women have encountered over the years.

The future

In the narratives about their motherhood, most of the women raised the issue of the future, although in a peculiar way, as in relating to the upcoming old age. When describing past events, they

have not mentioned the vision of the future that they had back then. From what they said it appears that it begun to change when they started to notice that they grow old, both physically and psychologically. Reflections on ageing are the immanent part of human existence. They are present at various stages of life, concerning life recapitulation, and achievements. Old age in the narratives of interviewed mothers is associated with the lack of strength, physical and psychological exhaustion, but mostly with the concern for the child's future.

Maria: What is most difficult right now? Well... I suppose it's the fact that I'm old now and I just lose my strengths, I feel tired more often... I keep thinking what will happen with my daughter.

Renata: I'm old now, and sometimes I'm exhausted, my arms ache.

Małgosia: I would really want someone to take care of our problems. To be honest, I'm tired. I am just too old for all this.

Thoughts on old age were mostly focused on the feeling of physical weakness, which in respondents' narratives was closely related to the fear of the perspective that a child would not get necessary support they now do. The women point out that their children have grown older along with them, and that means different, more absorbing and time-consuming kind of care.

Agnieszka: Now I can see the difference. My daughter grows older, I'm not young either, my back often hurts, it gets more difficult for me to bath her, all these duties...

Beata: I'm afraid of that day, when I won't be able to take care of her anymore.

Old age pictured by mothers is not related to their personal 'self', but to their physical and psychological exhaustion. The women consider the beginning of their parenthood the hardest time, as they must have dealt with difficulties they had a direct influence on. The ageing process is the stage at which they have to struggle with things they don't have any control of. Raising and caring for a child

are an integral part of life in terms of the women's existence. It has a strong impact on their reflections on future events, when their children will have outlived them or, the opposite, will have gone first.

Maria: I cannot imagine my life without her, it would all become meaningless.

Nela: I think about what will happen to me when my son dies, as he is severely ill now, he has got seizures more often these days. No one will need me then, I will be all by myself... I don't keep in touch with my family.

For years, the have women lived in solitary, taking on many roles not associated to the traditional idea of a mother; they have built their own homes submitting themselves to their children's needs. Being aware of the fact that they might be the ones to leave first evokes a truly scary perspective of a care home or rehabilitation centres. Most of the women have already been looking for this kind of place. Mother's greatest fears concern their children's daily living: their habits, difficulties which the women are able to manage thanks to motherly love. In the respondents' opinion, even the finest rehabilitation centre would not provide this kind of care for their children. It can be assumed that women value highly their own way of caring for a daughter or a son, and this attitude helps them to not give in, both psychologically and physically.

Maria: This thought that she will outlive me, that I will have to go too... I will have to leave her, this is the hardest and most tragic thing of it all. Even if she is put in the best rehabilitation centre, the best you can imagine...

Alicja: All I really care about now is to finish this house refurbishment already. So, when we're gone, someone young from the family would take care of our children, and we leave them the house. Just so they take care of our children.

Agnieszka: I consider a centre, a house for my daughter, where her sister can be close to her. I consider this option as well. I'm always joking though that for me the best way to go is to go together.

For the mothers, future poses some kind of a threat for their children. The women are searching for various ways of securing

their children's future. Some mothers reached for help within their families, but most of them lived in spiritual and social solitary. There are very few mentionings of the spiritual support for women in the research material. Therefore, in the attempt to answer the question about the determinant of the existential experiences in the reflections on future, once more we can consider it a difficult reality in which the mothers live; a life on the edge of burn-out, a state of a constant mobilisation, but also a lack of spiritual support and social acceptance.

Conclusion

The analysis of existential experiences of single mothers raising children with severe intellectual disability is an important area of research in terms of several sectors of social life. It develops foundations of creating a model of support for this group of families, which includes current trends in system legal and social assistance solutions. It is worth noticing that the current model does not include the spiritual support in a range which would suit women's needs. It has severe psychological consequences and may cause an existential vacuum. As the conducted analyses show, being a mother of a child with severe intellectual disability is associated with many existential problems, questions such as 'Why me?', and reflections on the meaning of life and future. They have different basis, although they all have a mutual determinant: the reality which, at the beginning of the motherhood, was full of powerlessness, a vision of unfulfilled parenthood, sacrifices, and transforming own 'self' into 'ourselves'. Life in constant exhaustion, every day care that requires from a woman some extreme physical and psychological strengths, provokes existential questions and experiences imbued with negative emotions. It is worth to notice that parents raising children with severe intellectual disability have a strong need of spiritual support. What is to be done:

- initiating institutional and non-institutional activities which aim would be to support mothers raising children with severe intellectual disability;
- organising a complex system of psychological and therapeutic activities, focused on supporting examined women who experience existential problems.

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The process of adaptation to the role of a parent of a child with Down syndrome as a stress management strategy

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The process of adaptation to the role of a parent of a child with Down Syndrome is very difficult, multi-staged and stress-causing both for mothers and fathers (Będkowska-Heine, 2003; Kościelska, 1998; Liberska and Matuszewska, 2011; Żyta, 2004). Coping with parental stress is a constant challenge for mothers and fathers of a child with Down syndrome and it increases the significance of different types of social support. The choice of the coping strategy can improve the parents' cognitive abilities and competences of emotional and behavioural control and it also facilitates a more positive assessment of their intellectually disabled child (Turnbull et al., 1993). If parents choose a more adaptive, problem-focused coping strategy, adaptation to the parental role proceeds more fluently and more adequately (Abery, 2006; Lackaye and Margalit, 2006; Van Riper, 2003). In addition, it has been proven that receiving social support and using accommodative coping styles may boost the process of adaptation to the role of a parent of a child with Down syndrome (Atkinson et al., 1995; Dunst, Trivette and Deal, 1988; Florian, Krulik, 1991; Friedrich, Wilturner and Cohen, 1985; Lam and Mackenzie, 2002; Sullivan, 2002; Van Riper, 1999).

KEY WORDS: Down syndrome, family with a disabled child, adaptation to the parental role, coping with parental stress, social support

The parental role. Introduction

Each person who belongs to the family system accepts specific tasks and shows specific attitudes and behaviours. The accepted role defines the type of activity and choices that should be and are made. By analogy, it is the assigned or accepted role within the family system that determines our relations and behaviours towards other family members (Będkowska-Heine, 2003). As life goes on, every person accepts or adopts various roles which have define the form and content of activity (Łoś, 1999). Amedeo *Cencini* and Alesandro *Manenti* (2002) argue that the social role is a culturally defined set of expectations towards individuals who have a specific position within the social structure. Norms define the role and the person's behaviour. They are interpreted by that person and constitute the sole explication of the individual system of meanings. It may happen that a person must adapt to the assigned or chosen role in a long process of learning to meet the related expectations and requirements, which is connected with the individual development (Łoś, 1999). For instance, the parental role is not always the outcome of giving birth to a child, but it may be a continuation of a role related to gender or marriage (Ziemska, 1973).

Teresa Rostowska (2009) believes that a family role usually means a model of behaviour (or of its image) that are manifested in social situations related to the functioning of a family (Rostowska, 2009). According to Maria Ziemska, the parental role is the acquired structure of cognition, aspiration and affection that drives the parents' behaviour towards their child (Ziemska, 1973). Parental roles cover behaviours common to both parents and others that are specific to the mother or the father. For instance, the mother conceives and gives birth to the child and then takes care of his/her proper growth and upbringing. The mother's role also includes showing affection, warmth and understanding to the child and bringing him/her into family life and traditions (Rostowska, 2009).

The contemporary expectations with respect to the father's role are different than the ones typical of the traditional, patriarchal family. As a result of social, cultural and economic changes, financial

support and economic stability are not the only expectations related to the role of the father. Today, the parental role of a man includes participation in house works, looking after the children and the active part in the upbringing process (Plopa, 2006; Harwas-Napierała, 2014). The differences between the mother's and the father's role become gradually blurred and their functions are more and more complementary.

By performing the parental role, parents can cater for the needs of their children and their own needs. Their own needs include: recognition, respect, self-development, maternity (paternity), conveying values, knowledge and their achievements to the children.

As regards the children's needs, parents drive their development in all aspects of life and prepare them to function successfully in the society (Rostowska, 2009). The engaged and proper performance of the role may contribute to the positive self-image, system of values, the sense of identity and the satisfaction from meeting the expectations related to the role (Ziemska, 1979).

Researchers distinguish two notions related to the parental role: one is the role requirement, i.e. social expectations related to the role, while the other is the role concept, i.e. the interpretation of this requirement by the individual (*Cencini, Manenti, 2002*).

The role of a parent of a child with Down syndrome

According to Ziemska (1979), parenthood is an important factor that gives a young person the sense of safety and defines his or her social status. Mother and father feel joy and pride, when their children are successful. Children often give their parents the possibility to indirectly experience successes which they did not have the chance to experience in their own life, so children can be a source of personal satisfaction for their parents (Będkowska-Heine, 2003).

It is different for parents of a child with Down syndrome. Studies indicate that the birth of a child with intellectual disability is a difficult situation, often unexpected and hard to accept (e.g. Będkowska-Heine, 2003; Kościelska, 1998; Liberska and Matuszewska, 2011;

Żyta, 2004). Małgorzata Kościelska (1998) argues that a majority of couples who decide to have a child cannot imagine themselves as parents of a disabled child. After birth they expect satisfaction from normal growth and developmental achievements of their child. In such cases, the medical diagnosis is an emotionally wrecking experience and the shock often makes some parents reluctant to take the child home with them. When the child is born and the parents hear the diagnosis of Down syndrome, they feel heavily depressed (Emde and Brown, 1978; Zahn Waxier, Duggal and Gruber, 2002).

Following the initial depression phase caused by the birth and the diagnosis, parents start feeling better until the moment when the child is 4 months old. The second depression sets in, because parents notice the symptoms of Down syndrome. They can see that the child is less responsive to the outside stimuli and smiles less than a healthy child would. Several waves of depression may also occur in the pre-school period, when parents notice their child's development difficulties in walking, speaking, using the toilet and, first of all, learning. Depression might also coincide with the child's period of adolescence and early adulthood. Intense emotional reactions tend to be a permanent element in the process of bringing up a child with Down syndrome at all development stages (Zahn-Waxler et al., 2002).

Stress related to the child's disability diagnosis

Psychological consequences for related to the prenatal screening test and emotional responses of parents who hear the diagnosis of their child's disability for the first time confirm the results of the study by Sue Hall, Martin Bobrow and Theresa M. Marteau (2000). The researchers performed analyses in three subgroups of parents having a child with Down syndrome. They were parents a) who received a false negative result of prenatal tests, b) who did not do the screening test, and c) who refused to do the test. Based on the research, Hall, Bobrow and Marteau determined that the negative emotions reached the peak intensity in the case of parents who re-

ceived the incorrect result of the prenatal screening test, i.e. were informed that the child was perfectly healthy. The false negative result of the test was positively correlated with the higher level of parental stress, a stronger tendency to blame others for the birth of the child and the increasingly negative attitude towards the child in comparison with the parents who refused to do the test. Other behaviours were manifested by the parents who received the correct prenatal diagnosis. As indicated by Hall, Bobrow and Marteau, the parents who knew that the foetus has Down syndrome features, but decided to have the child, showed lesser anxiety, more positive responses and acceptance of the child (Hall, Bobrow, Marteau, 2000). One can find similar results in the research by Brian Skotko (2005). The author argues that the positive emotional state of the parents (especially the mothers) who know that they will have a child with Down syndrome results from the gradual acceptance and becoming accustomed to the non-normative situation (Skotko, 2005). Skotko also observes that who decided to continue the pregnancy after the prenatal diagnosis of Down syndrome were driven mainly by personal beliefs and values. A majority of those mothers knew they would continue the pregnancy, when they took a decision to do the screening test. On the other hand, women who learned that the child will have Down syndrome, but did not yet decide if they would continue the pregnancy, wanted to get more information. Furthermore, a majority of those mothers showed frustration during interactions with physicians and emphasised the need to find the most recent research materials on Down syndrome, and they also asked for a referral to local support groups (Skotko, 2005).

The process of adaptation to the role of a parent of a child with Down syndrome

When analysing the role of parents of intellectually disabled children, one can speak about adopting or accepting the role, but a more precise term would be adaptation to the role. According to

Violetta Będkowska-Heine (2003), the process of adaptation to the role of a disabled child's parent covers the following stages: falling into the trap of the role, becoming accustomed to the role, identification with the role, imprinting of the role, growing into the role, autonomisation of the role, fetishisation of the role, negation of the role and creation of the role.

Stage one, i.e. falling into the trap of the role, comprises shock and confrontation with the diagnosis of disability. There appear many negative psycho-emotional reactions, e.g. fear, confusion, chaos, disorientation as well as anger and aggression. The family system is destabilised and young parents go through a crisis (see: Będkowska-Heine, 2003; Kościelska, 1995, 2000; Ziemska, 1997). At this point, parents see no positive aspects of parenthood.

The next stage is when the parents try to overcome the crisis by becoming accustomed to the role. When parents have the certainty that the child's disability and irreversible and incurable, they strive to cope with the crisis by various defence mechanisms such as denial, rationalisation or repression. At this stage, parents do not enjoy their role and see no positive aspects of difficult parenthood, but if they do not reject the child, they take all actions related to the care, upbringing and rehabilitation of the child.

The next natural stage is identification with the role which means they become more engaged in the tasks of the role. They gain experience and parental competences. They perform the parental activities more efficiently and as a result both mothers and fathers have more confidence and trust in their parental skills. Gradually, a common space of the parents and the child emerges.

The imprinting-of-the-role stage covers the conscious search and implementation of methods to bring up an intellectually disabled child. The parental identity is being formed. The mother and the father seek, learn and apply the ways and methods of upbringing. In this period, parents care more for happiness and peace of the child than for supporting the child's development.

When the predictable daily routine sets in, and the parental tasks and role are clearly defined, the period of growing into the role can

begin. The parent identity becomes generalized and the sense of alienation disappears. Parents of an intellectually disabled child stop perceiving themselves as stigmatized or worse. The child become a member of the family system and a part of the parent's mental structure.

The autonomization of the role occurs when the parental role brings satisfaction to the mother and the father who see it as an essential value in their life. The parents realize the development opportunities of their children and can provide information and support to other young parents of intellectually disabled children. They ask for specialist help without feeling guilty or embarrassed. This stage results from the acceptance of the parental role and the extended awareness of the child. The proper adaptation to the role of a parent of an intellectually disabled child means that both mothers and fathers take care of the child and raise him/her, but they also adopt a therapeutic attitude.

Będkowska-Heine (2003) specifies four additional types of parental roles which indicate the lack of adaptation of the mother/father of an intellectually disabled child to the parental role: fetishisation of the role, manipulation of the role, negation of the role and creation of the role. Fetishisation of the role means that parents focus entirely on the parental role. The author believes that such behaviours are often shown by mothers who let no one else look after the child (Będkowska-Heine, 2003). Personal needs are adjusted to the child's needs and the parent has no private life or leisure time. The development of the child's autonomy and self-reliance causes fear and objection in the carer. Manipulation of the role happens when the role of a disabled child's parent serves as a means to gain social and material benefits. Negation of the role refers to the situation when the child is rejected, the parent refuses to look after the child and denies the parenthood. Creation of the role means a compulsive performance of all other roles which are not needed or required by the environment. A special case of the creation of the role may be a decision about the sole parenthood.

A different process of adaptation to the role is presented by Kościelska based on the research conducted in 1993 by Anna Kraw-

czyk (see: Kościelska, 1998). The research by Krawczyk covered young mothers with disabled children in the period of up to three months after birth (see: Kościelska, 1998). The women were of similar age (average: 26 years) and shared a similar financial and family situation, i.e. each lived with the child's father, enjoyed proper housing conditions and finished at least secondary education. Krawczyk contacted the mothers three times and the purpose of the meetings was to conduct an interview and obtain such information as: a) the level of satisfaction from motherhood, b) the sense of competence in performing new tasks, c) emotions in interactions with the child, d) the mother's image of the child, e) the child's functioning, f) the time devoted by the mother to the child and the way of spending that time, g) the mother's image of changes in family life. Based on the obtained narratives, three groups of mothers were distinguished with respect to the level of adaptation to the maternal role: a) mothers well-adapted to the parental role, b) mothers having difficulties adapting to the parental role, c) mothers ill-adapted to the parental role.

Kościelska (1998) informs that mothers that are very well adapted to motherhood show high satisfaction from the parental role. These women felt joy and pride due to the very fact of being a mother, the contact with the child was positive, they devoted a great deal of time to the baby, showing warmth and positive emotions. The children became more peaceful when the mother was around. Both mothers and children quickly learnt about each other, which was the starting point for a mutually positive, strong bond based on the sense of safety, warmth, mutual understanding and enjoying the time together. The women manifested a high level of maternal competences and did not complain about the excessive number of duties or the lack of support by other family members. As a result of effective adaptation of the women to the maternal role, the fathers had the opportunity to develop their parental competences. Partners of well-adapted mothers of intellectually disabled children indicated that they developed as a carer, a father and a spouse.

On the other hand, mothers who had difficulties adapting to motherhood showed (Kościelska, 1998) high level of satisfaction from becoming a mother, but problems emerged when they learnt how to take care of the child.

These women spoke about their troubles with childcare, regulating the rhythm of sleep, lack of free time and the excessive duties they could not manage. In addition, the mothers mentioned physical ailments and needed time to develop parental competences and the sense of effectiveness. Their emotional sphere also started evolving. After the birth of the child, they felt ambivalent: joy, enthusiasm and happiness were mixed with fear that they lack skills and could inadvertently hurt the child. The image of the child was varied in this group of women. On the one hand, the mothers saw the child as the source of joy and love, but at the same time the cause of fatigue, irritation and frustration. Children of the mothers who were partially adapted to the role did not have a regular rhythm of sleeping and feeding, they cried a lot and had digestive problems. It must be noted that these women's partners worked, so the mothers had to do all housekeeping and chores. The women felt isolated and alienated, they wanted to find a job.

The third group specified by Kościelska (1998) included women who were ill-adapted to the parental role. The research indicated a low level of satisfaction from the role. They complained about numerous body ailments and suffered from excessive fatigue, lack of sleep and general malaise. All these women wanted to get back to work as soon as possible. They had low parental competences and needed a great deal of help and support from the family. Their emotional state was poor: the mothers showed more negative than positive emotions and they had a negative image of the child, i.e. they saw their children as troublesome, fussy, weepy and absorbing excessive time and energy. The children's functioning was disturbed: they slept little and in too short intervals, the parents devoted insufficient time to their babies and focused exclusively on care-related activities.

Change of the evaluation perspective regarding the influence of disability on the family system

In the last 4 decades, the research approach to the adaptation process of the parent of a child with Down syndrome switched from the perspective of pathology and crisis (Blacher, Neece, and Paczkowski, 2005) to the perspective of stress and coping with difficulties related to the atypical parenthood (Abery, 2006; Van Riper, 2003). This change may result from the need to get away from the reductionist, problem-oriented approach (Richardson, 2002).

The overview of studies related to families with intellectually disabled children from the period before the 1980s indicates that such a child may have a negative influence on the functioning and well-being of the parents as well as on various aspects of the family life and atmosphere (Hodapp, 2003).

The first studies in this field demonstrated that mothers of intellectually disabled children tended to be depressive and had problems with managing anger towards the children in comparison with mothers of healthy babies (e.g. Cummings, Bayley and Rie, 1966; Friedrich and Friedrich, 1981). Similarly, the fathers of intellectually disabled children were depressive and neurotic and they showed a lower level of domination, self-esteem and the joy of having children with intellectual disability in comparison with fathers of healthy babies (e.g. Friedrich and Friedrich 1981). In these studies, families with intellectually disabled children demonstrated a lower level of marital satisfaction and a higher level of marital conflicts and divorces (Cummings, Bayley and Rie, 1966; Friedrich and Friedrich, 1981). In those families, mothers were strongly engaged in looking after the child with intellectual disability, while fathers tended to be more reserved, both emotionally and physically (Beckman-Bell, 1981).

Since 1980, researchers change the approach to a disabled child as a cause of psychopathology by introducing the concept of stress factors in a family with a disabled child (Hodapp, 2003). In line with this change of perspective, stress factors in the family system may lead to negative parental effects such as malaise, a higher depres-

sion level (Friedrich and Friedrich, 1981) or a negative image of the child (Kościelska, 1998). On the other hand, the new research perspective allowed to see that the child's disability can also reinforce the parents. It was observed that as a result of experiencing the child's disability, parents may strengthen their personal qualities and thus the entire family system can be reinforced and consolidated (Greenberg et al., 2004; Hodapp et al. 2007).

Problem-coping skills of parents of children with Down syndrome

The overview of sources related to the family stress coping strategies in families with intellectually disabled children in comparison to families with healthy children indicates that the former show a higher level of stress and anxiety (see: Leinonen et al., 2003). Disproportions between the two groups are convincingly exemplified in the study of the parental stress level in groups that are similar in social and economic terms (Roach et al., 1999). In this comparison, it was observed that parents of children with Down syndrome spoke about considerable difficulties in taking care of the child, a higher level of stress related to upbringing (cumbersome tasks, no acceptance of the tasks involved in looking after a disabled child) and of parental stress (lack of competence, depression, health problems, deterioration of the parental role and the marital role) in comparison to families with healthy children. For both groups the maternal stress resulted from care-related difficulties, while the paternal stress was connected with the very presence of a child with Down syndrome. Mothers who manifested more engagement in looking after the child suffered from health problems and received less support from the spouse, while experiencing difficulties in performing the marital role. Fathers who were more involved in the care of the child had fewer difficulties with respect to parental competences. The parents also felt anxiety about the limited time for rest and leisure, which resulted in lower recreational activity and more need to plan the

rest. One must note that with respect to the level of satisfaction with free time management, parents of children with Down syndrome often observed the potential benefits of spending the free time together with children or the entire family (Wayne, Krishnagiri, 2005).

Richard R. Abidin (1995) distinguished the various sources of parental stress. He specifies two types of stress. The first is the parental stress felt by every parent and related to children's behaviours which generate troubles for the parents. The second is the stress resulting from the child's intellectual disability. In the latter case, the sources of stress may include the diagnosis of disability, non-adaptive behaviours of the child, developmental difficulties or additional health complications (Abidin, 1995). Brian Abery argues that the variables mentioned with respect to the first and the second type of stress refer to the sense of parental efficiency, the trust in professional help, the sense of competence as well as the parent's beliefs, values and expectations (Abery, 2006). According to Gary Peterson and Charlesa B. Hennon, both types of stress cause an increase of tension in the family system as well as emotional instability and excessive reserve in the family members' behaviour (Peterson, Hennon, 2005, p. 34). Regarding the emotional instability, one must underline that it is particularly excessive in families with small children suffering from Down syndrome. Hanna Liberska and Mirosława Matuszewska observe that such families show a chronic experience of stress (Liberska, Matuszewska, 2011). Such a situation can lead to social isolation or heavy depression (Beckman-Bell, 1981; Keller and Honig, 2004). Parental stress in families with small children seems to result from the discrepancy between the higher level of care-related needs in the case of children with retarded or irregular development and the parental competences and the level of acceptance of the child's disability (Saloviita, 2003). The low sense of competence, the insufficient adaptation to the parental role and the parents' sense of being in a negative situation constitute the key factors of the parental stress among parents who raise children with Down syndrome (Saloviita et al., 2003). In addition, it must be emphasised that mothers and fathers differ in the way they define their

role of a parent of a disabled child. For mothers the negative aspect of motherhood is related to the behavioural problems caused by the child, while fathers give more attention to the social lack of acceptance of the child (Saloviita, Italinna, Leinonen, 2003)

Studies of the parental stress also show that the stress related to the process of adaptation of the mother and the father of a child with intellectual disability to their parental role touches both the parents and the child and it can have a considerable impact on the disabled child's well-being as well as emotional and social development. Kościelska describes this interdependency as a mechanism of mutual influence between the mother and the child. While observing how mothers of intellectually disabled children fulfil their care-related and upbringing duties, the author noted that the mother's level of adaptation to the parental role had an impact on how the child functioned (Kościelska, 1998, p. 68).

Hanna Liberska and Mirosława Matuszewska (2011) arrived at similar conclusions. The researchers argue that a disabled child tends to disorganize the family life and destabilise the existing system to a larger or lesser degree. It can be seen in the basic spheres of life, i.e. emotional, social, axiological and economic (Liberska, Matuszewska, 2011). Moreover, when a disabled child enters the family and disrupts the balance in the system, other family members may lose the sense of safety (Kulik, Otrębski, 2011).

The achievement of the emotional balance and the related stability in the family can happen when the parent become fully adapted to the role of a parent of a disabled child in emotional terms (Liberska, Matuszewska, 2011).

Problem-coping strategies of parents of children with Down syndrome

There is a general consensus that the way parents cope with problems causes by the child's intellectual disability contributes to improvement of their cognitive abilities as well as the control over

emotions and behaviours (Turnbull et al., 1993). However, few studies contain an in-depth analysis of the problem-coping strategies among families of persons with Down syndrome. Problem-coping is defined as thoughts and behaviours used to manage external and internal requirements in order to deal with stressful situations (Folkman and Moskowitz, 2004). Two types of stress management strategies have been identified. The first strategy is problem-oriented and refers to the efforts that aim to cope with the stress sources through a change in behaviours of particular people, a change of environmental conditions or by combining these two. The second type is the emotion regulation which covers all efforts to reduce the emotional exhaustion and to maintain a satisfactory internal balance (Folkman, Lazarus, 1988). These types of stress-coping responses are interrelated: they complement each other and are strictly tied to emotional reactions. In general, parents felt better (a lower level of depression and psychosomatic symptoms, a higher level of self-reliance and self-acceptance) if they used the adaptive strategy in coping with stress (Folkman, Lazarus, 1988).

Very few cross-cultural studies on stress-coping strategies of parents raising children with Down syndrome demonstrated results similar to those revealed in the early research (Lam and Mackenzie, 2002; Sullivan, 2002; Van Riper, 1999). For instance, Lai-Wah Lam and Ann E. Mackenzie (2002) described the cases of Chinese mothers raising children with Down syndrome. The results showed that these mothers frequently used stress-coping strategies consisting in the avoidance of stress factors and the search of social support. Anthony Sullivan's comparisons of mothers and fathers raising children with Down syndrome revealed several gender-based differences in the parental strategies of stress management. Women scored much better than men in terms of seeking emotional and social support, control of emotions and their expression as well as limitation of competing activities (Sullivan, 2002).

Another study of the relation between the cognitive style of stress coping by mothers (acceptance, avoiding stress factors), the emotional state and sensitivity consisted in observing 56 mothers

and their children with Down syndrome for the period of 2 years (Atkinson et al., 1995). Stress coping was analysed in the context of cognitive processes and the regulation of affective disorders, while sensitivity was evaluated on the basis of the quality of the mother-child relations. Results indicated that approachability and the avoidance of stress factors kept stable for 2 years. These variables of stress coping translate in a complex way into the sufferings of parents raising children with Down syndrome. The mothers with a strong tendency to react to stress factors indicated more extensive affective disorders than the mothers who adopted a less sensitive approach to stress management. On the other hand, the cognitive avoidance of stress factors and affective disorders reduced the behavioural sensitivity of the mothers towards their children (Atkinson et al., 1995).

Social support and its importance in parental stress management in families with an intellectually disabled child

As mentioned before, the process of adaptation to the role of a parent raising an intellectually disabled child is difficult and extremely stressful for both the mother and the father. Coping with parental stress is a constant challenge for mothers and fathers and it increases the significance of the available types of social support. Social support gives the parent of an intellectually disabled child the sense of being cared for, the sense of belonging to a community of people with similar problems and the conviction that his or her experiences may be valuable and helpful to others (Dunst, Trivette and Deal, 1988).

Helena Şek, argues that the proper understanding of social support requires the context of the knowledge about how people function in a social group, in interactions with others, and in the existing problematic and difficult situations (Şek, 1986, p. 791ff.). Social sup-

port can be conceived in multiple ways: 1) as an individual perception of the supporting network that is available to the individual; 2) as a result of a supporting social exchange; 3) as a specific type of support given to the individual (Johnson, 1992). Usually, this term is used interchangeably with relations, ties, bonds and social relationships (Kacperczyk, 2006, p. 18). Following Żółkowska, it can be assumed that social support is dynamic and depends on the individual's current situation and the entire course of life. One should note that support is perceived subjectively and cannot be a measure of how the social environment responds to the individual needs of parents and persons with intellectual disability (Żółkowska, 2004, pp. 327-328). Social support brings many benefits, the most important being the affirmation of one's effectiveness, which may be crucial in rebuilding the faith in oneself in the face of weakened parental effectiveness (Lent, 2004).

Social support may take the form of simply being with and for the other person, providing financial assistance or vital information. Keeping someone company creates the feeling of closeness, recognition and appreciation. Financial assistance is about providing resources and actual help, while the informational support pertains to counselling and advice. Support and assistance may be given in various ways, e.g. a formal assistance (from psychologists and teachers) and informal help (from a friend or another parent)

The support satisfaction assessment is an important indicator of how parents evaluate the benefits of the support they receive and how capable they are of actually using that support (Shin, 2002). According to Hyun Song *Shin*, the factors that influence satisfaction are personal qualities of the parent of the disabled child, especially those which make the parent accept the offered support (Shin, 2002). Sullivan believes that gender may also impact the satisfaction with the support. The author considers the parental expectations regarding the support. According to Sullivan, women expected emotional support more often and needed to verbalise their experiences, while men tended to focus on the financial assistance and advice on problem solving (Sullivan, 2002).

Malka Margalit (Margalit et al., 2006) also performed some interesting research on the satisfaction with the provided support in the case of mothers having babies with Down syndrome. The studies revealed that the mothers' expectations regarding the support and direct assistance for the babies depended on their perception of their personal strength and the sense of their family's consolidation. Strong mothers that were confident about their efficiency, but experienced instability in the family and voiced their concern about the lack of social support, tended to see the early intervention personnel as a substitute of the family, saying: "I have found a new family."

Mothers lacking self-confidence but living in a consolidated family did not look for a "new family", but expressed their satisfaction with the family support programme, saying: "They help me believe that I can help my child" (Margalit et al., 2006). According to Victor Florian and Tamar Krulik (1991), the parents' sense of social isolation can be another factor that impacts the level of satisfaction with social support. Their research reveals a negative correlation between the accessibility of social support and the sense of abandonment among mothers.

Conclusion

In conclusion, parenthood is a significant factor that gives the sense of safety to a young person and defines his/her status in the family system and in society (Ziemska, 1973, 1979). By performing the parental role, men and women can satisfy their own needs, e.g. recognition, respect or self-development, and the children's needs, e.g. conveying values and knowledge, catering for their development and preparing them to function in society (Rostowska, 2009). On the other hand, the birth of a child with Down syndrome is a difficult situation, often unexpected and described as a trauma (e.g. Będkowska-Heine, 2003; Kościelska, 1998; Liberska and Matuszewska, 2011; Żyta, 2004). When referring to parents of intellectually disabled children, it is more adequate to define the role acceptance

process as a multi-staged adaptation to the parental role (Będkowska-Heine, 2003; Emde, Brown, 1978; Kościelska, 1998).

Since 1980, researchers have been modifying their perception of Down syndrome as the cause of psychopathology in a family by introducing the concept of the child's disability as the stress factor within the family system (Gath, 1977; Hodapp, 2003, Kościelska, 1998; Kulik and Otrębski, 2011; Liberska, Matuszewska, 2011). In line with this change of perspective, the child's intellectual disability as the stress factor in the family may lead to serious negative effects for the parents, such as mental stress, depression, somatic ailments as well as separation or divorce of the spouses (Cummings et al., 1966; Friedrich and Friedrich, 1981). On the other hand, the child's intellectual disability can reinforce the parents by giving meaning to their parenthood, which is also reflected in other aspects of the family life, e.g. the family's consolidation level, positive communication between parents or benefiting from social support (Będkowska-Heine, 2003; Greenberg et al., 2004; Hodapp et al., 2007; Kościelska, 1998; Liberska and Matuszewska, 2011; Żyta, 2004).

Parental stress seems to result from the combination of enlarged care-related needs of the child with retarded or irregular development and the emotional reactions of the family to the fact of disability (Saloviita, 2003). The choice of the coping strategy can improve the parents' cognitive abilities and competences of emotional and behavioural control and it also facilitates a more positive assessment of their intellectually disabled child (Turnbull et al., 1993). By analogy, if parents are able choose a more beneficial, task-focused coping strategy, adaptation to the parental role proceeds more fluently and more adequately (Abery, 2006; Lackaye and Margalit, 2006; Van Riper, 2003).

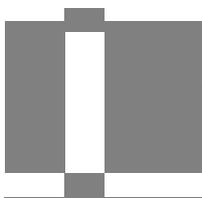
In general, the process of adaptation to the role of a parent of a child with Down syndrome is difficult, multi-staged and stressful for both the mother and the father. Coping with parental stress is a constant challenge for mothers and fathers of a child with Down syndrome and it increases the significance of different types of social support. Social support is vital for the adaptation process of

a parent of a child with Down syndrome to the parental role, since it develops the sense of being cared for, the sense of belonging to a community of people with similar problems, the sense that someone listens and understands and of being able to give support to other people with similar experiences (Dunst, Trivette and Deal, 1988).

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From being a teenage mother to adult life according to a woman with intellectual disability

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For women with intellectual disabilities, maternity is exposed to many factors that hinder this process. Related research shows that one of the main reasons for that is insufficient or inept support for this group of women within a wide range of realms, including educational, financial, cognitive and emotional support. Teenage mothers with disabilities face particularly difficult situations. This paper presents an analysis of statements by an adult woman with mild intellectual disability about her experience of teenage pregnancy and then motherhood as an adult woman. The humanistic approach of inviting the respondent to speak openly allowed the author to determine other meaningful matters in the woman's life (among others, her romantic relationships, her relationship with the mother, her vision of her own future and her financial situation). The research methodology used was qualitative. Two open interviews were conducted 8 months apart. The interviews were recorded with an electronic device. The material obtained was then transcribed. Triangulation of the sources was used (two family assistants were interviewed).

KEY WORDS: intellectually disabled woman, teenage pregnancy, maternity, inter-generational transmission, life difficulties

Introduction

Maternity is a concept that evades clear definition. From the humanistic perspective, maternity may appear to be steeped in subjects seen as valuable, or even essential, in life, and not just the woman's life. Maternity is essentially based on two entities: the mother and the child, the theme of motherly love being integral part of the contemporary concept of maternity. According to Małgorzata Karwowska, maternity is recognized as a social role that a woman plays with respect to her child, a role that stands apart from others due to the biological and emotional bond that comes with it. A woman may also undertake this role with a child other than her own by becoming a surrogate or adoptive mother.¹

The researchers investigating maternity in women with intellectual disabilities point to many problems in their pursuing this realm of life. Katarzyna Ćwirynkało and Agnieszka Żyta list three basic groups of factors that hinder the path to maternity, and maternity itself, in women with intellectual disabilities, namely: inadequate sexual education received by those women, adverse biopsychological pre-conditions and their communities. The said researchers argue that the biopsychosocial factors might be associated with intellectual disabilities. The community factors contribute to the quality of parenting more than parent's IQ does². Based on her own research, Dorota Lizoń-Szłapowska claims that maternity in women

¹ M. Karwowska, Being a mother to a child with intellectual disability (*Macierzyństwo wobec dziecka niepełnosprawnego intelektualnie*), Wydawnictwo Uniwersytetu Kazimierza Wielkiego, Bydgoszcz 2007, pp. 38-40.

² K. Ćwirynkało, A. Żyta, *The woman with intellectual disability as a mother – support issues (Kobieta z niepełnosprawnością intelektualną jako matka – problematyka wsparcia)*, "Niepełnosprawność. Dyskursy pedagogiki specjalnej" 2015, No. 18, pp. 113-129; cf. U. Bartnikowska, K. Ćwirynkało, A. Chyła, *Disability and maternity – possibilities and barriers. A phenomenological study of mothers with intellectual disabilities (Niepełnosprawność a macierzyństwo – możliwości i bariery. Studium fenomenograficzne samotnych matek z niepełnosprawnością intelektualną)*, "Studia nad Rodziną" 2013, XVII, No. 2(33), pp. 29-52.

with intellectual disability is full of contradictions and exclusions. Maternity is done by intuition, and the way those women pursue their roles of mothers is largely situational. This observation has been particularly noticeable in women with moderate intellectual disabilities. The quality of maternity depended on past life experience, mother's current life situation and their individual abilities and dispositions.³ The key problem in mothers with intellectual disabilities, especially those with more severe degrees, is their immediate families' disinterest in those women's maternity. They are often left alone with their life choices⁴. Women with intellectual disabilities approach maternity based on their own life experience⁵. Some researchers point to declarations or concrete actions by parents who assist their adult children with intellectual disabilities in many tasks essential from the perspective of this stage of life. These largely regard adequate housing conditions, assistance with finding a job and fulfilling necessary formalities, as well as taking care of their grandchildren. The examples they discuss, however, are related mostly to properly functioning families and people with light intellectual disabilities⁶. Although difficulties fulfilling maternity-

³ D. Lizoń-Szlapowska, *Motherhood in women with intellectual disabilities in the light of personal research (Macierzyństwo kobiet z niepełnosprawnością intelektualną w świetle badań własnych)*, [in:] *Człowiek z niepełnosprawnością w przestrzeni społecznej*. Volume 11 series: "Problemy edukacji, rehabilitacji i socjalizacji osób niepełnosprawnych", ed. Z. Gajdzica, Oficyna Wydawnicza "Impuls", Kraków 2009, pp. 53-57.

⁴ D. Lizoń-Szlapowska, *Maternity in women with intellectual disabilities in the light of personal research (Macierzyństwo kobiet z niepełnosprawnością intelektualną w świetle badań własnych)*, [in:] *Człowiek z niepełnosprawnością w przestrzeni społecznej*. Volume 11 series: "Problemy edukacji, rehabilitacji i socjalizacji osób niepełnosprawnych", ed. Z. Gajdzica, Oficyna Wydawnicza "Impuls", Kraków 2009, pp. 53-57.

⁵ A. Żyta, *Marriages and parenthood in people with intellectual disabilities – challenges of modern times (Małżeństwa i rodzicielstwo osób z niepełnosprawnością intelektualną – wyzwania współczesności)*, "Edukacja Dorosłych" 2013, No. 2, pp. 59-71.

⁶ M. Grütz, *People with intellectual disabilities as partners, spouses and parents – previous research reports (Osoby z niepełnosprawnością intelektualną jako partnerzy, małżonkowie i rodzice – dotychczasowe doniesienia badawcze)*, [in:] *Dorośli z niepełnosprawnością intelektualną w labiryntach codzienności. Analiza badań – krytyka podejść –*

related roles in this group of women are readily predictable, the problem is continues to be marginalized and relegated to the margins of social life.⁷

Teenage maternity is also related to a number of social, legal, economic and even medical problems. Researchers investigating teenage parenthood in people with intellectual disabilities point to multi-factor causes of this situation, including the search for emotional support, care and love, and loneliness, which result in relationships with random people, abnormal relationships with parents, living life from day to day, inability to predict consequences, and low sexual awareness.⁸ It is also worth mentioning that teenage pregnancy might impact one's capacity of building their future⁹.

Methodological assumptions of author's own research

This research aims to provide insights into how a woman with intellectual disability views her own teenage maternity and how she copes with maternity as an adult. This research project is dedicated to an adult woman's former experience of teenage motherhood as

propozycje rozwiązań, ed. B. Cytowska, Wydawnictwo Adam Marszałek, Toruń 2011, pp. 175-203.

⁷ D. Lizoń-Szłapowska, *Maternity in women with intellectual disabilities in the light of personal research (Macierzyństwo kobiet z niepełnosprawnością intelektualną w świetle badań własnych)*, [in:] *Człowiek z niepełnosprawnością w przestrzeni społecznej*. Volume 11 series: "Problemy edukacji, rehabilitacji i socjalizacji osób niepełnosprawnych," ed. Z. Gajdzica, Oficyna Wydawnicza "Impuls," Kraków 2009, pp. 53-57.

⁸ D. Sidorczuk, *Early maternity in women from special educational centres, and factors contributing to the phenomenon (Problem wczesnego macierzyństwa wychowanek ze specjalnych ośrodków szkolno-wychowawczych a czynniki powodujące powstawanie tego zjawiska)*, "Niepełnosprawność i Rehabilitacja" 2002, No. 3, p. 58; D. Lizoń-Szłapowska, *Usamodzielnianie wychowanek specjalnych ośrodków szkolno-wychowawczych*, "Problemy Opiekuńczo-Wychowawcze" 2004, No. 8, pp. 31-32.

⁹ Teenage Pregnancy – March of Dimes, cf. source: <http://www.marchofdimes.org/materials/teenage-pregnancy.pdf> [accessed: 15.09.2016].

well as her ensuing adult motherhood. The main question behind this research is the following: how does the woman with light intellectual disability view her once teenage maternity and ensuing adult motherhood? The author has also sought to answer detailed questions: What were the difficulties that the respondent had to face in her role as a teenage mother and then an adult mother? How did she cope with her duties as a teenage mother? How does she deal with her duties as an adult mother? Was she/has she been supported during her teenage and adult pregnancy? If so, how? What is her relationship with the daughter she gave birth to while being a teenager and with the children she gave birth to as an adult? The approach whereby the respondent was asked to speak openly helped the author to identify other relevant issues in respondent's life such as her romantic relationships, her relationship with her mother, her vision of her future, and her material status. Research methodology primarily used a qualitative strategy. Two free-form interviews were conducted, including one retrospective. Each interview took approximately one hour. They were held separately, at eight-month intervals, at respondent's place of choice. The interviews were digitally recorded. The content of the recordings was then transcribed. The author also provided for triangulation of sources by interviewing two family assistants. The respondent was picked deliberately. She was required to meet the criteria of sex (woman), having been diagnosed with intellectual disability and having experienced teenage maternity. At the time of the interviews, our interviewee named Alicja (all names have been changed) was 38 years old. She is a mother of four children: Magdalena (21 years old), Marcin (13 years old), Jeremi (10 years old) and Kamil (7 years old). She gave birth to Magdalena as she was nearly 17 years old. She got married for the first time with the father of the two youngest children. They have since divorced. Alicja completed elementary education and grew up in a complete family. She lives in an old house of basic standard (bathroom, kitchen, bedrooms). She does not work professionally. Her revenues largely come from her social pension and children benefits.

Analysis of the results

The analysis of the statements provided by my respondent helped me identify the main themes that materialized as early as the first interview. They were given relevant names that stress a given stage of my respondent's life, her roles, and point to people important in her life. Based on the themes identified, the author has carried out an analysis of statements that highlight a section of Alicja's life between her teenage maternity and the present day, with an emphasis on the problems she faced and the ways in which she coped with them. The research materials generated within this project are presented in the following chronological order: 1. Alicja, a teenage student; 2. Alicja, a teenage mother; 3. Alicja, a teenage daughter of a teenage mother; 4. Alicja, a mother to Magdalena and three sons; 5. Alicja and her partners; 6. Alicja and her future. During the second interview, Alicja said nothing that would require adding another theme. Not only has the second interview allowed the author to better understand many of the issues, but it has also revealed new situations, important not only to the respondent, but also to those around her. Thus, the originally defined analytical order has been kept.

Alicja, a teenage student

School appears almost in the very beginning of the interview. Alicja got pregnant as a teenager. She attended a special school at the time. She claims she had some child conception knowledge. When taking up her sexual life, she had little fear that she could get pregnant. She did not think about possible consequences of her actions. The respondent reduces sexual life and the related thought of a possible pregnancy to her ability of handling men, as she puts it. Her knowledge of sex life was rather superficial. My respondent said that she had had no negative emotions as she found out about her pregnancy. "I normally accepted it, not that 'Oh my God, what

am I going to do?’ and so on; no, or ‘what should I do to’, no, no.” It might be that the time between her teenage pregnancy and now has made her view herself as a kind of a heroine, a courageous and resourceful woman. Her description of the way her family members responded shows the merely apparent calm of the young girl she was at the time. Alicja continued to attend school while being pregnant. She did not feel alienated. She says: “I was not the first and not the last one. It was not a shock, as they say.” At that time, other girls were pregnant, too. Her saying that her friends were in much worse situations than herself reveals some concerns, or difficulties, that teenage Alicja had to face. She mentions that one of the students had her child taken away. She doesn’t understand why she didn’t get a set of infant necessities from the school, as opposed to her friend. She recalls incidental sex education activities at school (e.g. watching a film) and then sums up: “(...) but you know, school does not pay attention, right? Not at all.” Her school did not offer any infant care classes, either. The woman did not feel the need to talk to a psychologist, a counsellor, or a trusted teacher. She does not recall any initiative of this kind on the part of the teaching community. She attended all of the classes yet she was released from physical education classes. She handled pregnancy well. However, nobody prepared her until she gave birth. She gave birth naturally, just as she did with the second child 8 years later (another two babies were delivered with a Caesarean section). She does talk much about the childbirth itself. She does not remember her midwife well. Following the childbirth, she discontinued her education. She was in the first grade of the vocational school. She did not return to school. Her teacher encouraged her to continue studying but she did not want to. The school, specifically a school counsellor, advised young Alicja to put the child in an institution. She says that she had been a sociable person before she got pregnant. She admits to have had skipped classes sometimes and hung out with boys, but she has changed her lifestyle since she found out she was pregnant.

Alicja, a teenage mother

As she recalls her teenage pregnancy, she pictures herself as a mother girl who was self-reliant and able to cope well with new responsibilities. She appears to have been a stubborn and consistent girl, able to plan every day, something that, in her opinion, allowed her to combine her being a student and a mother. However, Alicja's statements that follow put that harmony into question. She did not complete the first grade of the vocational school. She confidently asserts that it was her own decision. An argument for that choice was her daughter's health problems, and, arguably, her difficult relationship with her own mother. The latter did not help young Alicja play the roles of both a mother and a student. Asked about her emotions and feelings at the time the first child appeared, and her ways of coping with the new situation, she gives an impression of certain indifference about that event. To her, that event comes down to arranging for the necessities for the infant, which took several months. Alicja could not name anyone who helped her prepare for the childbirth or develop childcare skills. She points to her mother, but she also says her mother was highly critical of her, and despotic, and this led to conflicts between them.

Alicja, a teenage daughter of a teenage mother

The respondent claims that her mother offered her virtually no help as Alicja became a teenage mother, not the way she was supposed to. She says that her mother „did not fulfil her role as a grandmother". In Alicja's view, "she did not fulfil her promises," which irritated her. Alicja's statements might suggest that the appearance of the child gave rise to conflicts between them. She recalls: "She minded [my child, A.M.], as I left, but she didn't quite feel like it, so to speak." Importantly, the duty of care was taken

over by the mother of young Alicja. In Alicja's view, legal aspects prevailed. Alicja's statements about her relationship with her mother show Alicja's mother as a dominant figure, firm in her stance, possessive, and sometimes even aggressive. Importantly, Alicja claims that her mother in fact "did not fare well." In their strictness and inability to solve life problems, the two women seem very similar. In some situations, they voiced similar views. Certainly, the decision to take care of the child by the family itself rather than to put it in an institution, as advised by the school, was very significant. Alicja resents her mother and harbours a grudge against her for her dominance and imposing style in assisting Alicja with becoming a parent. Her mother did not accept Alicja's being a mother. Alicja tried to fight for her own position, which caused frequent conflicts. The way Alicja's mother helped her might have denied Alicja's new parental identity. The statements of the respondent show that Alicja wanted to fulfil the role of a mother. She did not want to give it up. However, she felt being pushed aside, even in situations she could have tried to tackle. Her mother did not explain various decisions regarding the child to Alicja. These circumstances have likely caused an increasing sense of disorientation and helplessness. The disturbed relationship between the mother and the daughter have continued to be so to this day. Alicja feels that her mother incessantly criticizes her and does not take her seriously, nor does she understand adult woman's needs. She explains: "You know, she's come here lately and tried to impose things on me, said I shouldn't do this or that. It's not that I want to have a relationship with another man; it's just that I need someone to visit me and spend some time with me, too. She thinks that a man coming here means 'we're having sex'. It does not (...). It is not about that. I say 'Mind your own business. I'm almost 40 and you're telling me what to do. You must be out of your mind!' (...) I think we will never agree on that point." Rejected in her becoming a mother and devoid of emotional support, Alicja has been losing trust in her mother.

Alicja, a mother to Magdalena and three sons

Magdalena was an unplanned child. The mother claims that Magdalena has never asked about her biological father. Similarly, Alicja's son Marcin has never asked about his (Alicja's another partner). The woman is experiencing parenting difficulties. Undoubtedly, the conflict with her ex-husband is one of the factors that loosen the relationships between family members. Alicja is concerned about her ex-husband's conduct that can impact the relationship between the siblings from the other relationships. The youngest sons see their father on weekends. Alicja dedicates a vast section of our conversation to Magdalena, mostly her current situation. It is easy to see the pattern of biographical themes of a mother and daughter, and even of a grandmother, being replicated. Alicja believes that her daughter is immature. During our first conversation, the respondent expressed her concern over her daughter's pregnancy, even though her daughter is 21 years old (during an interview with the family's assistants and another meeting with Alicja, it turned out that Magdalena was not pregnant). Alicja pictures her daughter as a careless woman that does not cope well with basic home chores. The tone critical of her daughter masks her actual anxiety about her daughter's future: "(...) Sometimes, I fear that they might take it away. I really do. – A child? [A.M.] – Yes, because she is really unprepared." Alicja excludes the possibility of supporting her daughter: She justifies it with a statement: "My mother says she doesn't want her". It seems that she is still under her mother's influence and cannot cope with some of Magda's difficult behaviours. Magda is a graduate of a special school previously attended by her mother. She is currently working abroad. This puts Alicja's pessimistic claim that her daughter is not resourceful in question. The relationship with her is conditional, even when it comes to providing help. Alicja presents a world that is a threat to her daughter: "you either work here and chip in or we have to say goodbye to each other. Go and rent a room or rent it with someone. You will see what it means to pay bills (...) She was scared because she knew she

wouldn't handle it. When I was moving out myself, I kept wondering if could fare well, too." The last part of the statement shows that the mother understands her daughter's emotional state because she had experienced similar situations herself. However, Alicja does not justify Magda's conduct, which she considers reckless, or irresponsible, as she says: "You know, she lives from day to day; if there is tomorrow, then there is tomorrow; if there is not, then there is not." Magdalena's inability to predict consequences and her carefree life, pointed to by Alicja, characterize Alicja, too. This manifests itself in many parts of her life (her finding out about her pregnancy - "milk has spilled out;" expected parents' reactions to the news about her being pregnant - "she [mother, A.M] wouldn't do anything to me, anyway;" her being pregnant while at school - "I was not the first one and not the last one;" preparation for the first childbirth and related emotions - "well, what is going to be is going to be, right?" To compare the way Magda and Alicja were becoming adults, Alicja failed to complete her vocational school and secure professional qualifications and find a job. Unlike Magda, who has completed school and became qualified as a cook, and has gained some work experience working abroad, first in the Netherlands and then in Germany. However, despite their life narratives being different, both of them seem to be disoriented on the verge of adulthood. The elements of helplessness correspond with being 'here and now', living from day to day. Alicja's statements imply that Magda has failed to keep a job for a long time. The mother's statements point to several reasons for that: a mistakenly chosen career, helplessness, irresponsibility, and avoiding difficult situations. Magda has also been unable to keep any romantic relationship for a long time. Alicja argues that Magda is the one to blame for the breakup, although she also mentions that Magda's partner abused alcohol (Alicja was in a relationship with an alcoholic, too). She is happy to see that her daughter is not pregnant. She claims that "a child is not a toy" and calls a situation in which a hypothetical father would turn out to be like her daughter 'a disaster'. The mother's concerns are likely related not only to the alleged irresponsibility in her

daughter's adult life. Alicja's relationships with men have also ended in failure. Perhaps the awareness of what being a single mother and related difficulties are like adds to her concerns about the future of possible grandchildren, and Magda. The cross-generational inability to express one's feelings is evident in many statements made by Alicja, including in the context of her relationship with Magda. Magda's fate is arguably not indifferent to her mother. The distance between them results from Alicja's being incapable of building healthy relationship with her child. At times, she tries to understand her daughter. She points to her own experience. She says that she worries about her future. Having raised the first child alone, the limited support from specialists, as well as the patterns of the original family are likely the reasons for problems with another child, which are now aggravating. Alicja explains that Marcin has talked to a judge due to his improper conduct and truancy. After school, he has to attend a sociotherapy centre. He is also provided with support by a court-appointed guardian. Sometimes, a social worker meets the boy, too. Alicja tries to light-heartedly excuse Marcin's conduct by saying that he has not always played truant – sometimes he has just stayed home. However, she hopes that the specialists will successfully influence Marcin and help him change his conduct. When it comes to the two youngest sons, the only thing Alicja says about them is that they have learning issues.

Alicja and her partners

Alicja said little about the father of the first child. It seemed that she did not quite feel like talking about that relationship. The man was 7 years older than her. She describes that relationship in vague terms. As for the circumstances of the first meeting and then her pregnancy, she says curtly: "You know, I didn't give much thought to that. Well, here is a child." She says that they had known each other for quite a while. He was not an accidental man. Asked about how he impressed her, she says: "Well, as usual, as any, as they say,

boy would." He might have not been mentally mature enough to fulfil the role of a father and life partner. The woman recalls: "You know. Well, he learned of my being pregnant, and not that he was dissatisfied; no, he was not against it; well, the milk has spilled out, as they say. On the other hand, though, he showed no resolve to have a family, have a child and so on. You had to hold his hand through this, like a small child. But I don't regret that I was then left alone with the child, that this ended up this way." Alicja has no contact with Magda's father, as is the case with the father of her second child. They do not get to see their fathers, either. She pictures her second life partner, Marcin's father, just as she does the first one. He was a submissive man, but just as uninvolved. Alicja seems to be a woman who is dominant in her relationships. She tells me about her third life partner during a conversation about her attempt to live an independent life. "When the third child had been born, I kind of prompted that partner to do some things with respect to me and my children. If he doesn't, it is over. I tried to make him just make some decision. I prompted him to work, asked him not to do things I don't accept, that is drinking alcohol, 'no hanging out with your buddies'; 'then we will talk', I say. And in the beginning, you know, he was fine with it, but then, well... (...)." Alicja married and then divorced that man. Being a single mother comes with responsibilities she cannot cope with. The difficult relationship with her mother made her fumble around in the dark looking for support in someone else. She has relationships with men who cannot provide herself and her children a stable life, not just in terms of financial support, but also in a sense of security. She is very strict in the way she deals with men. She asks them to meet requirements that are impossible to fulfil 'here and now.' The reasons are certainly addictions, a lifestyle that manifests learned helplessness, and probably a replication of patterns existing in their communities. This kind of authoritarianism with respect to one's life partners is also present in Alicja's mother. My respondent has sought various solutions to improve her marriage, but all of them ended in fiasco. The conflict between Alicja and her former husband has not been

resolved. My respondent is currently meeting a man who is 10 years older and has adult children. Alicja again puts a clear boundary in this relationship: "I am one of those who mean 'yes' when they say 'yes' and 'no' when they say 'no'. I have to make a decision, not him". Is this a manifestation of a strong Alicja who learned to put boundaries and say 'no' from professionals and express her needs and expectations? Or is it building a relationship based on her ideas? It is also possible that she replicates patterns regarding family relationships that she observed and experienced in her own childhood and then adult life. Alicja's mother also comes across as a dominant woman, and her husband is a secondary figure. Alicja stresses the need to make a decision about her relationship only by herself. She does not take her partner's stance into account.

Alicja and her future

Alicja says that she is not ready for a serious relationship with another man. She doubts that she may yet have a satisfying relationship. She argues that the main reason is that she has four children. Her female dreams boil down to having a flat of her own. Asked about children, she says that she would like to provide them with a sense of security, that is to provide them with their own place. Alicja's dreams are entangled in her complex life matters. During our second conversation, she said: "Well, I am just thinking about the apartment; the day after tomorrow, I'm going to see a lawyer because my ex-husband reported a change of my address and is going to deprive me of this apartment, so that I wouldn't be its co-owner".

Summary

Alicja's recollections point to a few important issues significant from the pedagogical perspective. The first theme regards the very phenomenon of teenage maternity in girls with intellectual disabili-

ties. The scale of this phenomenon is yet to be identified. Just as the phenomenon of fatherhood in male teenagers with intellectual disabilities. Another problem identified that is stressed in literature is the low level of sexual education in persons with intellectual disabilities¹⁰. Since teenage pregnancy is a phenomenon that also occurs among students of special schools, educational programmes using infant simulators might be an interesting solution to address to those with more profound intellectual disabilities¹¹. The question remains: do today's school and other institutions help teenage mothers go through pregnancy, prepare for childbirth, develop child care skills more than at the time my respondent grew up? This applies especially to the group of young women who cannot rely on their families. Teenage motherhood may entail more than a risk of delayed educational process. Contemporary schools, with the support of Psychological and Pedagogical Counselling Centres, make it possible for teenage mothers to continue and complete their education. However, one cannot exclude a situation where girls on the verge of adulthood make decisions to discontinue their education due to the lack of support from their families, thus making such a choice out of necessity. The failure to complete her education has had a large impact on my respondent's life later on. Alicja has been unemployed and has not secured professional qualifications to this day. In fact, until recently, she has lived in a dysfunctional commu-

¹⁰ W. Dykciak, *Preparing young people with intellectual disabilities for sexual lives as part of prospective marriage and family life (Przygotowanie młodzieży upośledzonej umysłowo do życia seksualnego jako element przyszłej samorealizacji małżeńskiej i rodzinnej)*, [in:] *Drogi samorealizacji młodzieży dorastającej*, ed. L. Niebrzydowski, Wydawnictwo Uniwersytetu Łódzkiego, Łódź 1997, pp. 165-172; A. Mach, *Young people with intellectual disabilities in the light of marriage and family life (Młodzież z niepełnosprawnością intelektualną wobec życia w małżeństwie i rodzinie)*, Wydawnictwo Uniwersytetu Rzeszowskiego, Rzeszów 2015, pp. 71-84.

¹¹ A. Gonera, *Infant simulators and learning parenting (Symulatory niemowlęcia a uczenie się rodzicielstwa)*, "Niepełnosprawność. Dyskursy pedagogiki specjalnej" 2015, No. 20, pp. 190-200; cf. R. Kijak, *Sexuality in man with intellectual disabilities and family matters (Seksualność człowieka z niepełnosprawnością intelektualną a rodzina)*, Wydawnictwo Lekarskie PZWL, Warsaw 2014, pp. 107-120.

nity and her attempts to change it would have been much easier if she had a job. The financial aspect aside, employment usually affects one's self-esteem and provides opportunities to meet other people. Employment usually provides opportunities of detaching oneself from their adverse community and thus finding a life alternative, another lifestyle. Educational deficiencies that often affect teenage mothers make them less competitive in the job market¹². Mieczysław Radochoński et al. argue that "premature parenthood is correlated with many other risk factors that might affect the future of a child such as low economic and professional status and single parenthood. As a result, such a child's physical, intellectual and emotional growth might be compromised compared with their peers, and this facilitates transmission of behavioural disorders from one generation to another."¹³ While examining respondent's statements, it is easy to see that the respondent replicates her mother's life patterns and methods of interacting with her loved ones, including those who she does not accept. These similarities are also noticeable in Alicja's daughter. It turns out that, in parenting, women are the carriers of tradition, whereas men are the carriers of change. Accordingly, the women of the three generations demonstrate similar expectations, values and judgments, as well as expectations regarding the time of parenting (young-adult mother; mother-grandmother; young adult-grandmother)¹⁴. The presented sections of respondent's life reveal difficulties in establishing personal, partner, marriage and parenting relationships.

¹² Cf. Jones K. H., Woolcock-Henry C. O., Domenico D. M., Wake up call: pregnant and parenting teens with disabilities, "The International Journal of Special Education" 2005, Volume 20, No. 1, p. 97.

¹³ M. Radochoński, L. Perenc, A. Radochońska, *Family and antisocial behaviour (Rodzina a zachowanie antyspołeczne)*, [in:] *Psychologia rodziny*, ed. I. Janicka, H. Liberska, Wydawnictwo Naukowe PWN SA, Warszawa 2015, p. 523.

¹⁴ M. Farnicka, H. Liberska, *Intergenerational transfer - processes occurring between generations (Transmisja międzypokoleniowa- procesy zachodzące na styku pokoleń)*, [in:] *Psychologia rodziny*, ed. I. Janicka, H. Liberska, Wydawnictwo Naukowe PWN SA, Warsaw 2015, p. 201.

The support for teenage mothers, including with disabilities, should take their families into consideration. What best explains it are the words of my respondent about her own experience, which has determined her life to come: "Regret? I don't regret. But if I had had my head screwed on like I do now, then that wouldn't happen. Maybe it would happen later; well, maybe. But it just happened so, let it be so, then. I dunno, maybe I just copied that, you know, from my mother. Because my mother was about 17, too [laughs], I dunno, it seems hereditary, doesn't it? I dunno".

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Special gerontology (geragotics) as the area of research and reflection for special pedagogics: Selected issues

ABSTRACT: Iwona Chrzanowska, *Special gerontology (geragotics) as the area of research and reflection for special pedagogics: Selected issues*. Interdisciplinary Contexts of Special Pedagogy, No. 17, Poznań 2017. Pp. 117-141. Adam Mickiewicz University Press. ISSN 2300-391X

In the text, an attempt was made to analyse selected issues related to gerontology in the relationship to people with disabilities. The context of analyses is the tendency of social ageing tendencies, observed in Poland and in the world, especially in European countries. Selected areas of reflection are combined with the conviction that there is a need for research which would fill in the gap in the field of research carried out so far, focused on the issue of the broadly defined life situation of the people with disabilities in the senior years, which is in the scientific merit of Polish special needs education (pedagogics). There is a justified fear that these individuals are more likely to experience marginalisation and exclusion in many areas of life than people of similar age in the general population.

KEY WORDS: old age, person with disability, life situation

Introduction

The issue of disability and the functioning of people with disabilities has been the focus of many disciplines in recent decades, not only in the field of social sciences. More frequently people with dis-

abilities are taken into consideration while designing buildings, or urban infrastructure. There are entire sections of technological sciences devoted to the design of medical and rehabilitation equipment, as demand is growing and the forecasts, especially demographic ones, indicate that it will continue to grow.

Undoubtedly, the development of the humanities and social sciences, the dissemination of the tendencies promoting human rights to general rights, as a basis for building social order, have also contributed to the development of interest in the issue of disability and people with disabilities. As a consequence, the slogans of necessary counteraction to exclusion and marginalisation of human beings due to any aspect of developmental impediments, which are in relationship to individual socio-cultural, economic or geographical conditions of life, have emerged.

Human rights, identified with the natural laws that all people have, meant in fact that people could not be differentiated for any reason and therefore be assigned with different catalogues of rights. Such understanding became common (at least in part of the world) not so long ago, only in the second half of the 20th century. The formal beginning of the primacy of such a way of thinking could be seen at the turn of the 1940s and 1950s, when the Universal Declaration of Human Rights was enacted¹. From this point, international documents dedicated to particular groups of people with disabilities also began to appear. In others, records that refer to selected categories of social order, problem areas, signalling the lack of equal treatment, the right of people with disabilities, appeared².

¹ Universal Declaration of Human Rights, http://www.unesco.pl/fileadmin/user_upload/pdf/Powszechna_Deklaracja_Praw_Czlowika.pdf [accessed on 2 February 2013].

² *Declaration on the Rights of Mentally Retarded Persons* (1971) stresses the fact that mentally disabled persons have the same rights as other people and establishes specific rights for these people, resulting from their needs <http://www.ohchr.org/EN/ProfessionalInterest/Pages/RightsOfMentallyRetardedPersons.aspx> [accessed on 31 May 2014]; *Declaration on the Rights of Disabled Persons* (1975), confirming that persons with disabilities have the same civil and political rights as other people <http://www.ohchr.org/EN/ProfessionalInterest/Pages/RightsOfDisabledPersons>.

The socio-political doctrine, which was undoubtedly dominant in Poland until the 1990s, was not without significance for the development of ideas and research related to the issue of equal treatment, exclusion and marginalisation of people or social groups. Years of delay resulting from the past social system are still a burden for many scientific disciplines in the social sciences and the humanities. In the case of special needs education, the examples of delays are best illustrated in the ratification of UN and EU declarations, resolutions, directives on human rights, equal treatment and disability. For example: The European Social Charter, enacted in Turin in 1961, was ratified by Poland in 1997; The Charter of Fun-

aspx [accessed on 31 May 2014]; General Assembly Resolution from 1976, establishing the year 1981 the International Year for Disabled Persons. That year, the international, regional and national action schemes for people with disabilities came into existence, envisaging contribution for equalization of opportunities, healthcare, rehabilitation and preventing the onset of disability; *World Programme of Action Concerning Disabled Persons*), adopted as a UN General Assembly Resolution on December the 3rd, 1982; http://www.who.int/disabilities/policies/standard_rules/en/ [accessed on 31 May 2014]; *Tallin Guidelines for Action on Human Resources Development in the Field of Disability*, adopted in 1989, pertaining to education and employment of disabled people by government institution and at all levels of public authority jobs, in order to equalize the opportunities for the people with disabilities. <http://www.un.org/documents/ga/res/44/a44r070.htm> [accessed on 31 May 2014]; *Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care*, adopted in 1991 as one of the last documents of the UN Decade of Disabled Persons, proclaimed in the years 1983-1992 by the UN General Assembly. The document contains 25 main rules that regulate the rights of the people with intellectual disabilities. <http://www.un.org/documents/ga/res/46/a46r119.htm> [accessed on 31 May 2014]; *The Standard Rules on the Equalization of Opportunities for Persons with Disabilities*, adopted in 1993 by the UN General Assembly. The document defines the desired directions for the solutions concerning people with disabilities and is considered the basis for creating politics and programs for people with disabilities. <http://www.un.org/documents/ga/res/48/a48r096.htm> [accessed on 31 May 2014]; Convention on the Rights of Persons with Disabilities, adopted by the UN General Assembly in 2006 in order to confirm the rights of people with disabilities, <http://www.mpips.gov.pl/spoleczne-prawa-czlowieka/konwencja-o-prawach-osob-niepelnospawnych/ratyfikacja-konwencji-o-prawach-osob-niepelnospawnych-przez-polske/> [accessed: 1 June 2014].

damental Rights of the EU adopted in Nice in 2000 and the Treaty of Lisbon from 2007, which entered into force in 2009, were adopted by Poland with restrictions; The United Nations Convention on the Rights of Persons with Disabilities, adopted in 2006, signed by Poland in 2007, was ratified (entered into the Polish legal system) at the end of 2012. Ratification of legal acts is delayed due to the need to adjust the internal law of a given state to international regulations. In this case, however, there is an irrefutable reflection that the work on this adjustment is conditioned by the legislature's determination, which in a sense derives from the social rank of the issue. Another problem, not so much of a legislative nature, but more of a social one, is the willingness to receive, accept the suggested solutions³. Against the background of other EU countries, Poland is perceived as a conservative country. Acceptance of differences, resulting from disability, religion, sexual orientation is often a serious problem. Even the existing formal and legal solutions do not pre-judge the possibility of certain discriminatory practices.

Despite the indicated conditions, there is no doubt that the end of the 20th and the beginning of the 21st century became a period of multidisciplinary research on issues of equality, counteracting exclusion or marginalisation, and in this context the phenomenon of disability. Based on this work, it is worth considering the fields of future scientific analyses in the field of special needs education, but also interdisciplinary studies.

Old age of persons with disabilities

An almost absent research issue of Polish special needs education is the old age of people with disability. Either of people with disabilities from birth, early childhood, or with the acquired ones.

³ For example, Poland is currently seen as one of the ethnically „purest” countries of the EU. Because of this, forcing the implementation of the models for coexistence in the multi-ethnic society may be challenging.

In the context of the indicators of the observed, especially in Europe, growth of the elderly population, without the categorisation of people with disabilities, it is also necessary to intensify the cooperation of the pedagogical sub-disciplines of pedagogy (education), especially special needs education, social pedagogy, pedagogy of elderly and ageing people (geragogics) in the field of scientific research, but also practical activities, building systemic activities for the sake of the elderly. This is due to the fact that old age is the time when more and more health problems appear, resulting in reduced efficiency or loss of functionality. It would be worthwhile, however, to ensure that this minimises the quality of human life as little as possible.

For a long time, such activities (subdisciplinary studies on issues) have been undertaken in the case of children and young people. The issue of educational integration, and in recent years especially inclusive education, has prompted researchers of the issues, in the case of special needs education, as well as other sub-disciplines of pedagogy, which are focused on children and young people, to undertake research, analysis and reflection related not only to the isolated group of e.g. students with disabilities or without them, but to recognise the educational situation of the whole group of students. To find the determinants of effective solutions in this area, taking into account the needs of the whole group. Analogous actions must, in my view, be taken also in the context of the problems of old age and ageing.

As Adam A. Zych points out, 'traditional geragogics has so far been concentrated on a normally ageing human being, but the beginning of our century clearly draws attention to the social issues of elderly people with disabilities, the evidenced of it is the creation of special geragogics'⁴. The goals of special geragogics are the same as for gerontopedagogics (geronto-education), but they are explicitly

⁴ A. A. Zych, *Pedagogy of the persons with obtundation as the new field in special needs geragogy (Pedagogika osób z otępieniem jako nowy obszar geragogiki specjalnej)*, LABOR et EDUCATIO, no. 2/2014, p. 275.

addressed to disabled people who are ageing⁵. The author points out that within analysing and reflecting on the 'traditional' pedagogy of ageing and old age, focusing on healthy elderly and ageing people, which develops its sub-disciplines (gerontology of education, geragogics of free time, culture and media, music geragogics), the issue of disabled elderly people remains on the margin of consideration⁶.

An ageing person, even a person who has not experienced disability in the past, will certainly lose efficiency within many functions of the body, so his or her characteristics in old age will be closer in this period of life (than in any previous) to the one of a person with a disability. The experience of special needs education, academic merit of the discipline, can provide important knowledge about not only the difficulties in functioning, but also the consequences of losing efficiency and fitness.

A well-recognised phenomenon in literature is the issue of marginalisation and exclusion of the elderly people in the social sphere. It was the subject of interest of many authors, whose area of scientific interest is a person in senior age. Most often, among the areas of exclusion, there are: poverty (i.a. Kubiak 2011, Szatur-Jaworska 2000, Trafiałek 2003), financial services market (i.a. Kubicki 2013), medical services (i.a. Derejczyk 2001, Trafiałek 2003), digital exclusion (i.a. Szmigielska, Bąk, Hołda 2012) or cultural activity⁷.

⁵ A. A. Zych, *Special needs geragogy – necessity, need or moral obligation? (Geragogika specjalna – konieczność, potrzeba czy moralny obowiązek?)*, in: *Special needs pedagogy in service of the family (marginalisational, resocialisational and psychological aspects) (Pedagogika społeczna w służbie rodziny [aspekt marginalizacyjny, resocjalizacyjny i psychologiczny])*, K. Gąsior, T. Sakowicz (ed.), Kielce: Świętokrzyskie Centrum Profilaktyki i Edukacji, vol. 2, 2005.

⁶ A. A. Zych, *ibid.*, 2014.

⁷ M. Kubiak, *Poverty or exclusion of elderly people (Ubóstwo czy wykluczenie ludzi starszych)*, in: M. Popow, P. Kowzan, M. Zielińska, M. Prusinowska, M. Chruściel, (ed.), *Faces of poverty in modern Poland (Oblicza biedy we współczesnej Polsce)*, Gdańsk: Wydawnictwo UG 2011; B. Szatur-Jaworska, *Elderly people and senility in the social politics (Ludzie starzy i starość w polityce społecznej)*, Warszawa: Wydawnictwo ASPRA-JR 2000; E. Trafiałek, *Old age in Poland in the age of changes (Polska starość*

In the case of people with disabilities in the senior age, the phenomenon of marginalisation and exclusion seems even more serious, as it results from the overlap of exclusion areas resulting from disability and ageing. There is, however, no scientific research that would identify the phenomenon, its severity and consequences for the life situation of this group of people.

Today, in developed countries, averagely one in seven people (in the general population) is over 65 years old. In 2030-2040 it will be every fourth citizen of the world. The projections for the year 2030 indicate that most people over 65 will live in Europe. 43.2% of the continent population will be at age 65 and over.⁸ According to Eurostat's demographic projections, the population ageing process will be even faster after 2035. In Poland, after 2060, median age is expected to exceed 54 years and will be the highest, apart from Slovakia, in the EU⁹.

w dobie przemian), Katowice: WN „Śląsk” 2003; P. Kubicki, *Elderly people on the financial services market. Analyses and recommendations (Osoby starsze na rynku usług finansowych. Analizy i zalecenia)*, Warszawa: BRPO 2013; P. Kubicki, *Poverty and the social exclusion of elderly people (Ubóstwo i wykluczenie społeczne osób starszych)*, www.eapn.org.pl/wp-content/uploads/.../Ubostwo-i-wykluczenie-osob-starszych.pdf [accessed on 24 August 2017], J. Derejczyk, *Geriatrics and the healthcare reform in Poland (Geriatrics, a reforma ochrony zdrowia w Polsce)*, *Służba Zdrowia* nr 61-64, 2001, B. Szmiłgińska, A. Bąk, M. Hołda, *Seniors as the Internet users (Seniorzy jako użytkownicy Internetu)*, *Nauka* 2/2012, L. Frąckiewicz, *Exclusion and social cohesion in view of the process of the aging of population (Wykluczenie i spójność społeczna wobec procesu starzenia się ludności)*, in: M. Halicka, J. Halicki (ed.), *To leave a mark on earth (Zostawić ślad na ziemi)*, Białystok: Wydawnictwo Uniwersytetu w Białymstoku 2006.

⁸ Italy is growing to be one of the oldest countries of the world, demographically speaking. In 2000, over 18% of Italians has reached the age 65 and more; in Greece and Sweden – 17,3%; in Japan – 17%; in Spain – 16,9%; in Belgium – 16m8%; in Germany – 16m2%; in France – 16%, Z. Szweda-Lewandowska, [in:] P. Błędowski, B. Szatur-Jaworska, Z. Szweda-Lewandowska, P. Kubicki, *Report on the situation of elderly people in Poland (Raport na temat sytuacji osób starszych w Polsce)*, IPiSS, Warszawa 2012, p. 21.

⁹ P. Błędowski, *Consequences of the demographic process of population aging as a task for the public administration (Konsekwencje procesu demograficznego starzenia się ludności jako zadanie dla administracji publicznej)*, [in:] P. Błędowski, B. Szatur-Jaworska,

Table 1. The forecast of the population of 65+ people in different regions of the world in 2030

Region	65-75 years	75-80 years	Above 80 years
Europe	24,3%	11,8%	7,1%
Northern America	20,3%	9,4%	5,4%
Oceania	16,3%	7,5%	4,4%
Asia	12,0%	4,6%	2,2%
Latin America	11,6%	4,6%	2,4%
Middle East and North Africa	8,1%	2,8%	1,3%
Sub-Saharan Africa	3,7%	1,3%	0,6%

Source: own elaboration on the basis of K. Kinsella, V.A. Velkoff, *The Demographics of Ageing*, "Ageing Clin. Exp. Res" 2001, 14, p. 160 on: Z. Szweđa-Lewandowska, *Ageing and Old Age - General Characteristics (Starzenie się i starość - ogólna charakterystyka)*, in: P. Błędowski, B. Szatur-Jaworska, Z. Szweđa-Lewandowska, P. Kubicki, *Report on the situation of the elderly people in Poland (Raport na temat sytuacji osób starszych w Polsce)*, IPiSS, Warszawa 2012, p. 20.

With the increase in the population of elderly people, the state expenditure connected with social and health care will increase. Elderly age does not have to be a synonym for poor health and disability. Socio-cultural factors play an important role here. The most important ones are, i. a. gender, social status or cultural experience.¹⁰ A team of researchers led by Piotr Błędowski points out that, among the diagnosed and important features of the ageing process of Polish society, there are: feminisation – by 2030 in Poland it is

Z. Szweđa-Lewandowska, P. Kubicki, *Report on the situation of elderly people in Poland (Raport na temat sytuacji osób starszych w Polsce)*, IPiSS, Warszawa 2012, p. 39.

¹⁰ *Operational Program Human Capital, National Strategic Reference Framework 2007-2013, Ministry of Regional Development (Program Operacyjny Kapitał Ludzki, Narodowe Strategiczne Ramy Odniesienia 2007-2013, Ministerstwo Rozwoju Regionalnego)*, Warszawa, 2007, see: I. Chrzanowska, *Old age with disability (Starość z niepełnosprawnością)*, [in:] *The person and the family in view of losing health and ability (Człowiek i jego rodzina wobec utraty zdrowia i sprawności)*, A. Nowicka, J. Bąbka (red.), Prymasowskie Wydawnictwo Gaudentinum, Lublin 2010, s. 98.

estimated that the percentage of men over the age of 65 will be 40.7%, and at the age of 80 and over approx. 33.5%; singularisation – forecasts indicate a possible high percentage of single-person households among the elderly people (by 2030, 53.3% of one-person households will probably be run by 65-year-olds); regionalization – forecasts for 2030 indicate that the largest percentage of people aged 75+ will live in Łódź voivodship – 12.6%, Dolnośląskie and Śląskie – 12.5%, 12.4%, the only region with a rate below 10% will be Podkarpackie Voivodship (9,9%)¹¹.

The problem of ageing society is becoming increasingly important for many countries (including the EU). Despite the fact that the forecasts have long been known, models of actions aimed at the diverse needs of a dynamically growing group of the elderly people have not been developed.

According to the Madrid International Plan of Action on Ageing, which was ratified by Poland in 2002, the most important areas of action for elderly people were identified. These include: building a friendly society for people of all ages; reduction of poverty among the elderly people (including the idea of productive ageing, employment of elderly workers, education of the elderly people, strengthening of intergenerational relationship); providing for good health of seniors; providing care for care-dependents; promoting intergenerational solidarity and a positive image of the elderly people¹². What are the priority areas for the disabled population? Are these the most important steps that need to be taken to identify the living conditions of older people with disabilities? What are the needs of disabled elderly people and elderly people who have not experienced congenital or acquired disabilities are analogous in old age? These are some of the questions that arise as those that need to be answered in the research of special needs education (pedagogy)

¹¹ P. Błędowski, B. Szatur-Jaworska, Z. Szweda-Lewandowska, P. Kubicki, *Report on the situation of elderly people in Poland (Raport na temat sytuacji osób starszych w Polsce)*, IPiSS, Warszawa 2012, p. 5-6, p. 27.

¹² P. Błędowski, 2010, p. 11.

in Poland, but also in interdisciplinary and subdisciplinary studies within the framework of pedagogy.

To a large extent, and in most countries affected by the problem, system solutions are focused on aid activities. They are often the cause of more or less distinct social divisions, dichotomising and opposing the interests of young people and older people, which, along with the increase of the ageing population, will increase. Especially in countries that did not respond to forecasts early enough and did not launch operations, i. a. educational activities aimed at shaping individual choices as well as social relationships in this field. There is no doubt that, in the case of disabled elderly people, at least some of the problems identified here will be more severe. Unfortunately, disabled people are expected to turn out to be a particularly vulnerable group within social divisions, with a much greater danger of marginalising their needs, and even more social roles.

Contemporary analyses, for example from the local area, which refer to the elderly population (excluding disaggregated analyses referring to disabled elderly people), clearly indicate the factors that determine the quality of life satisfaction of elderly people. These are:

- health condition – in general, the situation is not best among elderly people. Research shows that better educated people and people in the better financial situation have better health¹³. The situation of people with disabilities in the senior age in the context of ‘health condition’ is much worse. Cross-sectional analyses for some groups of people with disabilities show that, for example, people with intellectual disabilities often have additional conditions that, with age, tend to overlap and develop.¹⁴ It seems that education will not have a signifi-

¹³ B. Bień, *Health situation of the people of advanced age (Sytuacja zdrowotna osób w podeszłym wieku)*, [in:] *Geriatrics with elements of general gerontology (Geriatry z elementami gerontologii ogólnej)*, T. Grodzki, J. Kocemba, A. Skalska (ed.), Via Medica, Gdańsk 2006, p. 42-46.

¹⁴ A. Krause, A. Żyta, S. Nosarzewska, *Normalising of the social environment for people with intellectual disabilities (Normalizacja środowiska społecznego osób z niepełnościami intelektualną)*, Toruń: Wydawnictwo Edukacyjne akapit 2010, p. 95.

cant impact in the case of this group of people with disabilities. Financial situation, however, might have. A significant proportion of people with disability, not only with the mental one, get money for life from pensions and attendance allowances. If the elderly person with disabilities still has parents, this situation is overlapped by the additional necessity of the distribution of funds from the household budget for the treatment of the person with disability and his or her parents¹⁵. This is already happening in the period preceding the old age and it is likely to have consequences on the physical condition of people in old age;

- life activity - activity gives life meaning, makes it more interesting and valuable¹⁶. At the same time, it counteracts boredom and the feeling of emptiness, which can lead to the emergence of depressive episodes. And in the context of this indicator, the situation of people with disabilities in old age appears to be less beneficial. Disability does not have to be synonymous with passivity. Here, the significant conditions are the type and severity of disability, but also a number of other variables, which include: developmental support and its effectiveness, access to education, its various forms and its effectiveness, employment, access to employment in the common labour market. Recognition of these, but also other conditions, as well as the relationship between them seems to be a necessary area of scientific analysis in the field of special needs education;
- level of education - studies show that elderly people with higher education enjoy better mental well-being. Good mood is four times more common among people with higher educa-

¹⁵ *Ibid.*, 2010 p. 95.

¹⁶ H. Zielińska-Więczkowska, K. Kędziora-Kornatowska, *Determinants of the life satisfactopn in the late adulthood in view of research findings (Determinanty satysfakcji życiowej w późnej dorosłości - w świetle doniesień badawczych)*, „Psychogeriatrya Polska 7(1) 2010, p. 13.

tion than those with basic one¹⁷. Unfortunately, the situation of people with disabilities at senior age will be more problematic in this area than in the general population, for a simple reason – indicators of people with higher education in the population of people with disabilities are much lower than in the general population. According to BAEL (Study of Economic Activity of Population) data from 2016, 10.8% of people with disabilities have a higher education degree, with 28.6% among those without disabilities. Proportions are reversed for the lowest levels of education: lower secondary, basic, incomplete basic and uneducated: 24% and 9% respectively; vocational qualification: 39.9% and 25.3% respectively¹⁸. Recognising the validity of this criterion as essential for the feeling of the life satisfaction of elderly people with disabilities, it should be recognised that a greater proportion of people with disabilities than those without them will need support in old age in this range;

- optimism in life – as indicated by the results of the study, the highest is among those with higher education performing managerial functions¹⁹. Taking into account previously presented data on e.g. the education of people with disabilities, it seems that the indicators of the optimism of life of elderly people indicated by Janusz Halika will probably not be the most likely precondition for the life optimism of elderly peo-

¹⁷ J. Halik, *Mental wellbeing of elderly people and its conditions (Samopoczucie osób starszych i jego uwarunkowania)*, [in:] *Elderly people in Poland. The social consequences of the aging of the society (Starzy ludzie w Polsce. Społeczne skutki starzenia się społeczeństwa)*, J. Halik (ed.), ISP, Warszawa 2002, p. 71-75.

¹⁸ *Data pertaining to the education of the disabled persons on the basis of BAEL, 24 March 2017, Office of the Government Plenipotentiary for Disabled People (Dane dotyczące wykształcenia osób niepełnosprawnych na podstawie BAEL na dzień 24.03.2017, Biuro Pełnomocnika Rządu ds. Osób Niepełnosprawnych)*, <http://niepełnosprawni.gov.pl/bookmark/education/> (zakładka edukacja).

¹⁹ J. Halik, *Mental wellbeing of elderly people and its conditions (Samopoczucie osób starszych i jego uwarunkowania)*, [in:] *Elderly people in Poland. The social consequences of the aging of the society (Starzy ludzie w Polsce. Społeczne skutki starzenia się społeczeństwa)*, J. Halik (ed.), ISP, Warszawa 2002, p. 71-75.

ple with disabilities. The low proportion of people with disabilities with higher education and the probably lower of people with disabilities performing managerial functions does not necessarily mean that disabled elderly people are not optimistic about life. It is therefore important to recognise what factors condition this state for people with disabilities and, in the context of the elderly, this group of people;

- sense of coherence – the results show that people with a high sense of coherence are less depressive, are more adaptive, enjoy life more.²⁰ In the literature review, I have not found any scientific research directly related to the problem of coherence of people with disabilities in their senior years. In studies executed by Krystyna Kurowska and Iwona Szumacher²¹, which were held among disabled workers at supported employment enterprises in Bydgoszcz (mean age 46 years, age range 24-67 years), it was found that the type of disability is not a factor, which determines the level of coherence. However, the authors point out that the research was done on a small research group (69 people) of the working people, their socio-economic status was therefore higher than of those who were financially family-dependent (p. 97). The sense of coherence is recognised as an important determinant of life satisfaction²². Life satisfac-

²⁰ L. Zając, *Psychological situation of the older person and its determinants (Psychologiczna sytuacja człowieka starszego oraz jej determinanty)*, [in:] *Senility and personality (Starość i osobowość)*, K. Obuchowski (ed.), AB, Bydgoszcz 2002, p. 53-112; A. Antonovsky, *Unraveling the mystery of health. How people manage stress and stay well (Rozwikłanie tajemnicy zdrowia. Jak radzić sobie ze stresem i nie zachorować)*, IPN, Warszawa 2005.

²¹ K. Kurowska, I. Szumacher, *Sense of coherence and the received support among the disabled workers employed in sheltered workplaces (Poczucie koherencji a otrzymywane wsparcie wśród niepełnosprawnych pracowników zatrudnionych w zakładach pracy chronionej)*, *Problemy Pielęgniarstwa* 19(1) 2011.

²² H. Zielińska-Więczkowska, W. Ciemnoczołowski, T. Kornatowski i wsp., *Sense of coherence and the life satisfaction of the auditors in the University of the Third Age (Poczucie koherencji a satysfakcja życiowa słuchaczy Uniwersytetu Trzeciego Wieku)*, *Gerontologia Polska* 19(2) 2011.

tion, in turn, is linked to a sense of quality of life, and one of the most important determinants of it (quality of life) is health²³. Assuming that the health status of people with disabilities at senior age is worse than in the general population, the level of coherence of disabled elderly people should be expected to be low, at least lower than in the general population. Is that so? It is difficult to say, there is a lack of in-depth research in this field in the scientific merit of Polish special needs education. The specificity of the problems with regard to people with disabilities are indirectly reflected in the analyses and reflections of Stanisław Kowalski. Admittedly, in relationship to earlier life period – adulthood – the author writes that in the case of people with acquired disabilities, there might be the reduction of adulthood, the sudden transition to a condition that resembles old age, changes that resemble the situation of functionality loss in old age, which are impossible to reverse²⁴;

- family – especially relationships with adult children are important for a sense of life satisfaction (the higher it is, the higher the level of feeling of happiness due to achievements of a child is). It is also important to have a sense of intimacy with the family²⁵. Adam A. Zych²⁶, in the context of ageing and old

²³ B. Woynarska, *Health education (Edukacja zdrowotna)*, Warszawa: PWN 2007.

²⁴ S. Kowalik, *Adulthood of the disabled people in the light of the lost development theory (Dorosłość osób niepełnosprawnych w świetle koncepcji utraconego rozwoju)*, in: K. Rzeźnicka, A. Kobylańska (ed.), *Adulthood, disability, modern times. On the margins of special needs pedagogy (Dorosłość, niepełnosprawność, czas współczesny. Na pograniczach pedagogiki specjalnej)*, Kraków: Oficyna Wydawnicza Impuls 2003.

²⁵ M. Halicka, *Family – a factor influencing life satisfaction in the old age (Rodzina – czynnik warunkujący satysfakcję życiową w starości)*, „Annales UMCS” ; 59, Lublin 2004, p. 289-294.

²⁶ A. A. Zych, *Special needs geragogy – a special needs pedagogy of the people advanced in age (Geragogika specjalna – pedagogika specjalna osób zaawansowanych wiekowo)*, in: A. Nowicka, J. Bąbka (ed.), *The person and the family in view of losing health and ability (Człowiek i jego rodzina wobec utraty zdrowia i sprawności)*, Lublin: Wydawnictwo Uczelni Zawodowego Zagłębia Miedziowego 2010.

people, mentions violence in the form of neglect, age discrimination and prejudice. In the case of people with disabilities, in his opinion, he can even talk about double discrimination due to incomplete functionality and because of age and gender. In addition, there is a widespread perception that people with disabilities will not be able to, or at least to a large extent, be hindered by their performance in the role, which stimulates able elderly people to activity, for example in the role of grandparents taking care of their grandchildren. Again, there is no scientific study confirming this 'colloquial knowledge'. It cannot be stated which groups of people with disabilities and to what extent these restrictions will apply. What will their determinants be like? It seems that it is worth the effort to acquire knowledge on this subject.

Studies on the subject group of people with disabilities in senior age are justified by the fact that the index of people with disabilities aged 65+ in 2011 (national census results) was higher than in the general population and equalled almost 41% (to 14.7% in the general population). More than half of this group (57%) have legal proof of their disability²⁷. It is notable that, compared to 2002, the percentage of older people with legal certificate of disability degree declined (from 71% to 57%), the percentage of elderly people with biological disabilities has risen by nearly a half, from 29% in 2002 to more than 43% in 2011. Particularly high growth was observed among people living in rural areas (from about 31% to almost 50%, in urban areas the rate increased by 12% (from about 28% to 40%)). According to NSP 2011 (national census) data, the largest number (from 42.2% to 47%) of people with disabilities aged 65+ live in Podlaskie, Mazowieckie, Lubelskie, Małopolskie and Opolskie voivodships. The rates at level of 38.8% - 42.2% were recorded in the fol-

²⁷ *The demographic situation of elderly persons and the consequences of the aging of the population of Poland in the light of the prognosis for the years 2014-2050 (Sytuacja demograficzna osób starszych i konsekwencje starzenia się ludności Polski w świetle prognozy na lata 2014-2050)*, GUS, Warszawa 2014, p. 18.

lowing voivodships: Łódzkie, Świętokrzyskie, Podkarpackie, Śląskie and Dolnośląskie, at the level of 36.6% – 38.8% in Pomorskie and Zachodniopomorskie voivodships. The lowest number of 65+ disabled people live in Warmińsko-Mazurskie, Kujawsko-Pomorskie, Wielkopolskie, Lubuskie²⁸. Given the demographic forecasts, it is expected that the population of elderly people with disabilities (especially those with biological disabilities) will increase, if additionally, as it was in years 2002 to 2011, the high rate of incidences of incapacity for independent living, people requiring professional support in the area of care, treatment and rehabilitation emerge. This is undoubtedly also a challenge for special needs education (pedagogy) in the context of the design of human resources training that will be able to accomplish such tasks. A challenge that should be taken promptly, but with parallel activities constituting a new occupational group of assistants of elderly people with a disability.

The life situation of people with disabilities in older age is, as indicated earlier, much more difficult than of the elderly people in the general population. It is not a simple sum of limits that each of these situations entails. Apart from the obvious in this case health issues, they can also be seen in the social and material sphere. Taking into consideration the sanitation and technical conditions of flats in which people with disabilities live, it can be stated that they are more difficult than in other cases. Only 45% of families with a person with a disability (about 65% in urban areas and about 14% in rural areas) have access to the water supply, bathroom with toilet, central heating and gas (52.5% in the general population). The economic status of most families with people with disabilities is low²⁹. According to GUS (Central Statistical Office) data, 95% of people

²⁸ *The demographic situation of elderly persons and the consequences of the aging of the population of Poland in the light of the prognosis of Central Statistical Office of Poland for the years 2014-2050 (Sytuacja demograficzna osób starszych i konsekwencje starzenia się ludności Polski w świetle prognozy na lata 2014-2050, GUS, Warszawa 2014), p. 18-19.*

²⁹ M. Zrałek, *Disability in the elderly (Niepełnosprawność osób starszych)*, [in:] J. T. Kowaleski, P. Szukalski (ed.), *Our aging society. Hopes and dangers (Nasze starzejące się społeczeństwo. Nadzieje i zagrożenia)*, Wydawnictwo UE, Łódź 2004, p. 101-103.

with disabilities get money from retirement pensions, 28.1% from disability pensions, 5.5% from family pensions, 3.7% from social pensions, 0.8% from unemployment benefits for the unemployed and 0.4% from benefits and pre-retirement benefits and social welfare benefits³⁰. If we realise, in addition, that an elderly person with a disability is most likely a person with low education, the possibility of changing the economic status seems almost impossible. If this is due to the loss of strength and efficiency resulting from old age and pre-existing disorders, a significant proportion of people with disabilities will appear as unable to live independently, without control over it and the ability to decide on anything.

The results of the research on the issue of adolescence and old age of people with disabilities show that one of the main fears of parents of people with disabilities, especially those whose type and degree of disability significantly impair their ability to live independently, for example with a deeper mental disability, is anxiety for the future. Parents still think about with who and where their children will live when they become adults and parents will not be with them anymore³¹. It is important in this context, and not the undertaken issue, how people with disabilities can cope with traumatic stress after losing their parents, the need to live in a new, unknown place, among strangers.

Another problem, which is well recognised in the general population of elderly people³², but not recognised in the case of people with disabilities at senior age is the phenomenon of violence and neglect. The prevalence of this phenomenon has led to the definition of 'elder abuse' at the WHO forum³³. It is understood as single or

³⁰ http://www.stat.gov.pl/gus/5840_14834_PLK_HTML.htm

³¹ A. Krause, A. Żyta, S. Nosarzewska, 2010, p. 93.

³² M. Halicka, J. Halicki (ed.), *Violence against elderly people. On the example of the survey field studies in the podlaskie voivodeship (Przemoc wobec ludzi starszych. Na przykładzie badań środowiskowych w województwie podlaskim)*, Białystok: Wydawnictwo Temida2 2010.

³³ B. Mikołajczyk, *International protection of the elderly persons' rights (Międzynarodowa ochrona praw osób starszych)*, Warszawa: Wydawnictwo Wolters Kluwer Polska 2012.

repetitive actions, or lack of such action (abandonment, e. g. neglect), occurring in relationships where trust and care should be expected, and which cause harm and danger to the elderly people³⁴. The understanding of the concept is very broad, it means not only physical and mental violence against the elderly, but also all forms of exploitation, including financial one. Malgorzata Halicka and Jerzy Halicki (2010) suggest, basing on a literature review of typology, and point out various possible forms of violence against older people. They include physical, psychological, financial, sexual, symbolic, neglect, abandonment (2010, p. 26-27). Symbolic violence refers to enforcing behaviour that is comfortable for dominant groups. Neglect, in turn, is a recurrent deprivation of care and help, which are needed for elderly man in important daily activities. In the world, the problem of violence against elderly people, as Halicka and Halicki point out, was of interest in the 1950s, but public recognition of the problem dates back to the 1970s. In Europe, the problem has been seriously dealt with since the late 1980s and in the 1990s the phenomenon of violence against the elderly was undertaken by the WHO. Estimated indicators of the phenomenon (based on studies in five developed countries: Canada, Finland, the Netherlands, the United Kingdom and the United States) are 4%-6% (taking into account physical, mental and financial abuse and neglect).³⁵ These indicators are different in different countries. For example, according to Halicka and Halicki, in Korea it is 6.3%, in Israel 18.4% (with predominance of neglect) and in the Czech Republic up to 20% (various forms of violence against 60+ people)³⁶.

In Poland, the origins of research on the subject date back in the 1970s. The problem was then signalled in the context of other stud-

³⁴ B. Mikołajczyk, *ibid.*, 2012, s. 51.

³⁵ M. Halicka, J. Halicki, *ibid.*, 2010, p. 33; D. Jaszczak-Kuźmińska, K. Michalska (ed.), *Domestic violence againsts the elderly and the disabled. A guide for the first contact social workers*, (*Przemoc w rodzinie wobec osób starszych i niepełnosprawnych. Poradnik dla pracowników pierwszego kontaktu*), Warszawa, MPiPS 2010, p. 44.

³⁶ M. Halicka, J. Halicki, *ibid.*, 2010, p. 33.

ies, e. g. concerning intergenerational conflicts. The first systematic study of the elderly people as an object and subject of social pathology date back between the 1980s and 1990s. They confirmed the existence of a sense of danger, abuse and neglect in relationship to people in senior age.³⁷ Violence against elderly people is very common in families, but also in all types of institutions, which were established to help, provide services to elderly people. According to PAN (Polish Academy of Sciences) studies commissioned by the Ministry of Labour and Social Policy (2010), 11.8% of Poles isolate older family members, 13.2% use economic violence against.³⁸

Violence in the family is primarily directed towards those who are physically weak, often unable to defend themselves. Factors that influence the increase of the risk of suffering among elderly people are: cognitive, physical impairment and social isolation. In turn, cultural risk factors are: discriminatory attitudes (in this case against elderly people), sexism, tolerance of violence. Such phenomena can foster the emergence and intensification of violent attitudes: loss of traditional roles of elderly people, erosion of the family and social ties, high unemployment. Risk factors may also be the characteristics of victims, among them there are: limited functional capacity, problems caused by illnesses (e. g. dementia) or social isolation of people.³⁹ These are important findings in the context of the threat of

³⁷ The Halicka's research from the years 90 of the XX century shows that over 20% of men aged 70 were complaining about the lack of care, 13% had a feeling of being separated from the family matters; there were instances of the negligence of care in case of 13%-17% women; 14% of women aged 80 was neglected in the psychological sphere (withdrawal of affection). About 12% of the elderly people was taken advantage of financially; in the group of the 80 years old this rate equaled 19% (Halicka, Halicki 2010, s. 35). More on the phenomenon of violence against the elderly in the publication of Halicka, J. Halicki, 2010.

³⁸ D. Jaszczak-Kuźmińska, K. Michalska (red.), *Domestic violence againsts the elderly and the disabled. A guide for the first contact social workers (Przemoc w rodzinie wobec osób starszych i niepełnosprawnych. Poradnik dla pracowników pierwszego kontaktu)*, Warszawa, MPiPS 2010, p. 12.

³⁹ *Ibid.*, 2012, p. 40-42.

violence against people with disabilities. The association of violence and disability with the role of the person with disability as its victim, is present in Polish literature in the field of social sciences.⁴⁰ However, in this case, there were no studies analysing the occurrence of the phenomenon in relationship to the senior age of people with disabilities or individual types of disability. The research conducted by Krzysztof Korzeniowski and Piotr Radkiewicz on the phenomenon of violence against people with disabilities, taking into account their age, ends in category 60+ (there is therefore recognition of the issue in regard to seniority). The results of the study for the 60+ group indicate that, in the case of physical, economic and psychological violence, the average score on a scale from 1 - never, to 5 - very often, was in the context of violence outside of family and the first three types of violence 1,6, sexual - 1,4. In regard to family violence respectively: 1,2 and 1,1.⁴¹

When authors analyse the phenomenon of violence against people with disabilities, they usually focus on two groups of people with disabilities: intellectual and physical (Zima 2010, p. 71, 73)⁴² (health problems: physical or mental, Korzeniowski, Radkiewicz

⁴⁰ K. Korzeniowski, P. Radkiewicz, *Violence against the elderly and disabled persons. The report on the all-Poland research from the year 2015 and the comparative research from the years 2009-2015. (Przemoc w rodzinie wobec osób starszych i niepełnosprawnych. Raport z badania ogólnopolskiego 2015 r. oraz badania porównawczego z lat 2009-2015)* Warszawa PAN IP 2015; D. Jaszczak-Kuźmińska, K. Michalska (ed.), *Domestic violence against the elderly and the disabled. A guide for the first contact social workers. (Przemoc w rodzinie wobec osób starszych i niepełnosprawnych. Poradnik dla pracowników pierwszego kontaktu)*, Warszawa: MPiPS 2010.

⁴¹ K. Korzeniowski, P. Radkiewicz, *ibid.*, 2015, p. 75. It's worth adding that the analyzed group didn't consist of the people with disabilities; the research was conducted in the group of 1000 respondents, in a cluster sampling representative for the inhabitants of Poland aged 18 and more, p. 13.

⁴² M. Zima, *Violence against the disabled people (Przemoc wobec osób niepełnosprawnych)*, in: D. Jaszczak-Kuźmińska, K. Michalska (ed.), *Domestic violence against the elderly and the disabled. A guide for the first contact social workers (Przemoc w rodzinie wobec osób starszych i niepełnosprawnych. Poradnik dla pracowników pierwszego kontaktu)*, Warszawa: MPiPS 2010, p. 71-73.

2015, p. 60). They also point out that in Poland there is no reliable data on the phenomenon of violence against people with disabilities (Jaszczak-Kuźmińska, Michalska 2009, p. 82).

Monika Zima⁴³ indicates that violence against people with disabilities, as evidenced by research, may be related, for example, to unattractive external appearance, which may lead to disturbances in the formation of the link and indirectly to the occurrence of violence. Estimates also show that people with intellectual disability, in connection with violence, suffer three times more severe injuries than those without disabilities. The analyses of the relationship between the phenomenon of violence and disability show the worse situation of people with disabilities in this range, compared with the people without disabilities. This applies to all types of violence: economic, psychological, emotional, physical, sexual. The effects of overlapping disability with ageing, in the context of family and institutional violence, have not been recognised due to the old age and institutional, instead of family care. Particularly, as shown by the results of the conducted studies, the percentage of estimation of violence against people with disabilities outside of the family is higher. The combined responses of frequent and very frequent violence (observed over the past few years) provide percentages in the systems: outside of the family and in the family, respectively, for physical: 10.1% and 5.7%, economic: 12.2% and 7.4 %, psychological: 13.3% and 6.3%, and sexual: 3.8% and 2.4% violence. The results are slightly lower most frequently, when the respondents were asked about the last year (respectively, physical 9.1% and 5.5%, economic 10.6% and 5.8%, psychological 9.7% and 5, 7%, sexual 3.6% and 2.4% violence)⁴⁴.

In conclusion, it is worthwhile to note the necessary areas of analysis that should be considered in the context of special needs education (pedagogy), and which would broaden the scope of deliberations to identify phenomena connected with gerontology (geragotics) as this area appears to be particularly 'neglected' in the

⁴³ M. Zima, *ibid.*, 2010, p. 84.

⁴⁴ K. Korzeniowski, P. Radkiewicz, *ibid.*, 2015, p. 77-78.

reflections of special needs education (pedagogy). This will not be a closed list, as it only refers to selected issues, which are raised in the text. It seems therefore worthwhile to undertake research on:

- the characteristics of the ageing process of people with disabilities, even in relationship to those indicated by Piotr Błędowski and his colleagues⁴⁵, which are observed in the general population e. g. feminisation, singularisation, regionalisation, as well as looking for other, specific for persons with disabilities in senior age;
- satisfaction with life, including health condition, vital activity, quality of life, including one of its important indicators, i.e. the sense of coherence of disabled elderly people with regard to e.g. the type of disability, level of education, family situation, etc.;
- violence in and outside the family (the so-called institutional violence), against people with disabilities in their senior years, intensification of the phenomenon, its determinants.

Few indicated areas of research that I believe are necessary, derive from the author's choice of area of reflection in this text. In reality, however, the analysis of the scientific merit in the field of ageing and old age leads us to reflect on the need to conduct research within the range of special needs education (pedagogy) aimed at recognition of life situation, identifying problems and getting to know the determinants of life of people with disabilities in the senior age. In this aim, it is also worth pursuing interdisciplinary research, or even sub-disciplinary one within the range of pedagogy. Comparative studies of the population of elderly people and elderly people with disabilities also appear to be an unquestionable value. It would give basis to the expectation of creating a coherent support system, designing systemic actions aimed at the actual needs of each group, and thus avoiding the scenario of 'lost old age', referring to the group of people of senior age.

⁴⁵ P. Błędowski, B. Szatur-Jaworska, Z. Szweda-Lewandowska, P. Kubicki, *Report on the situation of elderly people in Poland (Raport na temat sytuacji osób starszych w Polsce)*, IPiSS, Warszawa 2012.

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The analysis of the statements of nursing home workers on the perception and experience of adulthood by their charges

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Experiencing the institution by adults with intellectual disability still evokes controversy in source literature. The study presents the results of the research based on the analysis of narratives by nursing home workers. The reality they experience revealed the 'subjective truth' about the adulthood of intellectually disabled people. The analysis of the narratives showed personnel's work that can support, initiate and shape the lives of adults in the institution or can impair their functioning to such an extent that they become passive, withdrawn and isolated. Experiencing the institution, intellectually disabled adults more frequently face limitations that affect their lives and shape them according to a particular pattern. The adulthood of intellectually disabled people depends on the personnel's approach and attitude towards this group.

KEY WORDS: adulthood, intellectual disability, nursing home

Interdisciplinarity in the approach to disability

Man is a complex creature that has still not been fully explored and whose actions are unpredictable. Despite the continuous progress in the area of science and medicine as well as scientists' in-

volvement in revealing human secrets, it still poses a great challenge. The phenomenon of human being is underlined by B. Śliwerski, who writes that 'Man is not measurable, directly available to others, but only indirectly through their life expressions'¹. It happens, since, as pointed out by the author, 'Interpersonal influence and interactions undertaken consciously in relation to a person cannot be subjected to standardisation and empirical operationalisation processes'².

The above-mentioned complexity, especially when it comes to a disabled person and their functioning in various spheres of life, requires close interdisciplinary cooperation and the exchange of information by researches in various areas of science. A multifaceted approach to the issue of disability and disabled people allows 'for the confrontation of different points of view and, consequently, and the supplementation of disciplinary knowledge without lowering the awareness of the complexity of the examined issue. The intellectual roots of the interdisciplinary approach to disability should be placed in humanities and social sciences and the knowledge of rehabilitation'³.

A multifaceted approach to the improvement of the situation of disabled people will result not only in holism, but also broadly defined modernity and creativity in the methods and manners of influence. This innovative understanding of rehabilitation 'forces the necessity of obtaining knowledge from various sources, e.g. medicine, pedagogy, sociology, psychology, as the undertaken comprehensive rehabilitation is a multidimensional social process. The purpose of the efforts undertaken by the rehabilitation team is to restore to people in need the maximum ability to live independently

¹ B. Śliwerski 'Cóż po pedagogice w ponowoczesności?', *Annales. Etyka w życiu gospodarczym*, 2012, vol. 15, p. 321.

² B. Śliwerski, 'Cóż po pedagogice w ponowoczesności?', *Annales. Etyka w życiu gospodarczym*, 2012, vol. 15, p. 321.

³ Z. Urbanowicz, 'Od interdyscyplinarnego do transdyscyplinarnego spojrzenia na niepełnosprawność', *Ogrody nauk i sztuk*, 2012(2), p. 445 [after:] G. Albrecht, K. Seelman, M. Bury, 'Introduction. Formation of disability studies', [in:] *Handbook of disability studies*, G. Albrecht, K. Seelman, M. Bury (ed.), London 2001, p. 2.

in one's family, environment and society, but, most of all, to make them able to work and truth about create'⁴.

The functioning of disabled people – despite interdisciplinary research – still evokes controversy and implies numerous problems that cannot be solved. This may result from the fact that '(...) disability is not an explicit category. It can be recognised objectively (documented, certified); it can be noticed by the environment, attributed to an individual, without meeting the certification conditions'⁵. The complexity of this phenomenon also requires close cooperation and open dialogue in the field of science in order to not only define the existing problems, but also find the explanation to them that will facilitate the existence of disabled people in various areas of the social life. The cooperation of various disciplines related to disability and man is therefore recommended. Such joint efforts will enable appropriate support in the area of broadly defined rehabilitation, intensifying the participation of disabled people in social life. Moreover, it contributes to the greater awareness of deficiencies and shortcomings, which sets the directions of research activities.

Drawing on other sciences, such as psychology, cognitive science, social science, medicine, economics, law, IT, telecommunications or, recently, neurobiology, in pedagogical research is necessary⁶. The close cooperation between these areas contributes to the systemic and comprehensive exploration of the phenomena and issues covered by the research. Each discipline that cooperates with special education offers significant 'contribution of knowledge both in respect of theoretical solutions and practical applications. This is mainly true for broadly defined rehabilitation, therapy and resocialisation, which allows for their comprehensive and multicontextual presentation'⁷.

⁴ S. Wrona, J. Rottermund (ed.), *Interdyscyplinarność w opiece i wsparciu osób niepełnosprawnych*, Wydawnictwo Uniwersytetu Śląskiego, Katowice 2015, p. 10 (from the introduction).

⁵ K. Parys, 'Zakres oddziaływań współczesnej pedagogiki specjalnej na tle dotychczasowych przemian', *Niepełnosprawność*, 2011, no. 5, p. 35.

⁶ J. Gnitecki, *Zarys pedagogiki ogólnej*, Zysk i Ska, Poznań 1994, p. 39.

⁷ J. Gnitecki, *Zarys pedagogiki ogólnej*, Zysk i Ska, Poznań 1994, p. 39.

Researchers' statements on the close cooperation are even more reasonable as disabled people '(...) not only face new challenges, but also become a new challenge themselves, both for sciences focused on supporting disabled people and for practical solutions in the area of education, rehabilitation and social support systems'⁸. Therefore, the functioning of a disabled person is closely associated with the cooperation between various environments and institutions that – as pointed out by W. Dykcik – integrate and coordinate their activities to ensure the greatest possible result of broadly defined rehabilitation⁹. The effective cooperation of professionals dealing with various academic disciplines as well as parents, teachers, carers, educators and therapists becomes the impetus for particular actions, both individual and collective ones.

Finding interdisciplinary solutions to the life problems of disabled persons results in giving them the right to lead a normal life. Solutions that enable them to participate in various spheres of social life and adopt different social roles, taking into account their dignity and subjectivity, have been worked out as a result of the efforts of various specialists to tackle these issues. For researches representing various fields of science, a disabled person poses a challenge not only here and now. Their future also implies numerous questions. Thus, as Z. Gajdzica writes, 'The permeation of various theories and concepts not only makes it possible to look at particular issues from various perspectives, but also favours the creation of new quality established on interdisciplinary knowledge. (...)'¹⁰, which becomes a basis for further considerations and reflections on disability.

⁸ K. Ćwirynkało, A. Żyta, 'Czy praktyka pedagogiczna dotrzymuje kroku zmianom w teorii pedagogiki osób z niepełnosprawnością intelektualną?', [in:] *Kierunki rozwoju pedagogiki specjalnej*, ed. K. Ćwirynkało, Cz. Kosakowski, A. Żywanowska, *Impuls*, Cracow 2013, p. 76.

⁹ W. Dykcik (ed.), *Pedagogika specjalna*, Wydawnictwo UAM, Poznań 2001 (from the introduction), p. 5.

¹⁰ Z. Gajdzica, *Sytuacje trudne w opinii nauczycieli klas integracyjnych*, *Impuls*, Cracow 2011, p. 7.

Applied methodology

The purpose of the paper is to present the results of research concerning the interpretation and construction of the lives of intellectually disabled people at a nursing home from the point of view of the employees of this institution. I was interested how this group of people experiences adulthood at a facility providing hospitality, care, aid and education services. I wanted to find out how nursery home workers experience the adulthood of their charges and how they construe this adulthood from the point of view of their experience.

The purpose of the research was to reconstruct the stories and get to the subjective meanings imposed by nursing home workers on the adulthood of their intellectually disabled charges within the confines of the institution. It covered subjective meanings, intentions and interpretations of nursing house workers in respect of the adulthood of intellectually disabled people living at this facility. I therefore examined how nursing house workers experience, through their speech, the adulthood of their charges and how they structure it.

The studies were embedded in the interpretative paradigm. This approach was selected on purpose, as the aim was to find the answer to questions that I found important in the fragments of reality presented by the nursing home workers. I was inspired by three perspectives: phenomenology, hermeneutics and symbolic interactionism. As a consequence of the applied interpretative perspective, it was possible to use the biographical method. It involved the analysis of a fragment of reality – created by nursing home workers – which makes it possible to observe the adulthood of intellectually disabled people living at a nursery home. An attempt to learn and understand this fragment of social reality, that is, the social world stored in the workers' memory, was possible based on the stories of their lives. The biographical method allowed me to obtain the 'real' knowledge on the adulthood of intellectually disabled residents. The reality structured by the workers resulted from their subjective

perspective and experiences related to their work at the nursing home.

The application of the biographical method implied the use of the narration analysis. Narration based on people's history – points out Dorota Klus-Stańska – is 'one of the ways people understand the world'. The author stresses out that narration is a 'natural way required to understand life'.¹¹ Selecting a research method, I was guided by Bruner's words, quoted by E. Kos: '(...) the life of an individual is not what it is, but how it is described and interpreted by them¹². In other words, a narrative reveals the way the reality is understood by an individual'¹³. Narrative conversations were conducted with 4 workers of nursing homes for intellectually disabled adults in Warmińsko-Mazurskie Voivodeship with 10 years of experience. Two persons requested anonymity and the change of their names.

Research material analysis

Facilities for persons requiring 24-hour care have various obligations resulting not only from applicable regulations, but also the fact that they work with people having an absolute right to respect and dignity. Personnel working at such facilities has the greatest experience related to disabled people and the implications of their disability. The reconstruction of these experiences reveals the subjective truth about the functioning of intellectually disabled adults at such an institution. Each story is exceptional and shows a range

¹¹ D. Klus-Stańska, 'Narracja w badaniu i kształceniu nauczycieli', *Forum Oświatowe*, 2002, p. 111.

¹² E. Kos, 'Wywiad narracyjny jako metoda badań empirycznych', [in:] *Badania jakościowe w pedagogice*, D. Urbaniak-Zajac, E. Kos, Wydawnictwo Naukowe PWN, Warsaw 2013, p. 95.

¹³ E. Kos, 'Wywiad narracyjny jako metoda badań empirycznych', [in:] *Badania jakościowe w pedagogice*, D. Urbaniak-Zajac, E. Kos, Wydawnictwo Naukowe PWN, Warsaw 2013, p. 95.

of individual senses, meanings and interpretations. The narratives reflect the truth about the reality experienced by facility workers.

In the analysed fragments of the workers' stories, certain threads common for the narratives as well as totally different ones start to emerge. They cover **subjective definitions of the adulthood of intellectually disabled people** of the workers, who understand the sense of it and define it in their own way. This is exemplified by the words of Dorota, for whom:

'(...) adulthood is when a person thinks and decides independently and is self-reliant in everything they do. Unfortunately, there is no such self-reliance among our charges; if they were self-reliant, they wouldn't be here'.

Marek shares this view, but adds that residents need their support and the organisation of life in which they are not able to adapt to the rules and standards. The narrator underlines that in the case of persons with intellectual disability, adulthood occurs only in terms of age:

'despite their age, they display no other signs of adulthood. The residents have problems with basic things, not to mention taking the responsibility for their actions'.

Jowita also thinks that intellectually disabled people, due to their deficits related to their disability, do not enter the phase of adulthood. They are not able to function independently, both individually and socially:

'We all know what adulthood is, as we all go through it, but we also know that we cannot expect these people to behave like adults, as it is impossible. They will never function like adults both emotionally, mentally and socially'.

Agnieszka also mentions the fact that her charges are not self-reliant, which – according to the narrator – blights their chance to become adults:

'First of all, can we talk about adulthood in the case of such people? I think we can't, as most of them don't know that they should wash themselves or clean their room if you don't tell them to do so. They will, of course, do it perfectly, but only under our supervision'.

The analysis of the narrative shows that the adulthood of disabled people **is achieved to a limited extent**. This may result from the specific nature of the institution as well as the consequences of intellectual disability:

Dorota: 'Our residents can have their personal belongings and arrange their rooms as they wish (...) they invite us to show it to us (...) they are very satisfied if they can do something themselves'.

Marek: '(...) they can do the gardening, plant flowers if they want to; they do it at our house even at their own initiative (...) and even if they will later root them, because they will mistake them for weeds, they feel that they do something on their own'.

The analysis of these narratives shows the workers' happiness with any activity of their charges that involves self-determination, which gives them the sense of authorship, decisiveness and independence. Although the decisions they take are related to trivial things and matters, one can conclude from the narratives that they are extremely important to intellectually disabled people and treated by them with priority, as this is how they express themselves and their adulthood.

However, I have a different impression analysing other narratives, which imply that the workers do not initiate any activity among the residents and do not observe signs of adulthood in them:

Jowita: 'When they have money, they want to go to the shop, but when we are at the shop, they buy sweets, coke and other such things (...) it is natural that if they live like 16-year-olds, their decisions will be the same'.

Agnieszka: '(...) they can watch TV or listen to the music all the time (...) they rarely have any ideas (...) we have a resident who messes up all the time (...) we don't do much, as there is no time for it'.

The narrators do not notice that their charges verbalise their needs and show initiative, for example, in relation to the organisation of their free time. These ideas are ignored by the personnel due to the excess of duties related, in particular, to the completion of documentation.

Another important issue that is present in every narrative is **the atmosphere at the facility**. The workers' stories show that it affects the residents' mood and their activity at the facility.

Dorota: 'our facility is small (...). There are, of course, certain advantages of this fact, as we know our residents very well, (...) But the drawback is that you must get involved in various matters. (...) but the atmosphere is good, as our boss wants to make the residents feel like home (...) we get them involved in various duties and activities, like at home'

The analysis of the narratives shows that a small facility is characterised by pleasant and friendly atmosphere between residents and personnel. According to the author, it results in greater involvement in the residents' affairs. It is expressed by taking into account their opinions and involvement in their everyday duties. The narrative of another worker of the same nursing home has similar overtones:

Marek: 'we are lucky to work with people who treat disabled people normally, that is, they take into account their needs and expectations. People do not laughs at each other. We try to create a place where we all feel well. And we manage to do so, I guess (...) I think our residents feel comfortable here'.

The narrator's statement is very uplifting, as it underlines the significance of the competencies of other facility workers for whom intellectually disabled people are not only objects of their care, rehabilitation and social influence.

The stories told by another interlocutor have a different character, as they do not mention good atmosphere. Working conditions are harsh, which makes them tired, stressed and discouraged from

the work they perform. The relations between the workers are tense, which affects the working atmosphere. As a result, people living at the facility are treated like objects and they get involved in hardly any activity. The residents' lives at the facility are limited – as the author points out – to basic living activities:

Jowita: 'The atmosphere here is not positive. Everything is performed in a rush and everything must be done yesterday. What is more, we have difficult charges and it is hard to spend time with them in a nice atmosphere when they are aggressive. Besides, it is hard to treat someone seriously if they behave like a child or worse. This is the truth and there is no point hiding it, as it is obvious how such people live'.

Agnieszka: 'When I started to work here, I had a different vision about this job, but life rapidly proved the truth. The work here is hard, as there are both ambulant and bedridden residents and we just can't cope with everything. People don't cooperate with each other; but I can't give up this job'.

Another thread that was highlighted in the narratives was **the social life / loneliness of the residents**. The stories show that the charges feel lonely, as they do not have families, they are rarely visited by anyone or taken home for Christmas. The residents miss their relatives – mainly persons that stay at the facility due to their parents' or carers' death:

Dorota: 'Not all of them have families, some of them were left by their relatives and forgotten (...) every situation is different, (...) you can see sadness and a kind of disappointment that they are not taken home or visited (...) they are very envious when someone else is visited by an aunt or someone else (...) they are even proud when they are visited by a neighbour or a member of their family (...). There are parents who don't want to take their children even for Christmas (...) and we know they can afford it; dysfunctional families is a different story'.

This loneliness stems from the fact that some adult charges do not have parents any more. However, those that are visited are very satisfied with this fact, which means that any relationship outside

the facility is of great importance to the residents. However, one should point out that the contacts of the charges with their families are incidental:

Marek: 'I'm aware of the fact that people who live here do not have parents or their families cannot take care of them, and I understand that this place is supposed to be their home. But they sometimes seem to feel lonely and abandoned, some of them even say it'.

My interlocutors' statements reveal that the adulthood of the residents involves social life that is limited to contacts and relationships within the confines of the facility. The facility is located in a small place, where the local community no longer stigmatises, but still treats the residents with reserve. Another problem that limits the residents' social life is the lack of time and willingness of the personnel to organise their free time in a constructive and interesting way that would favour the establishment and tightening of the relationships:

Jowita: '(...) the charges talk to each other, do something together, but they rarely go to meet people or are visited by anyone. Besides, people in our village used to protest, but it has already subsided. There is no time to go out for ice-cream or for a walk, only somewhere in the vicinity (...) but they sometimes don't even want to go out of their rooms, and I won't drag them by force after all'.

The following fragments of the story reveal a very sad reality, as the narrators mention not only **the infantile treatment of adult people by the personnel, but also the task-oriented attitude towards them**. The residents do not show any initiative – as one of the interlocutors points out – but it may result from the personnel's excessive control or treating the residents like objects:

Agnieszka: '(...) one can see that these adult people are treated like children here, they are given everything, nobody asks them about anything, everything is done for themselves, but without themselves (...) it is also us who select room-mates for them, decide what they are to do, I have an impression that everything is mechanical (...) they do not

display any initiative; as I said before, they behave like children who needs to be guided’.

Another narrative also reveals that adult residents are treated like objects and there is no understanding of their specific way of functioning:

Jowita: ‘It is often me who is the bad one, I say something and there is no response; I understand that they are disabled, but I’m alone here and everyone wants something (...) Bedridden residents also must be taken care of, fed and washed’.

The narrators’ stories often refer to the **passiveness of the residents**. It may result from the personnel’s attitude, which does not motivate or initiate any forms of activity:

Agnieszka: ‘(...) they do not show any initiative, as I said before, they behave like children who need to be guided’.

Jowita: ‘(...) but they sometimes don’t even want to go out of their rooms, and I won’t drag them by force after all’.

In order to provide the context, it is worth mentioning those narratives that prove not only great activity of the charges, but also their creativity and artistic activity. The subjective and individual approach of the charges as well as their open attitude towards the residents and treating them seriously bring positive effects:

Dorota: ‘(...) I am in charge of the arts workshop, and we have a resident called Adam who wants to sleep all the time and nobody does anything with him. I took a brush and showed him that he can use various colours, and now he keeps coming to the workshop and wants to paint’

Dorota: ‘(...) but the residents are mostly interested in sports and recreation as well as cultural classes, as this is when they are in their element and integrate not only with each other, but also with the residents of the village and other facilities. Sometimes they come and ask: ‘Dorota, when can we organise a disco?’ or ‘It is soon Christmas and we must prepare cards’. So they show great initiative, you only need to let them do it’.

One of the fragments refers to the activity of the house residents, who are supported by the personnel. Moreover, one can see great openness among the residents to any integration activity both at the facility and outside. This openness may result from the attitude of the personnel towards the residents and their respect for them, great involvement in their affairs and outstanding sensitivity to their needs. Treating the residents and their needs seriously leads to a relation based on attention and trust.

Conclusion

Institutional support is very important for intellectually disabled people, especially if they do not have families or relatives that could take care of them. Life at the institution is very specific and thus the adulthood within its confines has a different meaning than outside it. The stories told illustrate maturity experienced at nursing homes by intellectually disabled people. The workers of these facilities presented 'their own' truth about this group of people and their lives by reconstructing their own experiences. It is only a fragment of knowledge concerning intellectually disabled people, presented from the point of view of the subjective experience of workers.

The analysis of the narratives reveals two different worlds of the same institution. The first one proves that most services performed at nursing homes not only does not satisfy the needs of the residents, but even limits and impairs their functioning. Disabled adults do not take part in the life of the facility, they are left on their own and are only the objects of the personnel's care, which has a negative impact on their functioning. Work at the facility and too much burden related to the completion of documentation, or maybe the lack of will and initiative of the personnel, isolate the residents from the environment, limit their independence and self-reliance and, consequently, violate their human rights. Not all workers of nursing homes notice that these people want to decide for themselves, take

decisions concerning their 'existence' at the facility, perform their social roles, meet other people and integrate with other residents.

The narratives I have analysed have proven that experiencing institutions, intellectually disabled people experience also limitations that influence their lives and shape it in accordance with a certain pattern. The residents do not have much freedom to decide about their adulthood or prospects for their own life at the facility. However, if there are workers who are open to the needs of this group of people, there is hope that their needs associated with their age and condition will be verbalised and taken into account. There is a chance that these persons will be able to express their adulthood. Otherwise, the needs of the charges are ignored, as they cannot decide about their lives in such a situation.

The consequences of disability and random events cause that intellectually disabled adults can only count on the support of the facility workers. The narratives prove that the other face of a nursing house are workers for whom a charge is, above all, a human. The narrators notice not only the needs, but also the potential of these people. They focus on the self-reliance of residents, create situations in which the residents can show their initiative and creativity. The narratives show that most intellectually disabled people want to spend time actively. These people want to help in the kitchen, garden or other works, but are also willing to take part in integration meetings both at the nursing home and outside it. They like spending time together and listening to the music, watching TV, but are also eager to participate in recreational and sports, artistic as well as other activities offered to them.

The conducted studies were mainly supposed to show how intellectually disabled adults experience adulthood within the confines of a nursing home. The necessity for the cooperation between specialists in various areas in a pursuit to standardise the living conditions of the facility residents was a secondary consequence of my deliberations. Such an approach makes it possible to take into account all the needs, possibilities and limitations of disabled adults based on the respect, dignity and subjectivity of these people.

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The Microworld of Differentness of Adults with Intellectual Disability: A Research Report

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The present paper is an attempt to describe the phenomenon of differentness experienced by persons with intellectual disability. The author presents the results of research which forms a part of a larger research project concerning social worlds of adults with intellectual disability. Kathy Chamaz's methodology of constructive-interpretative grounded theory has been utilised both as a strategy of collecting research material, and as a method of its analysis. The group of respondents consists of 14 adults with intellectual disability attending to the Communal Home of Mutual Aid, and their carers (among them parents and workers of the Home). The results show differentness as a phenomenon experienced by almost all persons with intellectual disability.

KEY WORDS: differentness, adults with intellectual disability

Introduction

The aim of this paper is to depict the phenomenon of differentness in experiences of adults with intellectual disability. The paper forms part of a larger research project conducted by the author,

with a main focus on comprehension of the world of adults with intellectual disability¹. Granted that said persons, alike other adults, have certain personal traits, that they face and experience various situations and events, take on specific social roles, are involved in variety of interpersonal relationships, and have their own world of values and beliefs, the author has aimed at comprehension and examination of social worlds of adults with intellectual disability. A. Schütz claims that people experience reality and take actions within the frameworks of various microworlds² (social worlds). A microworld, conceived as 'coherent and relatively independent complex or system, a separate structure of reality'³, forms a sublime part of subjectively perceived reality. Author's research perspective is based on Ewa Skibińska's assumption⁴ that microworld is a world experienced by a single person who lives simultaneously in many various worlds (micro-worlds) comprised of their basic activities⁵. The analysis of research material allowed to select a number of mi-

¹ The subject literature provides material about research on adults with intellectual disability, which shows their way of perceiving world and themselves. One of the key positions is *Difficult Paths to Acceptance. Emancipation Motives in the Analysis of the Situation of Adults with Intellectual Disability in Contemporary Polish Society (Trudne drogi adaptacji. Wątki emancypacyjne w analizie sytuacji dorosłych osób z niepełnosprawnością intelektualną we współczesnym społeczeństwie polskim)* by Beata Cytowska (2012) or *Living with Down Syndrome. Biographical Narratives of Parents, Siblings and Adults with Down Syndrome (Żyjąc z zespołem Downa. Narracje biograficzne rodziców, rodzzeństwa i dorosłych osób z zespołem Downa)* by Agnieszka Żyta (2011).

² Manterys A., *The Multitude of Realities in Sociology Theories (Wielość rzeczywistości w teoriach socjologicznych)*, Wydawnictwo Naukowe PWN, Warszawa 1997, pp. 24-25.

³ James, 1901, as cited in: Manterys A., *The Multitude of Realities in Sociology Theories (Wielość rzeczywistości w teoriach socjologicznych)*, Wydawnictwo Naukowe PWN, Warszawa 1997, pp. 19.

⁴ Skibińska E., *The Microworlds of Women. Autobiographical narratives (Mikroświaty Kobiet. Relacje autobiograficzne)*, Wydawnictwo UW, Warszawa 2006, pp. 335-336.

⁵ According to PWN Dictionary *micro* means 'the first element of compounds, indicating very small size or scale of what is named by the second element; very small: www.sip.pwn/slownik/mikro

croworlds⁶, among them the social world of differentness: a subject of the below dissertation. Therefore, it is worth to mention that presented research report concerns one of several categories, appointed by the author. The text consists of several parts: first part regards the research methodology, the second part focuses on the experience of differentness of adults with intellectual disability, and last part is an attempt of recapitulation.

Research methodology

The author's dissertation combines different fields of studies, chiefly andragogics and special education, and puts forward the following questions: What is the world of adults with intellectual disabilities like? What are the elements of this world? What are these social worlds characterised by?

Designing the research project, the author decided to utilise the constructivist-interpretivist paradigm, based on the acknowledgement of the input in research process of respondents and their competence as capable of co-creating and interpreting social reality. By giving voice to the respondents, the author considers them to have their own way of perceiving, experiencing and dealing with reality, and to not only be the object of research, as it has usually been in this kind of research, but its most competent subjects. The author follows the thought of F. Zaniecki, who claimed that cultural reality should be regarded as a world of values, and empirical facts must be considered in a way they are being perceived by individuals who experience them⁷. A researcher - participant observer 'will never obtain a knowledge deeper than actors possess, a foreigner will

⁶ In the research project other microworlds of adults with intellectual disability have been outlined as well, among them microworld of professional activity, human relationships, institutions, leisure time, or family.

⁷ Szacki J., *The History of Sociological Thought (Historia myśli socjologicznej)*, Wydawnictwo Naukowe PWN, Warszawa 1986, pp. 90-92.

never be able to understand indigenous people's culture better than they do, but an observer and a foreigner can develop a different image of strangers' actions or culture than their actors and indigenous people have'⁸.

Granted that human actions are emergent – they happen in a process of constant construction and assigning meanings to things⁹ – the author assumed that the actions of individuals are something they actively construct, reinterpret and redefine. The *activity*, broadly defined, refers also to creating representation of oneself in their own mind.

Moreover, the constructivist-interpretivist paradigm allows to approach research with flexibility, and to limit preconceptualisation of research objectives. It helps maintaining so-called context of discovery¹⁰ – a space to search for and unravel previously unforeseen phenomena which emerge during research process.

Presented research fits into qualitative research methodology, and the author utilises technique of constructivist-interpretivist grounded theory of Kathy Charmaz. This choice has been dictated by both specificity of the objective of research (deep comprehension of the phenomena in its processual form), and the attempt to discover the reality perceived by its social actors. The grounded theory has been utilised both as a strategy of collecting research material, and as a method of its analysis. The theory allows to collect data by using various methods typical for all kinds of qualitative research (i.a. participant observation, document analysis, interviews), as well as other techniques (among others textual analysis, qualitative inter-

⁸ Czarniawska B., *New Techniques of Field Research: Shadowing (Nowe techniki badań terenowych: shadowing)*, [in:] D. Jemielniak (ed.), *The Qualitative Research. Methods and Tools (Badania jakościowe. Metody i narzędzia)*, Vol. 2, Wydawnictwo Naukowe PWN, Warszawa 2012, p. 73.

⁹ Blumer H., *Symbolic Interactionism: Perspective and Method*, Prentice-Hall, New Jersey 1969, p. 82.

¹⁰ Konecki K., *The Studies on Methodology of Qualitative Research: The Grounded Theory (Studia z metodologii badań jakościowych: teoria ugruntowana)*, Wydawnictwo Naukowe PWN, Warszawa 2000, pp. 26-27.

views)¹¹. Research material in discussed project has been collected using non-structured focused interview method¹², i.e. a way of leading conversation which allows for loose arrangement of questions sequences, and, more importantly, for adjusting language to needs and capabilities of respondents. The procedure has been implemented using the 'skeleton', i.e. a list of main questions essential for the interviewer's research purposes. At this stage of research, interviews have been conducted both with persons with intellectual disability (altogether 14 respondents between 29 and 51 years old, 8 females and 6 males), and with their parent/legal guardians (8 respondents), as well as with the employers of the Communal Home of Mutual Aid¹³ (6 respondents), where the research has been conducted¹⁴.

It is worth emphasising that one of key instruments used in the research has been the person conducting interviews, i.e. the author herself. The research project has allowed the interviewer to get close-

¹¹ Charmaz K., *The Grounded Theory. The Guide on Qualitative Analysis (Teoria ugruntowana. Przewodnik po analizie jakościowej)*, Wydawnictwo Naukowe PWN, Warszawa 2009.

¹² Konecki K., *The Studies on Methodology of Qualitative Research: The Grounded Theory (Studia z metodologii badań jakościowych: teoria ugruntowana)*, Wydawnictwo Naukowe PWN, Warszawa 2000.

¹³ The research is conducted in one of the local Communal Home of Mutual Aid in Łódź Voivodeship. The respondents, especially workers of the centre, wish to keep the details of the institution confidential.

¹⁴ The main criterion of respondent selection was the stage of life, i.e. maturity (age over 18 years old), and intellectual disability. All respondents have disability degree certificates. 10 of the respondents have moderate, 3 - mild, and 1 - severe degree of disability. Nevertheless, the degree of disability has not been a significant factor neither in the process of data collection, nor in its analysis. The author's objective was to examine the world of adults with intellectual disability without using disability degree certificates as labels and looking at them through their limitations. During the research process some data collected in the interviews appeared to lack some information and broader perspective, which convinced the author to include the parents, legal guardians and the Home workers in the project. Respondent group consists of: 7 parents (2 fathers, 5 mothers, and 1 aunt - a legal guardian of one of the adults with intellectual disability) and 6 employers: 4 females (the director of the Communal Home of Mutual Aid, a psychologist, 2 rehabilitation therapists, and 2 males: a rehabilitation therapist and a administration worker).

er to personal world of adults with intellectual disability, and therefore to attempt identification and description of the world experienced by respondents.

Collected material has been subjected to coding process, open at first (arranging data and assigning labels to it), then selective (orienting the research to the search for connections with the centre category), and finally, focused (emphasising interactive background). The analysis has allowed to reveal several different microworlds within which respondents exist. Among them the author distinguished: microworld of family, education, human relationships, leisure time, institutions, and freedom. Their boundaries are not permanent and solid, and they tend to fathom each other out. It is worth mentioning that the project is still in process, and, according to the utilised method, evolves in time.

Experiencing the differentness - the analysis of own research

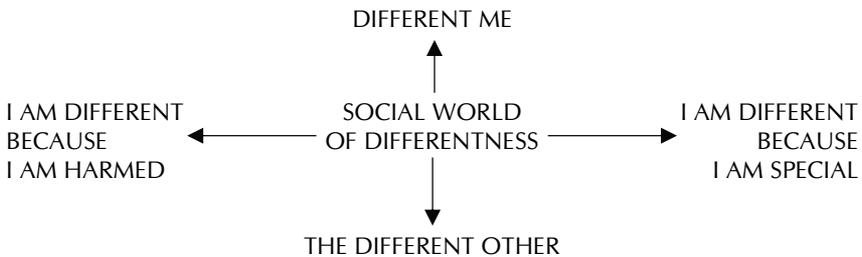
The analysed research material showed many threads focused on differentness. Almost each narrative of the respondents with intellectual disability has been referring to this phenomenon in one way or another. More importantly, the issue has been revealed in the narratives of parents/legal guardians and employers/therapists as well. In order to present synthetic facts, events, but, above all, their interpretations, and the process of assigning meanings to them and the language as a means of expression and communication of respondents, the author utilised the strategy used in grounded theory, i.a. focused coding of categories. The aim of this manoeuvre is to sort, synthesise, and organise large group of data¹⁵, and to present a way in which the information is connected.

¹⁵ Charmaz K., *The Grounded Theory. The Guide on Qualitative Analysis (Teoria ugruntowana. Przewodnik po analizie jakościowej)*, Wydawnictwo Naukowe PWN, Warszawa 2009.

Experiences related to differentness have served as a centre of many categories which have provided answers to such questions as: if and why the respondents feel different? What are the dimensions of being different? What are the consequences of being different? In which areas of life does this sense of being different reveal itself? These are the main questions which, according to the Strauss and Corbin’s thought¹⁶, let a researcher more accurately describe analysed experience and indicate connections between categories and sub-categories, as well as connect data anew.

Synthetically presented phenomenon of ‘differentness’ of respondents with intellectual disability can be described in terms of the above diagram:

Diagram No. 1: Microworld of differentness of adults with intellectual disability



Source: study based on own research

The following section is an attempt to outline each of the above fields.

Different me

As the research material indicates, persons with intellectual disability faced their first experiences of differentness at school. No

¹⁶ Strauss A.L., Corbin J. 1998, *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*, Second edition, Thousand Oaks, Sage.

references to earlier life stages have been made in the interviews. The analysis has showed that many respondents recall school years as a time of dealing with practices which can be described as an experience of differentness. The language used by the adults with intellectual disability in their narratives about these experiences suggests that most of them understood them. Most of the narratives have been larded with very articulate or even crude expressions or, on the contrary, with rather laconic phrases.

Following are a few statements exemplary for the selected category. Respondents have situated their experiences in context of peer interactions:

Marek, 51 years old: *'At school, on breaks or after class, I was alone, I would rather walk by myself, they didn't like me much, those kids were so mean to me, rude they were, these cruds';*

Iza, 37 years old: *'When I was at school, I remember that other kids would laugh at me because I didn't know how to do this or that, they would push me, spit on me, and shout at me that I'm a moron, nutcase, or Down, at first I cried, but then I just got used to it';*

Mateusz, 37 years old: *'I always felt I was different than my colleagues at school. They were much more calm. They would look at me and not understand me, but sometimes I quite liked to come to school anyway. There was a lot of those harmed'.*

They often name people, facts, or events, engraved in their memory as objectifying (creating differentness):

Irena, 42 years old: *'I had this class tutor, she was so mean, she had me repeat grade. And so I had this commission exam, a psychologist, and some other therapist, and so they put me into a special school. It wasn't so great there, I was overgrown, different than others';*

Iza, 37 years old: *'one time this lady said I was the stupidest one in the whole class, and that I didn't belong there'.*

References to this issue can be found in narratives of the respondents' parents:

Mateusz's mother: *'You know, he was different than those kids back then at school. He was apart, he didn't have any friends, they were picking on him, cause he was disparate, just different, and so were saying the teachers';*

Kasia' father: *'My daughter is a bit different, apparently an adult, but still a child, you might say. Our younger daughter, that's completely different, she's got a husband, children, in general, and the older one, she is slightly different'.*

The same pattern emerges from the narratives of the employers of the Communal Home of Mutual Aid:

A female therapist No. 1: *'Most of them was already in the doghouse at school. I listen to it sometimes, as they recall those tough years, being laugh at, picked on, who knows what else there was. They were usually excluded, because they were different, you might say they didn't fit in'.*

The nature of discussed school experiences is displeasing. They are mostly related to the incidents at school, but also to informal or everyday life situations. Former ones are clearly and unambiguously identified by students with intellectual disability as a sign of disrespectful or even hostile attitude of some teachers towards them, and it concerns both so-called 'normal' students, and those from special schools.

It is worth mentioning that differentness, marked by other people, can manifest in appearance of respondents as well as in their behaviour. Analysed interviews contain narratives indicating that some respondents are aware of the fact that people around them notice particular external symptoms of their disability. This is how a 38 years old woman gives an account of her experiences:

'(...) when people look at me, or these old women, when they look at me with this: 'oh, a disabled one!', I'm quite scared. Well, when people look, I just turn away my head, and I don't look at them, I don't pay attention'.

People's reactions intimidate her and make her anxious. Similar aspects of social perception have been identified by a 27 years old woman, who have extrapolated her own experiences on the situation of every person with disability.

Kasia: *'I know that when a normal person sees someone like me, they laugh at them, and I can see it sometimes, but I know what it's like, I can feel whenever someone doesn't like something about me'.*

Granted that a person builds their identity in relation to other people, based on their words, gestures, and glances, which perform a role of a feedback for every individual, it can be assumed that described experiences had a significant influence on the way respondents have been building their world, and the image of themselves. If, according to Buber's words, *I* constitutes itself when encountering *You*¹⁷, then violent interactions experienced by respondents might have made them develop the attitude of dependence, weakness and submissiveness.

Another two contexts can be identified in the area of 'different me': the differentness of needs and of capabilities of adults with intellectual disability. There is a noticeable subjective perception of what respondents need in the analysed narratives. They demonstrate lack of trust, and distance towards what is new and not entirely familiarised. They obviously present a different perception of needs:

Daria, 36 years old: *'I don't know how to use ATM, honestly, I can't withdraw cash, but I don't need to, it's not necessary, my sister or my mom do that';*

Mateusz, 37 years old: *'Computer is not for me, what would I need it for? Well, Internet, maybe, it's easy, but other programs? What for, so I can mess something up?';*

Iza, 37 years old: *'I receive a pension, I don't have to work. I get the money once a month and it has to do. You know, for food, for clothes, but I manage'.*

The differentness and limitation of needs were shaped by earlier experiences and have caused a sense of differentness perceived as strangeness.

¹⁷ M. Buber, *I and Thou. Selected Philosophical Writings (Ty i ja. Wybór pism filozoficznych)*, Pax, Warszawa 1992, p. 45.

Another context of differentness have been revealed in terms of different capabilities, clear in following narratives:

Grzegorz, 34 years old: *'These things are for others, not me';*

Iza, 37 years old: *'I'm not fit for it'';*

Maria, 29 years old: *'When you're disabled as I am, you can't do much'.*

Respondents with intellectual disability do not feel strong and qualified enough to act by themselves:

Maria, 29 years old: *'Oh, no! I can't live by myself. There's lot of things I can't do. You know, things like sandwiches, something simple maybe, but dinner or groceries, it's my mom who takes care of this. I'm not sure I would be able to manage by myself. No, I don't think I would. No, I don't know if I would be able to manage, just on my own.*

Grzegorz, 34 years old: *'No, not to live independently, not yet, I'm not sure how it is going to be with bills and other stuff, I prefer to live with my parents for now. No, I think I would not be able to take care of myself, and why would I?'*

Iza, 36 years old: *'I couldn't raise a child, I can't have children, it is beyond my abilities. Maybe I could give birth to one, but not raise it, no. Because I would not be able to teach them about life, show them, it's hard. I have issues taking care of my nephew and niece, I'm just not good at it.'*

The different Other

Some of the respondents with intellectual disability have perceived themselves as different than other persons with disabilities. One man remembered his difficult experiences at work. He said that in a tough situation he had not been able to help himself and he had 'burst out'. He explained that he had not understood why 'normal' employers had laughed at him when he had been coming earlier to work or made mistakes while performing his duties.

Tomasz, 32 years old: *'I got mad, everything was wrong, I couldn't control myself anymore, because I got mad, and I don't even know why they would pick on me, they even minded me coming earlier, these normal employers, everything bothered them'.*

The respondent called his colleagues from work 'normal', despite the fact that they also have intellectual disability. 37 years old Iza, who participated in a camp with rehabilitation program for people with physical disability, describes her experiences in a similar way:

'I was in rehab there. Sometime earlier I had been there as well, and I had met this nice boy Adrian, he had lived next door with those on wheelchairs, because he couldn't have walked, and not with us normal ones, as I had'.

The ways the respondent has described the circumstances reveals the phenomenon of adopting the schemes of perceiving persons with (physical, in this case) disability. Social reproduction of an image of persons with physical disability among able-bodied members of society may cause internalisation of social environment's view toward individuals with other disabilities, and differentiating perception of persons with physical disability.

It seems that perceiving one's own, as well as another persons' otherness, has been one of the main emotional experiences of a human being. The dichotomic division between Us and Them is of such a kind which is hard to imagine existing in a world without. The natural need to search for similarities and differences plays a significant part in constitution of identity.

I am different because I am special

Being different because of being special is a kind of achieved differentness. The keynote here is engagement in a particular area of activities in which respondents feel qualified, successful, and appreciated. The narrative of 32 years old Dawid is exemplary here:

'I have talent, I'm not like the others. Not everyone can sing like that, I'm a really good singer and I often perform on stage. I really, really like to sing. I win prizes in competitions, because I have talent.'

Dawid's musicality is his special skill. He succeeds in this area of living. Dawid is a solo singer and a kind of a leader of a band in the Communal Home of Mutual Aid. Friends and workers of the House call him a star and a 'stage animal'. The therapist supervising the band claims that

'Dawid cannot do many things, as a result of his deficiencies, but despite this he is very special, because he can sing beautifully. He has a good ear, great voice with nice timbre, and a vocal range. What's more, he is capable of interpreting a song. He actually understands what he is singing about, he gets music. He has a feel for it, he shows emotions, and he is in it with every fibre of his being. And it is special, not everyone can do that. If he was different, fully abled, and he could perform in some talent show, he could even win.' (Worker No. 2, a female).

Another words of this therapist are though-provoking:

'When performing, Dawid is a different person. He stands up on a stage, takes a microphone, and changes completely. He sings and he actually changes. You might say, he is not disabled anymore. He deserves to be called a 'star', he's a star on stage without a doubt.' (Worker No. 3, a female).

Another example of engagement in an activity requiring a special talent is Mateusz. This 37 years old man demonstrates artistic talent. It can be said that painting is the respondent's main occupation:

'I like to paint so much, I can do it all the time. I paint at home too. I have paints, paintbrushes, and I sit and paint, because I like it. I have a lot of paintings, and all of these, hanging on the walls, and in the corridor, and next to the door, they are mine too, and they put them on exhibitions, and I have successes.'

Another area of achieved differentness is sports. An example of a person particularly talented in this field is 34 years old Piotr. The

respondent demonstrates advanced sports skills. Currently he practises four sports disciplines, all of them with good results:

'(...) I really like to attend sports competitions. These cups right there, they're mine, well, not all of them, but many. It is really cool. People arrive from other centres, from various places, and we meet, we practice, and there are competitions (...)'. I am very good, everybody praises me, others aren't that good, but Tomek runs with me anyway.'

A therapist supporting Piotr says:

'Piotrek is a really talented boy. He is strong and determined, he is willing to train, he practices. He is special, because he's not easily discouraged or tired like others'. (Worker No. 4, male).

Being different is seen as being special both by persons with intellectual disabilities and by people close to them. It results in a person's status change in their closest environment, their higher position in group, and their sense of prevalence. Achieved differentness means searching for one's own identity, and using it to constitute oneself. This kind of differentness is accepted, or even desired.

I am different because I am harmed

The narratives of respondents with intellectual disability depict one more concept of differentness, i.a. perceiving oneself as a person harmed by fate, miserable, affected by a disorder, suffering. One of the respondents, telling about her experiences during her visit in a local clinic, has recalled words of an old woman waiting in line with her.

Iza, 37 years old: 'This lady said to me: 'Oh, you are such a poor thing', well, I know I am so poor, other people don't have to suffer as much as I do. And she was right, because what do disabled people exist for? Why did God do that? Nobody knows.'

Another respondent, 37-year-old Mateusz, has told about his experiences in an emotional way:

'Sometimes I think it would be better if I had never been born, because why was I? I wouldn't have to feel ashamed (...) and suffer. Who would laugh at me? If I wasn't disordered.'

Some of the narratives outline the way in which respondents identify their disability with a disorder:

Daria, 36 years old: *'This disability of mine, it's a disorder, it's not like with other people, because I am sick, diseased'.*

Iza, 37 years old: *'When you're sick, this is how it's like, you have such problems as I have. That's why I have a pension.'*

Mateusz, 37 years old: *'My life is really sad. I don't want to remember about it anymore (...), all I want is to live as a healthy, normal person. So I can just be at home, eat dinner, go shopping, have some time for myself in the morning, not just the Home all the time. I like it here, but it's just better to be normal and healthy'.*

This way of seeing disability can be recognised in narratives of the parents of adults with intellectual disability:

Maria's mother: *'I worry, because of her disability she's different, she's so poor, more vulnerable and naive, so helpless sometimes. Fate has been hard on her. Sometimes I wonder why she has been so harmed'.*

Daria's mother: *'Once in a while I cry over her fate, you know what I mean, she is so poor'.*

This kind of differentness might be a consequence of the need to prevent stigmatisation. Persons with intellectual disability carry a much heavier stigma than persons with other diseases. The sense of social isolation and marginalisation switches focus from intellectual disability to the state of disease. There is a clear pattern of 'preserving' the losses resulted from deficiencies and learned helplessness. This condition may lead to giving up on undertaking various activities, and give both adults with disability and their carers

a false sense of security. The situation of a person whose differentness is identified as being harmed may appear as socially more acceptable.

Conclusions

To sum up, analysed research material allows to outline many-sidedness of the phenomenon of differentness, which is relative and mutual, and at the same time universal due to its range and various interpretative perspectives. As noticed by E. Goffman, social roles of Others and 'normal' ones are not a once-and-for-all kind of roles. In particular situations, the Other – a different one – can be normal, and it can work the other way around as well¹⁸.

It is also worth highlighting the phenomenon of undertaking and staying in a role of the Other. Respondents with intellectual disability not only feel different, but they are treated as they were. It is manifested in many ways, among others in giving up on undertaking some social roles, evading some responsibilities, or expecting assistance. Persons with intellectual disability are expected to behave in a proper, nonabrasive ways, and to submit, but not to evolve and actively participate in social life. It is partially society which stigmatises persons with intellectual disability with differentness, and marginalises them, and partially it is themselves who withdraw from social scene. As Beata Cytowska notices, 'persons who diverge from the preferred pattern are willing to internalise group ideologies which place them on a bottom rung of a social ladder, thereby giving up on their beliefs and values'¹⁹. The re-

¹⁸ E. Goffman, *Stigma. Notes on the Management of Spoiled Identity (Stygma. Historia zranionej tożsamości)*, GWP, Gdańsk 2007.

¹⁹ B. Cytowska, *Difficult Paths to Adaptation. Emancipation Motives in the Analysis of the Situation of Adults with Intellectual Disability in Contemporary Polish Society (Trudne drogi adaptacji. Wątki emacycyjne w analizie sytuacji dorosłych osób z niepełnosprawnością intelektualną we współczesnym społeczeństwie polskim)*, Impuls, Kraków 2012, pp. 122-123.

spondents with intellectual disability are mostly aware of the fact of their own differentness, lower social position, and negative assumptions and perception related to it. Socially pigeonholed, they internalise lower social status, limit their self-evolvement, and get used to their disability²⁰. The differentness of experiences of persons with intellectual disability increases social isolation, and it is a source of creating and deepening a sense of alienation.

The phenomenon of differentness is bound up with prejudices, stereotypes²¹, stigmatising²², and discrimination²³. Prejudice is an assumption (often biased) of a group or an individual, usually based on their imaginary characteristics²⁴. It contains beliefs, as well as emotions and readiness to act. S. de Beauvoir wrote that 'The category of the Other is as primordial as consciousness itself. In the most primitive societies, in the most ancient mythologies, one finds the expression of a duality – that of the Self and the Other'²⁵. The reality we live in 'forces' us to encounter the Other, but the nature of these encounters is constantly open and complex, and their consequences depend largely on ourselves. Today there are many motivation and integration programs, aimed at helping persons with intellectual disability to leave social margin. They are subject of concern and held in centres where, in comfortable conditions, they

²⁰ M. Skura, *Me – The Other. Social Relationships of Persons with Disability (Ja – Inny. Relacje społeczne osób z niepełnosprawnością)*, Wyd. UW, Warszawa 2016, p. 8.

²¹ Elżbieta Zakrzewska-Manterys wrote about the 'persistentness' of the stereotype of a child with intellectual disability, see: *An intellectually disabled child: the inevitability of stereotypes (Dziecko upośledzone – nieuchronność stereotypów)* (2003).

²² One of the most significant works on the process of stigmatisation is *Stigma. Notes on the Management of Spoiled Identity (Piętno. Historia zranionej tożsamości)* by Erving Goffman, published in 1963.

²³ Stanisław Kowalik wrote about discrimination, see: *Psychological and Social Foundations of Rehabilitation of Persons with Disability (Psychospołeczne podstawy rehabilitacji osób niepełnosprawnych)* (1999); *Between Discrimination and Integration of Persons with Disability (Pomiędzy dyskryminacją a integracją osób niepełnosprawnych)* (2001).

²⁴ www.bezuprzedzen.org/dyskryminacja/index.php?&tekst – on 12.03.2017

²⁵ S. de Beauvoir, *The Second Sex (Druga płeć)*, Czarna Owca, Warszawa 2003, p. 27.

are supposed to live a 'careless' life. But isn't such an attitude toward adults, based on adjusting their environment to their intellectual abilities rather than to the stage of life and their physical and social maturity, discriminatory itself?

It is worth mentioning that the analysis of research material have led the author to the point where a reflection on characteristics and descriptions of persons with intellectual disability in subject literature shows itself as necessary. Traditional, based on clinical research mainly in the area of clinical psychology, these accounts mostly focus on deficits identified as irreversible and affecting whole personality of an individual²⁶. This way of thinking appears to be inadequate to the data acquired using interpretative research methods, rather limited, lacking of broad perspective including all areas of life, and therefore insufficient. It can be said that they build an image of persons with intellectual disability.

In conclusion, presented research shows that differentness is a significant element of reality of persons with intellectual disability. It is counterproductive to uniform their experiences and problems; on the other hand, the analysis of research materials shows that the phenomenon of differentness is a common issue among almost all respondents. It has, nevertheless, various aspects and consequences. It may be a source of discriminations, as well as a factor determining safety and being taken care of (e.g. it protects from undertaking challenges, responsibilities or social roles, but it also gives a sense of security by highlighting unhoped-for achievements).

It can be only concluded then that if differentness is a phenomenon experienced by almost every person with intellectual disability, it requires further research which allows to examine it from various perspectives, and to broaden the field of reflection. It is necessary to carry out theorisation of results, according to utilised methodology, which the author will attempt to do at the closure of the conducted project.

²⁶ See also: J. Kostrzewski 1981, H. Borzyszkowska 1985, R. Kościelak 1989, J. Lausch-Żuk 1987, Ż. Stelter 2009.

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The life plans and dreams of residents of social care homes for people with intellectual disabilities

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Adult residents of social care homes for people with intellectual disabilities are a group of people who are rarely asked for an opinion, even about themselves. What are their plans and wishes, what do they dream about, how often do they dream and what are the characteristics of such dreams? In this article I will try to analyse the above issues using the material collected through narrative interviews and open interviews conducted in this group.

KEY WORDS: life plans, dreams, social care homes, adults with intellectual disabilities

Justification of the selected topic

The topic of plans and dreams, constituting the title of this paper, was one of the many issues which appeared during my biographical research on the everyday life and adulthood of residents of social care homes for people with intellectual disabilities. At this point, I would like to underline that the research was conducted through narrative interviews and open interviews carried out

among residents who were able to take part in such interviews. These were people diagnosed with intellectual disability (mild or moderate). The study presented in this paper is part of a wider research project on the adulthood of residents of social care homes for people with intellectual disabilities. The topic of dreams and plans appeared either spontaneously in the respondents' narratives (though very rarely) or as a response to a direct question. When analysing the research material, I had some reflections that I will try to discuss in this article.

Human activity is usually purposeful and subordinated to specific plans and dreams. Plans constitute the basis for taking up specific actions, staying ahead of them, as well as for continuing and abandoning activities. Intellectual disability, the related cognitive limitations and the specifics of life in an institution affect the creation and implementation of plans and dreams. The analysis of interview material allows for a description of how the residents of social care homes define their life plans and dreams.

A few theoretical reflections related to the concepts of life plans and dreams

Nancy Cantor and John F. Kihlstrom,¹ define a life plan as a life task, i.e. a problem that has been formulated and recognized by the individual as his/her own, involves the individual and requires the individual's time and energy to solve it. In this sense, it is an everyday human activity. Włodzimierz Szewczuk² describes a life plan as a system of goals to be pursued by the human being, and the principles that apply to it. Tadeusz Mądrzycki³ defines a life plan as the

¹ Cantor N., Kihlstrom J.F. (1987), *Personality and social intelligence*, Englewood Cliffs, New Jersey, Prentice-Hall.

² Szewczuk W. (1966), *Psychologia. Zarys podręcznikowy*, Vol. 2, Wydawnictwo Naukowe PWN, Warsaw.

³ Mądrzycki T. (2002), *Osobowość jako system tworzący i realizujący plany Nowe podejście*, Wydawnictwo Uniwersytetu Gdańskiego, Gdańsk.

main objective accepted by or created by the individual and the related goals, and the principles of operationalization of these goals. Therefore, one life plan contains many plans – actions, its implementation is spread over a longer period of time and it is important for the individual. Mądrzycki⁴ believes that the definition of a life plan can be used interchangeably with the term purpose of life, however, he points out that purpose is determined only by intention, the aim to which the person strives, whereas a life plan also includes the manner in which we act – the manner in which we implement the plan. The author also differentiates a life plan from single-task plans, which are usually implemented by the individual in a shorter period of time (for example, a life plan would include the idea of living in one's own apartment, and a single task would be, e.g. saving money to buy a carpet we dream about). Life plans vary in the following manner⁵:

scope – i.e. the number of individual plans, and the time and effort required to implement them,

content – the richness of content and its diversity,

diversity – they cover one or more areas of life,

number – from a few to a dozen for a given person,

degree of difficulty – which reflects the level of aspirations,

degree of importance – more significant plans bring more satisfaction, but require more effort and their implementation takes more time,

feasibility – related to the assessment of the real external and internal conditions affecting the implementation of the plan,

detailing – creating the outline and detailed „map of the plan”,

long-term plans usually have a more general outline and

short-term plans are prepared in more detail, flexibility –

adjusting the plan to action, level of integration, hierarchy.

All plans should be in line with moral norms, both in terms of the objectives and the way they are implemented. The diversity

⁴ Mądrzycki T. (2002), *Osobowość jako system tworzący i realizujący plany Nowe podejście*, Wydawnictwo Uniwersytetu Gdańskiego, Gdańsk.

⁵ Mądrzycki T. (2002), *Osobowość jako system tworzący i realizujący plany Nowe podejście*, Wydawnictwo Uniwersytetu Gdańskiego, Gdańsk, pp. 133-138.

of plans is the result of both the personality of the individual who creates the plans, as well as the social conditions in which he/she lives.

In colloquial speech the term dream is identified with the terms: fantasy, imagination and associated not so much with goals (as in the case of plans), but with emotions. Dreams, according to Tomasz Maruszewski,⁶ are a form of creative thinking, non-oriented, autistic (i.e., personal, idiosyncratic, including fantasies, dreams, unconscious reactions, and ideas that cannot be verified by external reality).⁷ Bronisława Dymara⁸ describes dreams (1999, p. 21), as an „imaginative-mental activity, the object of which is to satisfy the aspirations, intentions concerning one's own life, which are often strictly personal.” Dreams can be divided into day dreams and night dreams. In this study I will focus only on day dreams, which are conscious and require a larger time span. They concern both the past, the present and the future, and their content is mostly related to social relationships, success, heroism, etc. They consist of events in which the dreamer is usually the main character and of scenography, i.e. objects that are desired or displaced⁹. Dreams, unlike plans, do not have to be realistic and do not require a specific action plan. Tadeusz Mądrzycki, when comparing plans and dreams, points to the above characteristics. He talks about plans when they are associated with the choice of valuable goals, possible to implement, and linked to deciding about future actions. Dreams, on the other hand, are dictated by emotions and do not refer to specific decisions, they remain in the sphere of imagination, desire and do not take into account the conditions necessary for their fulfilment.¹⁰

⁶ Maruszewski T. (2002), *Psychologia poznania*, Gdańskie Wydawnictwo Psychologiczne, Gdańsk, p. 342.

⁷ Zimbardo P. (1999), *Psychologia i życie*, PWN, Warsaw, p. 413.

⁸ Dymara B. (ed), (1999), *Dziecko w świecie marzeń*, Oficyna Wydawnicza „Impuls”, Kraków, p. 21.

⁹ Maruszewski T. (2002), *Psychologia poznania*, Gdańskie Wydawnictwo Psychologiczne, Gdańsk.

¹⁰ Mądrzycki T. (2002), *Osobowość jako system tworzący i realizujący plany Nowe podejście*, Wydawnictwo Uniwersytetu Gdańskiego, Gdańsk, pp. 130-132.

The plans of adult residents of social care homes

As mentioned in the introduction, the issue of life plans rarely appeared in spontaneous responses. Most often they concerned the future place of residence or shopping. Plans concerning the respondents' future, which appeared in spontaneous narratives, may be described as „plans which can be explained“, i.e. not plans as such, but rather explanations of the present state of affairs. My interlocutors associated their plans mainly with the present, with what is known, tamed, accessible:

We will probably stay here forever. Because it is difficult to set a family this way. My brother has his own family. And I'm here. And I don't want to bother my brother. Because he has things to do, take the kids to school, get ready and get his own things done.

Well, here. Here. Because people get used to it all, right? To friends, to the room, to the carers. To everyone. If I were to live alone, I would miss this.

Lady, I will be here, it's a good life, otherwise I would have to worry about everything, and here I have food, I have a place to sleep and I have nothing to worry about.

The third quoted statement shows how the external environment, in this case the social care home, affects the residents' life plans. By satisfying their basic needs, the institution released the residents from the obligation to take care of themselves, which in the case of persons with intellectual disabilities seems justified. Moreover, it can be concluded that residents are aware that they have been released from responsibility and that their life has become easier, but the lack of responsibility also results in the lack of the necessity/possibility to plan. Plans are not necessary in their everyday life, they do not have to plan. On the one hand, they have a sense of stability and security, and on the other hand they know that their lives are controlled from the outside, that someone: the carer, director, will plan the coming days and even their lives. Eve-

ryday life in an institution is planned, among other things, by the so-called daily schedule, designated by the time of meals and therapeutic activities or other additional events. It may also be assumed that such a state of affairs (i.e. lack of planning) has always accompanied the residents, being a model of upbringing of people with intellectual disabilities. What is interesting, a group of respondents admitted that even participation in additional events, such as St. Andrew's Day parties, carnival balls, sports competitions, was not their decision, as often the staff determined which residents would attend a given event. Of course the residents express their willingness or lack of willingness to go, but frequently the number of people who can go to another care centre to attend e.g. a carnival ball, is dependent on the number of seats available in the bus at the disposition of the given social care home. Hence, when talking about plans for the coming days, I noted such responses:

Irena (a carer – annotation by BTN) will decide whether I will go or not. That depends if there's enough space in the bus, then I'll go.

The second type of plans mentioned in spontaneous narratives concerned shopping, most often items of clothing:

I'm saving money because I want to buy a suit for Christmas. We will go with the carer, so I can buy some blouses and trousers, I will tell my carer, so she will buy me everything I need, a sweater maybe.

Shopping plans are the closest, most independent, and most feasible, so we may say that residents of social care homes do not have to worry about their daily needs and their lives resemble that of teenagers, whose plans, mainly financial in nature, focus on fulfilling their own needs – e.g. saving money to buy necessary things. On the other hand, we may observe that the plans of residents of the institution are to a large extent reduced to basic needs which can be realized, for example, buying clothes, sweets or other trinkets. Whereas some of the statements prove that even this need has been reduced to the minimum:

I'll tell my carer to buy me something..., I do not care, I like everything. This reduction of needs seems to be characteristic for residents of institutions, as stated in the book by Jakub Niedbalski (see: J. Niedbalski, 2014).

In one interview, there was a plan concerning an apartment, a realistic plan combined with action. It is worth noting that this statement appeared spontaneously in the respondent's narrative and was connected with great emotions and the necessity to make a very important, risky decision. Both the decision itself and the accompanying actions were very important for the speaker: *It is hard for me to decide. Because I've been living here for 11 years, they help me and I'm just beginning there. It's difficult. This decision is very difficult for me. Because I feel good here. I can do anything I want. When I decide to live alone, I won't be able to afford trips. This year there is a plan to go to the seaside and I have a problem, because when I get the apartment I won't be able to go to the seaside. I have to decide whether to stay here or get my own flat. And this is our home.*

The author of this statement is in a special situation, he has the possibility to live outside the institution. Together with the carers, he undertook actions aimed at implementing this plan, received a proposal of a municipal apartment in which he could live. However, what is clear from the statement, he is afraid to make the decision to actually move out and live in his own apartment. He realizes that living in an institution, despite its obvious limitations, means that residents do not have to worry about everyday problems, it is like being on a "camp", where you have to do certain things, but you do not have to worry about bills, shopping, laundry, meals and the like. The fact that you are „released from responsibility“ for your own life is convenient, and well-developed in the everyday life of residents of care institutions.

Spontaneous statements also included unrealistic plans, although the goal was clearly determined and certain actions were taken, for example:

I'm going to get married, I've had a girlfriend for twenty years now – when the time comes, we'll think of something, we'll get a place to live, find a job.

She also lives in a care centre, but she has an apartment after her mother, so we would have a place to live and I can work, but that's in the future – male, 74 years old

While listening to my interlocutor, I had the impression that he realized the plan would never come to fruition, but the idea appeared spontaneously in his narrative, and one may wonder whether this plan is in fact a dream or even a nostalgia for „normal life”. For over twenty years, this resident of a social care home has had a „girlfriend” living in another social care centre. They meet from time to time, exchange text messages, call each other. Since I had the opportunity to talk to both of them, I could see that they talked about one another with great affection. They feel like a couple despite the distance between them. They talked about their partner with great pride, said they got from each other. The man’s statement was filled with delight over the beauty and care of the woman:

She is pretty, she has a very nice face, I remember how we met, it was a kind of theatre competition, she was dressed up as a highlander and she had these beads and a skirt, she looked really nice”... and she brings me so many things, coffee, tea, biscuits, sugar ..., so many things, and I got her a kind of music box, where you open the lid and it plays music, but you need batteries for that.

The woman also uses the term „fiancé” when she talks about her partner: *We have been seeing each other for a long time, I worry about him, I tell him what he needs to do and think about the things I will bring him ... when I get something I always save one thing for him and after a while there are many things: cookies, tea or sugar, ... but he also cares about me, he also gives me things and I have a photo of the two of us in my room.*

However, it should be emphasized that the woman did not mention plans for a common future, even when asked whether she would like to live with her fiancé, she said:

Never... I would be afraid, because he would have to look at my every step. I prefer to live here until I die.

The above statements allow to conclude that despite the fact that the respondents feel like a couple, they do not have common plans –

the man thinks about a possible future together, he has plans, though unrealistic, whereas the woman does not. These plans will most certainly remain in the sphere of dreams.

Life plans were rarely mentioned in the spontaneous narratives of the respondents. Therefore, I often inquired about them, and usually received answers indicating a lack of plans:

For now I have no plans, I haven't thought about it, I do not know if I will live here, I just don't know

and statements concerning the status quo:

I told you that I won't change anything, it's ok as it is, why should I change it. If I changed something, it would be for the worse, Lady, by the time I begin anything new, I'll be dead, I am 63, I will be a hundred in no time, see it was spring just a while ago and now it's already winter, the end of the year, in 5 months I will be 64, life is short now, the world is getting worse. They are constantly fighting, quarrelling.

When asked about plans, the respondents often talked about the future while presenting it as something unknown, unspecified and unplanned:

I don't know whether I would like to live alone or with my family, Maybe with my family, maybe someday, but right now I would like to help my aunt. I'm worried about my aunt and uncle, because they are sick and take a lot of medicines. I would like to help them.

When asked about plans, residents also mentioned work, which was often seen as a threat:

... I'm afraid of that. Because there are so many accidents and you never know, and it's hard. I wouldn't like to work.

No, no work. I'm ill.

Now I can help when I want to, otherwise I would have to – a statement by a woman who has been getting up early for several years to help the carers with washing her less mobile friends,

I don't plan to work, they would take away my disability pension.

Paid work is seen as a threat to health or finances (pensions) and freedom „I help when I want to”. People who mentioned work when asked about plans were usually those who performed certain tasks in the care home as volunteers. These include cleaning jobs, helping with less mobile residents, and even minor repairs in the case of men. None of the respondents planned to work permanently even in the social care home (if that was possible). This is probably due to many aspects, but also the lack of the need to take up paid work.

The life plans of adult residents of social care homes for people with intellectual disabilities should be considered by taking into account the age, the degree of intellectual disability and the environment in which the persons surveyed are living. My interlocutors were adults aged 24 to 74. The large age span did not differentiate their plans, the only exception was the above-mentioned plan of a thirty-year-old man with a mild degree of intellectual disability to live by himself in a municipal apartment. When talking about plans we should also take into account the degree of intellectual disability (mild or moderate) and the ability to anticipate the future, as some respondents mentioned unrealistic plans. Another factor that is worth mentioning, is the environment in which people live. In this case, we are dealing with social care homes, which are a guided environment, designed to provide help and care, but which also have rules, regulations, daytime schedules, as well as “imposed” activities for residents. It is an environment that is not conducive to making plans.

The life plans of adult residents of social care homes for people with intellectual disabilities can be characterized as follows¹¹:

scope - most often it is one plan, usually related to maintaining the current state of affairs or shopping that will be done in the near future, less often several plans - an example of a complex, multi-layered plan may be the one associated with living outside the

¹¹ Mądrzycki T. (2002), *Osobowość jako system tworzący i realizujący plany. Nowe podejście*, Wydawnictwo Uniwersytetu Gdańskiego, Gdańsk, p. 116.

care centre – which involves greater effort and a longer time of realisation – but, as the interlocutor pointed out, his effort is focused primarily on deciding whether or not to implement the plan, not so much with how it is to be implemented;

content – mostly simple, not complicated – as mentioned earlier, often related to basic needs;

diversity – usually one area of life – e.g. shopping,

number, if any, it is usually one plan, even in the case of the man who was considering living outside the institution. Although the plan should involve seeking and getting a job, it was in fact one plan, my interlocutor did not plan any employment;

degree of difficulty – low aspirations – low self-esteem – therefore, the plans also concern mundane matters, which are the easiest to implement;

degree of importance – difficult to assess, most of the plans were not important to the respondents – they did not undertake actions aimed at their realization. We may assume they were waiting for someone to help them implement the plan or even do it for them, we may also assume that the respondents did not believe the plan could actually be implemented. In the case of the man who had the chance to live outside the institution, the plan should be important – however, what was important was the decision whether to pursue the plan or not, it is difficult to assess whether the plan itself was important for him. We could risk saying that if the plan was important, the man would take concrete actions and implement it. However, his concerns, hesitations, related not only to the question „Can I handle it?“, but also the fact that he would gain something, but lose other things, prove that the plan was not internalised by the man. On the other hand, he feels honoured that his colleagues and staff in the social care home believe he would manage to live on his own, as evidenced by the following statements:

Everyone says that I can manage, even the Director and everyone. I know that I would keep order and I can cook and wash for myself, I can also work.

The lack of internalisation of the plan is also evidenced by the fact that the man had already been granted a municipal flat a year earlier, but resigned at the last moment, and now he is one of the first on the list to be allocated the premises. Theoretically, he has an action plan, he knows what he should do, he even has some of the equipment for the apartment, but in fact it seems more like an external plan of the carers, who are aware the resident could be independent, he is able to earn money, he could have his own apartment, and not the plan of the resident:

feasibility – the plans of the residents of social care homes for people with intellectual disabilities were either very realistic or mundane – mostly related to shopping. At the same time, they often included unrealistic plans – such as the plan of the 74-year-old man to get married;

details – not precise, lack of action plans – we should bear in mind that the described plans were mostly undeveloped, hence the lack of a map of plans. Plans related to shopping were based on the conviction that the carer would inform the resident in due time about sufficient means to go shopping;

flexibility – plans are rigid, which, on the one hand, is a result of the very essence of intellectual disability and related cognitive disorders, and on the other hand, is due to environmental reasons, including learned helplessness and passivity;

level of integration – hierarchy – plans can be extreme or very important, although sometimes unrealistic (though such plans were rarely mentioned in the statements), or not important – the individual does not identify with the plan (these were mentioned more often) in line with the moral norms – all plans in question were in line with the moral and social norms in force.

The dreams of residents of social care homes

The topic of dreams did not appear spontaneously in the respondents' narratives. Their responses concerning dreams were always answers to my questions. What do you dream of? This was

usually followed by a long silence and then a few responses. I tried to categorize them into the following groups: dreams of „great things“, dreams of loved ones, „dreams of power“, no dreams.

Dreams of „great things“

Several respondents mentioned dreams that could be classified as idealistic, concerning safety, peace in the world, happiness:

I would like the world to be peaceful, because it's dangerous now, when you watch the TV and see what's going on.

I dream about big things. I wish certain things wouldn't happen to my family. My mother passed away a while ago, and then my cousin, I wish such things wouldn't happen.

I wish people wouldn't fight, because here they sometimes do, I wish it would be peaceful.

The second group of dreams included dreams about having someone close, dealing with loved ones. Residents of the social care home mentioned the need to contact loved ones or find someone who would be „just for them“:

To have someone close, someone to get along with. That is my only wish, and the rest will work out. ... I dream about my family, for example. I would like my brother to visit me. He has promised that he would come many times, I dream and I'm happy that they will come for my names day in March, Krystyna – March 13, ... I would like to visit my family, just for a while

Living with many people, having friends or acquaintances, being in touch with the carers or the contact person is important, but it does not satisfy the need to have someone “outside“, which is particularly clear in a statement by one resident:

I wish somebody would take me for Christmas, or some kind of holiday. Just for 5 days, even four.

The author of the last statement was extremely determined to find or renew contact with someone he had known in the past, but whom he had not contacted for 40 years (from the day he came to live in the social care home). The need to leave the centre for a few days, for a holiday may be interpreted as a desire to break with the routine, from every-day activities, experience something that would be individual.

Another type of dreams are „dreams of power” as I like to call them. These dreams are characteristic to all of us and belong to the category of dreams that are most likely to fail:

I don't know. I would like to win the lottery. I would buy an apartment in Zakopane (laughter). This category of dreams appeared only in one statement.

Most often, however, when asked about dreams, my interlocutors answered:

I don't know. What should I say? I don't dream about anything.

... no money, no dreams.

Stop it, I don't have any dreams.

I don't understand... What I dream about?... I don't know, I don't dream about anything.

I don't understand, dreams, I don't know what you mean?

The lack of dreams or the belief that they are not necessary were the most common reaction to the question about dreams. We may assume that the aid institution is, unfortunately, a place where dreams become unnecessary, or they may become a reason for bitterness (e.g. in the case of the man who dreamt about leaving the care centre for a few days).

Summary

Plans and dreams are rarely mentioned in the respondents' spontaneous narratives. If they appear, they are often very limited. This is influenced by many factors related to the respondents' life-

long experience. Both the upbringing of people with intellectual disabilities and life in an institution is not conducive to planning and dreaming. Analysing the material, it may be concluded that the residents of social care homes live day by day, without the need to plan the future. We could also say that such an institution does not only reduce, but it also deters life plans. We should bear in mind that most of the residents, although satisfied with their life in the social care home, did not come to live there voluntarily or upon their own initiative. Most often other people decided to place them in a care institution. Perhaps this fact was also the reason that the residents did not make plans, because they have already experienced that they do not decide about their lives, control is taken over by third parties: carers, directors, staff of the institution, family ... Plans do not seem to have great significance in their lives, and dreams may be superfluous. It can be concluded that both life plans and dreams do not influence the lives of the discussed group of people.

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'Time Comprehension and Management Training' in Everyday Activities for Persons with Moderate Intellectual Disabilities

ABSTRACT: Magdalena Hinc-Wirkus, *'Time Comprehension and Management Training' in Everyday Activities for Persons with Moderate Intellectual Disabilities*. Interdisciplinary Contexts of Special Pedagogy, No. 17, Poznań 2017. Pp. 195-221. Adam Mickiewicz University Press. ISSN 2300-391X

A human is a social being, instinctively aspiring to become fully involved with the society. According to the statistics, however, one in ten Polish people is forced to overcome various problems in order to be active in the society. What are the main problems for a person with intellectual disability and their career? One of the main barriers for persons with intellectual disability, are the difficulties with the perception of the time; comprehending the very idea of the time flow and learning to use the watch or the calendar. A simple and cost-effective way to develop these skills is the training in time comprehension ('The Time Workshop'), which is the subject of this article.

KEY WORDS: moderate intellectual disability, the time workshop, comprehension of time

Introduction

A mild to moderate level of intellectual disability is a concern of¹ a minimum of 1% of the society. One of the major everyday

¹ According to the Polish Judicature a mild intellectual disability does not qualify as a disability (judicial decision of Ministry of Family, Labour and Social Policy or

difficulties for persons with intellectual disabilities is the perception of time, which works on the one hand in the psychic dimension of perceiving the reality (and one's reality cognition) and on the other, in the pragmatic applications of temporal notion, such as the usage of the calendar or watch and the rationale behind the very existence of such devices. There are, however, simple and cost-effective ways to develop the defective skills by a 'training in time comprehension and management' (usually shortened to 'time workshop').

It should be noted as part of the introduction that basic daily living skill training for people with disabilities are not only a separate form of operation in the context of social work (e.g. as social support provided by a social worker or a caregiver), but also a recognised component of special needs education. To follow an observation by D. Podgórska-Jachnik, the term 'training' is increasingly common in contexts where 'therapy' was used previously (as in e.g. occupational therapy)². Training does seem to offer more precision and better structural distinction for the required activities, and finally does appear more adequate to the actual tasks performed by the caregivers. The therapeutic effect of training is indisputable; however, the distinction mirrors the current tendencies in special needs education to apply the term therapy very sparingly and only when certain advanced forms of intervention are involved.³ The trainings tend to include a very narrow range of skills, tight pre-planned structure and methodology of competence acquisition, definite time

MPiPS). However, students with a mild intellectual disability are allowed to apply for special needs education (judicial decision of the Ministry of Education or MEN). Their education is based on the standard curricula with didactic modifications. Moderate and severe Intellectual disabilities translate to a different set of curricula and are qualified as disabilities in the judicial sense, which is tantamount to a number of limitations both in learning and social functioning.

² D. Podgórska-Jachnik, *Social Work with Persons with Disabilities and Their Families (Praca socjalna z osobami z niepełnosprawnością i ich rodzinami)*, Centrum Rozwoju Zasobów Ludzkich, Warszawa 2014, p. 140.

³ *Ibid.*

frame as well as highly operationalised and easily verifiable expected results.⁴ All of the above is very much an advantage in the context of special needs education.

Functioning difficulties resulting from moderate intellectual disabilities

To quote the World Health Organisation's definition, an intellectual disability *significantly impairs the overall level of intellectual and adaptive functioning before the age of 18 is reached*.⁵ According to ICD-10 moderate intellectual disability (F71) is diagnosed in adults with an IQ score of between 39 and 45 (Wechsler AIS)⁶, when the conditions of impaired social functioning and symptoms appearance during the development stage are met. Despite the various and elaborate characteristics of people with intellectual disabilities in circulation⁷, the most important difficulties can be structured as follows:

- Perception: *generally impaired, partial recognition of certain features but without discrimination;*
- Attention: *difficulties with focused top-down attention, prevalence of bottom-up attention;*
- Memory: *limited scope of memory, poor learning curve;*

⁴ J. Meder, *Rehabilitation (Rehabilitacja)*, [in]: A. Bilikiewicz, J. Rybakowski, S. Puzyński, J. Wciórka (Eds.). *Psychiatria (Psychiatria)*. Vol. II. *Basic Psychiatria (Podstawy psychiatrii)*, Wydawnictwo Medyczne Urban & Partner, Wrocław 2002, pp. 301-317.

⁵ *The International Classification of Diseases – ICD*, [online] <http://www.who.int/classifications/icd/> [Accessed on 20 December 2016].

⁶ *Ibid.*

⁷ K. Bobińska, T. Pietras, P. Gałecki, *Intellectual Disabilities. Etiopathogenesis, Epidemiology, Diagnosis, Therapy (Niepełnosprawność intelektualna – etiopatogeneza, epidemiologia, diagnoza, terapia)*. Wyd. Continuo, Wrocław 2012; R.J. Kijak, *Intellectual disabilities. Between Diagnosis and Action (Niepełnosprawność intelektualna: Między diagnozą a działaniem)*, Centrum Rozwoju Zasobów Ludzkich, Warszawa 2013; R. Piotrowicz, E. Wapiennik, *The Characteristics of Persons with Intellectual Disabilities (Charakterystyka osób z niepełnosprawnością intelektualną)*, [in:] D. M. Piekut-Brodzka, J. Kuczyńska-Kwapisz (Eds.), *Special Needs Education for Social Workers (Pedagogika specjalna dla pracowników socjalnych)*, Wyd. APS, Warszawa 2004.

- *Speech: Slowness in learning to talk, very simple sentences, incorrect or indistinct pronunciation, limited vocabulary, inaccessibility of abstract terms;*
- *Thinking: limited cause and effect thinking, low processing rate and lack of flexibility, impaired autonomy and self-control;*
- *Emotions: advanced emotional sensitivity, limited emotional control, emotional dysregulation and ambivalence;*
- *Motor activity: acceptable level of self-care skills, low motor precision and dexterity, slowness;*
- *Social skills: frequent limitations in adaptive behaviour and autonomy, usual top level of social skills comparable to a non-dysfunctional 10-year old;*
- *Learning: available in primary special needs education, occasionally in the so-called daily living education, basic training for unskilled labour, occupational therapy workshops;*
- *Occupation: adaptability to straightforward occupational tasks, ability to operate simple machinery under supervision, sheltered workshops⁸.*

As can be seen, persons with moderate intellectual disabilities are faced with considerable limitations in every aspect of life, resulting in a high level of dependency. The aforementioned perception of time is an important component of all of the above aspects of social functioning. Limited self-care skills and dependency on external support is on the one hand a defining factor of many people with intellectual disabilities, and a discriminative factor on the other, sub-dividing their population according to the level of required support, ranging from occasional and temporary, through limited and ongoing, up to permanent support and supervision throughout the entire life⁹. Persons with moderate intellectual disabilities require a limited level of support. The precise definition of which is a subtle, yet significant issue in itself, as this is exactly where their potential for personal inde-

⁸ Ż. Stelter, *The Characteristics of Intellectual Disability. Specific Questions (Charakterystyka niepełnosprawności intelektualnej. Zagadnienia szczegółowe)*, [in:] *A Good Start. Workshops for Providers for People with Disabilities ('Dobry Start' - szkolenia dla usługodawców osób niepełnosprawnych)*, Poznań 2006, pp. 91-94.

⁹ R.J. Kijak, *Intellectual Disabilities... (Niepełnosprawność intelektualna) ...*, op. cit.

pendence is contrasted with the risk of over-protectiveness which can hinder their development potential.¹⁰ According to S. Kowalik (2007), the most important discriminant of the situation a person with a disability, including intellectual disabilities, might be in, is the inadequateness of social expectations and the capabilities to fulfil them. T. Majewski and C. Miżejewski deem individuals with moderate intellectual disabilities as relatively independent in self-care and basic daily living skills¹¹, and, as shown by the results of B. Cytowska's research, their potential is sufficient to master a number of occupational tasks.¹² Regrettably though, people with disabilities are still faced with difficulties in finding employment in Poland, which seems to be a symptom of the certain randomness of the process whereby persons with disabilities can become emancipated from the sense of being dependent.¹³

¹⁰ B. Tylewska-Nowak, *Fulfilment of Developmental Tasks by Adults with Moderate or Severe Intellectual Disabilities (Wypełnianie zadań rozwojowych przez osoby dorosłe z umiarkowaną i znaczną niepełnosprawnością intelektualną)*, [in:] B. Cytowska (Ed.), *Adults with Intellectual Disabilities in the Labyrinth of Daily Life. Research Analysis, Critical Approach and Suggested Solutions. Analiza badań – krytyka podejść – propozycje rozwiązań*. Wyd. Adama Marszałek, Toruń 2011; M. Kościelska, *Experiencing Own and Others' Adulthood by Persons with Disabilities (Przeżywanie własnej i cudzej dorosłości przez osoby z niepełnosprawnością)*, [in:] R. Kijak (Ed.), *Disabilities in the Mirror of Adulthood (Niepełnosprawność w zwierciadle dorosłości)*, Oficyna Wydawnicza Impuls, Kraków 2012.

¹¹ T. Majewski, C. Miżejewski, *The Occupational Possibilities of Persons with Various Types of Disabilities (Możliwości zawodowe różnych kategorii osób niepełnosprawnych)*, [in:] T. Majewski, C. Miżejewski, W. Sobczak (Eds.), *The Borough and the Disabilities. The Borough Official's Handbook for Occupational Activation and Social Rehabilitation of Persons with Disabilities (Gmina a niepełnosprawność. Podręcznik dla samorządów gminnych z zakresu aktywizacji zawodowej i rehabilitacji społecznej osób niepełnosprawnych)*, KIGR, Warszawa 2007, p. 72.

¹² B. Cytowska, *The Programme of Sheltered Workshop for People with Intellectual Disabilities – A Trainer's Book (Realizacja programu 'Wspomagane zatrudnienie osób z niepełnosprawnością intelektualną – Trener')*, [in:] T. Zółkowska, M. Wlazło (Eds.), *Special Needs Pedagogy – Theory vs. Reality. Social and Pedagogical Aspects in Rehabilitation for People with Disabilities (Pedagogika specjalna – koncepcje i rzeczywistość. Socjopedagogiczne aspekty rehabilitacji osób niepełnosprawnych. Vol. III. Uniwersytet Szczeciński, Szczecin 2008.*

¹³ B. Tylewska-Nowak, *Fulfilment of... (Wypełnianie zadań) ...*, op. cit.; M. Kościelska *Experiencing Own... (Przeżywanie własnej) ...*, op. cit.; R.J. Kijak, *Intellectual Disabilities... (Niepełnosprawność intelektualna) ...*, op. cit., p. 12.

Working with people with profound disabilities requires a set of variables to be kept in mind, as the main determinants of what such a cooperation should be composed of. Firstly, even though working with adults, it is irresponsible to expect behaviour fully adequate to the biological age. The usual level of mental development reached by people with moderate intellectual disabilities is roughly equivalent to a non-impaired nine-year old, this being the approximate reference point for structuring the education and development tasks. On the other hand, the essential mindfulness to a person's dignity and their sense of subjectivity, as well as the risk of excessive infantilisation in the relationship¹⁴, should encourage a respectful and regardful manner of address, empowering the person's subjectivity and their right to make their own decisions. Even in the case of severe intellectual disability, respectful partnership with an affected person is mainly dependent on two factors: a profound respect for one's subjectivity on the part of the caregivers and the development of real-life social skills on the part of the beneficiary according to their actual capabilities, and including competences such as self-advocacy¹⁵, decision-making and assertiveness. The latter is an issue addressed directly in the new curriculum for persons with moderate to severe intellectual disabilities.¹⁶

¹⁴ E. Pisula, *The Adult Life of Persons with Intellectual Disabilities. Chances and Challenges (Dorosłość osób z niepełnosprawnością intelektualną – szanse i zagrożenia)*, Polish Association for People with Mental Handicap (PSOUU), Management Board, Warszawa 2008; B. Tylewska-Nowak *Fulfilment of... (Wypełnianie zadań) ...*, op. cit.

¹⁵ D. Podgórska-Jachnik, D. Tloczkowska, *The Self-advocate Movement as the Development of Competences in Autonomous Advocacy of People with Intellectual Disabilities (Ruch self-adwokatów jako rozwijanie kompetencji w zakresie rzecznictwa własnego osób z niepełnosprawnością intelektualną)*, [in:] D. Podgórska-Jachnik, *The Questions of Advocacy and Representation of People with Disabilities (Problemy rzecznictwa i reprezentacji osób niepełnosprawnych)*, Wyd. WSP, Łódź 2009.

¹⁶ See: *The Ministry of Education Decree of 27 August 2012 on the curricula in pre-school, primary and secondary education in the various types of schools (Rozporządzenie Ministra Edukacji Narodowej z dnia 27 sierpnia 2012 r. w sprawie podstawy programowej wychowania przedszkolnego oraz kształcenia ogólnego w poszczególnych typach szkół)* (Dz. U. of 2012 pos. 977), Appendix no 3: *Curriculum for students with moderate to severe intellectual disabilities for primary and intermediate schools (Podstawa programowa kształcenia*

Preparation for the 'time workshop'

Prior to working with persons with intellectual disabilities, a trainer should conduct a detailed diagnosis of their limitations and assets as well as assess the situations in which they function. Establishing the strengths and weaknesses of every beneficiary should be the first step of creating a strategy for the cooperation. In the everyday practice of oligophrenic pedagogues one of the most practical diagnostic tools proved to be the *H.C. Gunzburg (P.A.C.) scale of measurement of social development*. P.A.C. as a whole¹⁷ is comprised of three charts of an increasing task difficulty level, allowing for a good comprehension of the beneficiary's current development level as well as their zone of proximal development, and thus for well-planned education activities. Moreover, it can demonstrate which tasks the beneficiary won't be able to perform at the moment of the assessment, and which tasks may forever remain beyond their capabilities due to the existing limitations and handicaps. The planning stage should balance the pedagogical optimism with realistic outcomes¹⁸ as the two reference points upon which to build the framework of rehabilitation goals and milestones to be accomplished by the beneficiary. The skills measured under the P.A.C. charts can be divided into four groups: *Self-help*, *Communication*, *Socialisation* and *Occupation*. Every group is provided with adequate tasks of increasing difficulty level. The assessment should be updated every six months to better understand in which areas progress, or regress, was made.¹⁹

ogólnego dla uczniów z upośledzeniem umysłowym w stopniu umiarkowanym lub znacznym w szkołach podstawowych i gimnazjach).

¹⁷ PPAC, P-A-C 1 and P-A-C 2 [in:] T. Witkowski, *The Handbook for P-A-C 1 by H.C. Gunzburg for Evaluating the Social Skills of People with Mental Impairment (Podręcznik do inwentarza PAC-1 H.C. Gunzburga do oceny postępu w rozwoju społecznym osób z upośledzeniem umysłowym)*, Katolicki Uniwersytet Lubelski, Lublin 1996.

¹⁸ Cf. B. Tylewska-Nowak, *Fulfillment of... (Wypełnianie zadań) ...*, op. cit.

¹⁹ http://www.poradnikautystyczny.pl/post/kwestionariusze/skala_umiejetnosci_spolecznych_gunzburga_pac [Accessed on 31 December 2016].

Time comprehension, the main focus of the present paper, can be measured on the second or third grade, translating to charts P-A-C 1 and P-A-C 2. *Progress Assessment Chart P-A-C 1 by H.C. Gunzburg, for evaluating the social skills of people with mental impairment* contains the following tasks in this category:

- *correct usage of daytime expressions, such as: in the morning, in the afternoon,*
- *correct understanding of the days of the week and their names,*
- *correct understanding of the differences between time expressions, such as: day – week, minute – hour, etc.,*
- *ability to discern between a quarter of an hour and an hour,*
- *ability to tell the current time and associate the particular hours during the day with various activities and events*²⁰.

P-A-C 2 is designed to diagnose persons with mild intellectual disabilities, and as such it is comprised of tasks on a higher difficulty level. However, according to the Zone of Proximal Development framework they can be applied even in cases of more severe disabilities, in order to discover the potential assets a beneficiary could possess. The following tasks are expected to be understood, at least partially and/or with assistance:

- *understanding of time-related adjectives, such as: daily, brief, prompt, frequent, repeated,*
- *ability to read the clock and to associate the particular hours of the day with various activities and events,*
- *understanding of various ways to express the same moment in time, as in: 9.15 – Quarter past nine,*
- *ability to write down the time when dictated,*
- *understanding of time elapsed between given hours, such as between 3.30 and 4.30,*
- *correct indication of the time one or two hours previous to or following a given moment in time,*

²⁰ T. Witkowski, *The Handbook for P-A-C 1...* (Podręcznik do inwentarza PAC-1), *op. cit.*, pp. 7-8.

- *proper usage of measuring devices, such as a ruler or tape measure, understanding of quantifiers, such as: 'a half of', 'a quarter of'*²¹.

The assessment is conducted by means of observation and interview, with the answers marked on the appropriate diagram. Analysing the obtained data facilitates the design of an education activities schedule and its following evaluation, which should be done by comparing the previous, initial diagnosis with the current assessment results.

Another useful tool given the goals of the 'time workshop' could be the R. McConkey & J. Walsh's Index of Social Competence translated into Polish and modified by W. Pilecka i D. Wolska²². This index allows profiling in the following ranges of social functioning: Communication, Self-Care and Community Skills. Telling the time is included among the Community Skills, along with simple literacy skills and the ability to handle money. Comprehension of time flow is one of the components of being self-reliant, and can be assessed according to the following observations:

- monitoring the elapsed time by a frequent glance on the watch or clock, e.g. when expecting a phone call;
- ability to read the dial of a watch or wall clock;
- ability to tell the time using a wall clock;
- the ability to discern between specific events in a day (e.g. the start of a TV show²³), obvious from the person's behaviour.

²¹ T. Witkowski, *The Handbook for P-A-C 2 by H.C. Gunzburg for Evaluating the Development in Social Skills of People with Mental Impairment (Podręcznik do inwentarza PAC-2 H. C. Gunzburga do oceny postępu w rozwoju społecznym osób z upośledzeniem umysłowym)*, Katolicki Uniwersytet Lubelski, Lublin 1996, pp. 7-9.

²² D. Wolska, *the Influence of Social Adaptation on the Quality of Life of Adults with Intellectual Disabilities (Wpływ prawidłowego przystosowania społecznego na jakość życia osób dorosłych z niepełnosprawnością intelektualną)*, [in:] B. Cytowska (Ed.), *Adults with Intellectual Disabilities in the Labirynth of Daily Life. Research Analysis, Critical Approach and Suggested Solutions (Dorośli z niepełnosprawnością intelektualną w labiryntach codzienności. Analiza badań – krytyka podejść – propozycje rozwiązań)*. Wyd. Adama Marszałek, Toruń 2011, pp. 63-69.

²³ *Ibid.*, p. 66.

Lack of comprehension can in turn be diagnosed, when it can be suspected that the person is not aware of the time flow.

The time subscale of McConkey and Walsh's index can also be applied to design exercises for the 'time workshop', even though it tends to be less specific than the diagnostic tools of Gunzburg's chart.

Personal experience of the 'time workshop' – methodological case-study framework and initial diagnosis

To illustrate my personal experience with the training in time comprehension and management i have chosen a case study of Krzysztof²⁴, a young adult with moderate intellectual disability, living with his parents at his place of birth in a small town. The parents, motivated by the deep emotional bond with their child, were constantly seeking professional support to allow for the development of their son's potential. Regrettably, the time and place of Krzysztof's birth (nearly three decades past in a small provincial town) proved to be major obstacles to the fulfilment of their expectations. As a consequence, they had been hardly aware of the actual cause of their child's developmental handicap and the attempts at rehabilitation and therapy had been undertaken in a rather random fashion. Krzysztof started his education career in a public pre-school, and continued onto a public primary school. However, after three years he was moved to a special needs education facility wherein he concluded his primary education. For the past 10 years Krzysztof has frequented the workshops in a Centre for Community Self-Help (8 hours per working day). The education activities undertaken in his adulthood were somewhat compensatory, as, given proper support, he could have been mastered multiple skills earlier

²⁴ The name as well as pieces of sensitive information had been changed in order to protect the beneficiary's privacy.

in his life. It should be noted, that both parents were highly willing to cooperate, requiring only a degree of guidance and support as well as time and patience.

Due to the fact that the project has been realised according to Krzysztof's individual needs and in the premises of his own house (with concurrent support from the Centre for Community Self-Help), his case can be studied as a type of *action research*, whereby the work of committed, reflective pedagogues is a scientifically recognised method of studying the social circumstances of the researcher's endeavours, with the goal of improving the quality of services provided in such (and similar) contexts²⁵.

The research which i had undertaken can be regarded as a micro-scale project, aimed as it were not only at improvements in Krzysztof's personal functioning, but also in the way his whole family addressed various daily living situations (in which i have frequently participated, due to being engaged in the project for a considerable period of time). The workshops have been deeply embedded into the daily living routine and were of personal importance to myself, which also predefined my possible role in the research process. According to its fundamental methodology, action research should:²⁶

- be conducted by the same individual, who acts as the provider and makes decisions on the course of action, thus combining the role of researcher and practitioner; and should be with regards to matters of importance to the researcher themselves; this i mentioned above,
- result in practical outcomes; this being a realistic improvement of the beneficiary and their family's functioning,
- allow to draw broader theoretical conclusions from everyday practice; this was the methodological concept of 'time workshop';

²⁵ H. Červinková, D. Gołębiak (Eds.), *Action Research. Committed Pedagogy and Anthropology (Badania w działaniu: Pedagogika i antropologia zaangażowane)*, Wydawnictwo Naukowe DSW, Wrocław 2010.

²⁶ www.metologia-badan.wyklady.org/wyklad/7_badania-w-dzialaniu-action-research-.html [Accessed on 14 August 2017].

- be conducted with at least a degree of participation from the individuals involved in the researched situation; this was fulfilled by the subjective manner of participation on the side of Krzysztof, by working to further empower this subjectivity and by the parents' active cooperation

The goal i have undertaken was the assessment and improvement of the beneficiary's functioning with regards to timeflow-related issues, mainly to further the comprehension and cognition of time flow and time management. The workshops were aimed at practical facilitation in daily life, both of the beneficiary and his family. Due to the moderate level of intellectual disability in question the prospective results were placed in the range of minor, however noticeable, improvements in development. The main question of the accompanying research on the other hand (accompanying in the understanding of the *action research* methodology, wherein the research question is secondary to support practice, not a scientific goal in its own right) was: *In what manner is it possible to further and broaden the competences of time management among persons with moderate intellectual disabilities?* The realisation stage included a continuous participant observation with the application of H.C. Guznburg's diagnostic chart to assess the progress and evaluate the project as a whole.

Workshops with Krzysztof begun in July 2014 at his age of 26. Even though I knew him before, i decided to conduct a diagnosis, to better asses his capabilities and the later effects, using *the P-A-C 1 Chart by H.C. Gunzburg for evaluating the social skills of people with mental impairment*. The assessment took roughly 30 minutes, with Krzysztof's mother providing great help with the answers. Having analysed the acquired data, I concluded that

- Krzysztof is well able to manage basic daily self-help, although he requires support in more complicated tasks,
- He would never leave the house, even to the nearest vicinity without a supervising caregiver,
- He had mastered the principles of hygiene, though it has to be said he was seldom willing to complete the daily toilette,
- He was unable to tie shoelaces, ribbons or ties himself,

- He experienced difficulties in concentrating for extended periods of time, and consequently in memorising and completing given sets of tasks,
- He could not use a watch, nor understand temporal expressions correctly,
- He found it confusing to discern the nominal value of money, however he understood and appreciated the role of money in life,
- He could not read, even by the G. Doman method,
- He would refuse to participate in group sports,
- He required reminders, encouragement and ongoing support to be involved in any household tasks,
- He experienced minor difficulties with gross motor skills.

Working with Krzysztof took up to two hours once per week (depending on the current needs and his level of participation) over the course of three months. This time was devoted to individual development, but also to hearing Krzysztof with regards to his needs, concerns and expectations, as well as to consulting his parents. We would often adjust our cooperation *au courant* and according to the current needs, e.g. by updating the 'agenda' on our cork board. Simultaneously Krzysztof would practice every day with his parents. Their deep involvement was one of the key conditions of the programme's realisation. After the initial three-month period we would meet once every month to discuss the developments and further strategies. I would be false to deem this process completed, as the established methods had become deeply embedded into the family's routine, which does in fact mirror the methodology of reflective action research.

'Time Comprehension and Management Training', suggested exercises

According to the theoretical and didactic guidelines²⁷ as well as my own experience in researching the leisure time of people with

²⁷ J. Lausch-Żuk, *Pedagogy vs. People with Mild to Severe Intellectual Disabilities (Pedagogika osób z umiarkowanym, znacznym i głębokim upośledzeniem umysłowym)*, [in:]

intellectual disabilities²⁸, I intend to propose my own methodological proposal for the 'Time Comprehension and Management Training' for the above target group, as demonstrated with the programme realised with Krzysztof in mind. Firstly, I should complement the aforementioned basic methodological assumptions for training with people with intellectual disabilities with a series of additional pieces of information, below:

- The term 'Time Comprehension and Management Training', or 'Time Workshop' for the sake of brevity, should be understood in a brachylogic fashion, regarding on the one hand the process of formation of the notion of time as such, and on the other learning skills in the practical understanding of time flow and the time management in life as a person with intellectual disability;
- The subjective perception of time is predominantly dependent on everyday personal experience. Consequently, 'Time Workshop', or in a broader sense the training on the comprehension of the notion of time, simultaneously has to be an exercise in the formation, accumulation and recognition of the personal meanings of the beneficiaries' individual experiences;
- Due to the above, 'time notion training' should be included among the trainings of social skills, aimed at improving the adaptive potential of the people whose experience in this mat-

W. Dykcik (Ed.), *Special Needs Pedagogy. Composite Work (Pedagogika specjalna: praca zbiorowa)*, Wydaw. Nauk. UAM, Poznań 2006, pp. 149-165; M. Piszczek (Ed.), *The Manual for Teachers to Students with Moderate to Severe Mental Impairment (Przewodnik dla nauczycieli uczniów upośledzonych umysłowo w stopniu znacznym i umiarkowanym)*, CMPP-P, Warszawa 2001; J. Wyczęsany, *Oligophrenic Pedagogy. A Selection (Pedagogika upośledzonych umysłowo. Wybrane zagadnienia)*, Oficyna Wyd. 'Impuls', Kraków 2002; J. Wyczęsany (Ed.), *Special Needs Didactics. A Selection (Dydaktyka specjalna, wybrane zagadnienia)*, HARMONIA UNIVERSALIS, Gdańsk 2014.

²⁸ Research within the framework of PhD studies at the Casimir the Great University (UKW) in Bydgoszcz under the supervision of Hab. Dr D. Podgórska-Jachnik, Professor at UKW. Previously under the supervision of Hab. Dr Mariusz Cichosz, Professor at UKW.

ter can be somewhat deficient (e.g. in the range of own experience, role models, certain skills, or the deficit of intellectual capabilities, hampering the comprehension of various regulations of social life, etc.).

Social trainings, also known as *soft skills workshops*, serve to convey the specific daily living and self-help skills, which are diagnosed as deficient in each and every particular case.²⁹ Among them we can find trainings in areas such as cooking, home budget planning, outward appearances and hygiene, communication and conversation, occupation (both pre-service and on the job) or problem solving in various interpersonal situations. However, the above list is in no way complete³⁰. From the perspective of comprehension barriers and time management, time notion training occurred to me as extremely important in the lives of people with intellectual disabilities.

My set of proposals combines theory with practice; on the one hand it refers to the theoretical discourse on the revalidation possibilities in oligophrenic pedagogy and on the other, aims to demonstrate certain practical solutions in this field. For the latter to be valid, it must foremost take into account the specific situation and individual needs of a person with intellectual disability and their immediate surroundings. The cooperation with Krzysztof has also been preceded by a consultation with his parents, where we discussed the existing documentation (such as previous diagnosis or medical opinions) and the support received up to that date, as well as their difficulties, expectations and capabilities. The functioning diagnosis based on *P-A-C* allowed me to determine what ranges of skills Krzysztof had already learnt and what his potential for prospective development was. Following the diagnosis, we discussed which activities could be realistically undertaken by the parents in a regular and consistent manner. This was especially important due

²⁹ D. Podgórska-Jachnik, *Social Work with the Homeless (Praca socjalna z osobami bezdomnymi)*, CRZL, Warszawa 2014, pp. 113-115.

³⁰ *Ibid.*, p. 114.

to the need to create a common influence front, and the vast scope of the required influence, as well as the value in rehabilitation presented by functioning in family roles on the part of persons with intellectual disabilities.³¹ The above would not be possible without having settled on the shared responsibilities of the parents on one hand and the therapist on the other. In our introductory agreements we have set as our common initial goal to better mobilise Krzysztof into various activities and broaden his range of independent functioning. Aside from augmenting his overall motivation we decided on three main targets with regards to the above: 1. improving the level of personal hygiene; 2. encouragement to take his medication in a regular fashion; 3. training in systematic completion of minor household tasks. The targets had been clearly defined, realistic and settled upon as certain milestones to reach. It is worth to note, that the limited number of targets and the degree to which they were inscribed into Krzysztof's everyday activity were intentional and should be underlined. Time comprehension and management surfaced in our work as an essential, pragmatic tool, and as was obvious after the project's completion, was the common denominator of the training and a goal in its own right. This is what led to the training in time comprehension and management becoming separated as both a topic as such, and a set of practical exercises.

The work begun with the attempts to augment Krzysztof's motivation to act in general. In order to encourage Krzysztof, who seemed quite passive at first, to certain activities we used the so-called token economy system.³² Physically it was comprised of a cork board, on which we placed pictographs representing the tasks which he was meant to learn as a priority.

³¹ J. Wyczesany (2002), *Oligophrenic Pedagogy... (Pedagogika upośledzonych...)*, *op. cit.*, pp. 147, 156-157.

³² A. Kołakowski, A. Pisula, *Handling a Difficult Child. A Friendly Behavioural Therapy (Sposób na trudne dziecko. Przyjazna terapia behawioralna)*, GWP, Gdańsk 2016; T. Ayllon, *The Token Economy (Jak stosować gospodarkę żetonową i system punktowy)*, SPOA, Gdańsk 2000.

1. 'Go out to *community*' represented going out to attend the classes at the Centre for Community Self-Help;

2. 'Pills' represented systematic intake of the prescribed medication;

3. 'Clear table after dinner' represented a self-help task we deemed as essential. This particular one had been chosen due to its relative simplicity, its frequent occurrences during the day and the ease with which it could be isolated and assessed;

4. 'Clean teeth' represented the basic, daily hygiene practice, which needed no additional rationale, even though it was previously not included in Krzysztof's habits.

Training conducted with people with intellectual disabilities requires, especially at the initial stage, a set of simple, crucial tasks, which are both repetitive and verifiable.

Aside from pictographs the board was divided into weekdays, with their full names, so that the whole created a chart, crossing the days of the week with the planned tasks. Krzysztof had been tasked with the daily completion of all of the above tasks without complaining. As a reinforcer, a pin would be pushed into the relevant section of the chart. As the pins were varied in shape and colour they provided an additional side-training in discerning colours and geometric shapes. However, the pins could also be removed, when the results were negative (tasks not completed). Our board serve to develop Krzysztof's familiarity with the names of the days of the week, his systematic approach to daily tasks, the elements of cause and effect thinking. At the same time, we practised counting, which will be addressed in more detail below. Inspired by the use of attendance charts and wall calendars to initially shape the understanding of time, this method combined the didactic guidelines of the workshop centres' method\with the³³ reinforcement of target

³³ K. Sadowska, *The Basic Assumptions and Values of the Methodology in Special Needs Education Facilities (Podstawowe założenia i wartości metody ośrodków pracy w szkolenictwie specjalnym)*, Teacher and School (Nauczyciel i Szkoła), Issues 1-2(18-19)/2003, pp. 180-196.

behaviour³⁴ and the broader behavioural approach to competence management³⁵.

The contract we settled upon with Krzysztof was another important component. The beneficiary's informed consent and wilful participation were crucial to the strategy of empowering his own subjectivity within the project's framework. We agreed with Krzysztof and his parents that constructive behaviour would be rewarded, while disruptive behaviour should be fined with the loss of tokens. The above mentioned coloured pins would be used as the learnt reinforcers, and the following values were in place:

- 10 pins were worth a sheet of stickers (Krzysztof is passionate about sticker collages);
- 15 pins could be exchanged for a copybook to put stickers in;
- 20 pins were worth going out with Krzysztof's father 'to get ice cream';
- 30 pins were worth a family 'pizza' outing.

As is obvious, despite the material nature of the reinforcers, such as stickers or treats, they also contained a social component³⁶ to reinforce the relationships within the family³⁷.

Collecting pins can be used to familiarise the beneficiary with shapes and colours as well as to practice counting (up to 30 in our case). This is a matter of agreement however, and should depend on the current capabilities of the beneficiary. Further to the above, collecting pins is also an exercise in patience, as the reward is some-

³⁴ A. Zawiaślak, *The Questions of Autonomy of Adults with Intellectual Disabilities. Research in Education (Problemy autonomii osób dorosłych z niepełnosprawnością intelektualną: Nauki o edukacji)*, KPSW in Bydgoszcz Scientific Yearly (Rocznik Naukowy Kujawsko-Pomorskiej Szkoły Wyższej w Bydgoszczy), Issue 3/2008, pp. 41-59.

³⁵ P. Jurek, P. Pawlicka, *Functioning Diagnosis Questionnaire. The Handbook (Kwestionariusz Diagnostyki Funkcjonalnej: Podręcznik)*, Wydawnictwo Harmonia Universalis, Gdańsk 2015, p. 32.

³⁶ M. Zielińska, A. Bagińska, *Behavioural Interventions in Case of Severe Nutrients Selection (Interwencja behawioralna w przypadku wystąpienia skrajnej selekcji jedzenia)*, *Developmental Psychology (Psychologia Rozwojowa)*, Vol. 16, Issue 3/2011, p. 73.

³⁷ A. Kołakowski, A. Pisula (2016), *Handling a Difficult Child... (Sposób na trudne dziecko) ...*, *op. cit.*

what distant in time, and in decision making; whether to save the pins until a greater bonus can be obtained, or maybe collect a minor reward immediately? The simple use of pins allowed us to introduce a more sophisticated incentive system based on the token economy.³⁸

Since our main goal was to practice systematicity and time management, the watch soon became an important element.³⁹ Krzysztof could discern the particular numbers and count, he was not able however, to name them and co-relate the numerical values with written digits. As a result, we settled on a digital watch, fitted with an alarm, which could be set to mark every passing quarter of an hour with a brief sound. The very fact of owning a watch was a sort of nobilitation to Krzysztof, as a token of maturity and independence. The workshops included practising the ability to discern the particular hours, understood as recognising the visual indications on the watch (not necessarily reading them, as the fact that Krzysztof could not read digits made even the visual recognition a challenging task).

As a consequence, we created what was called 'the wall clock'. Krzysztof lined a doorframe with pieces of paper, illustrating some chosen events, situations or activities in colourful pictures.⁴⁰ These were painted together in mixed techniques, using not only a brush, but also hands, cotton wool, newspaper, etc. This was aimed at consolidation upon the images, and attributing them with emotional

³⁸ T. Ayllon, *The Token Economy (Jak stosować gospodarkę żetonową i system punktowy)*, SPOA, Gdańsk 2000.

³⁹ The ideas for using the watch were of my own design, however it should be worthwhile to consult the brochure newly published in Belgium: *Praktijk in beeld. Tijd en planning. Hoe kan ik je tonen wat straks komt? (Practice in Pictures. Time and Planning. How Can I Show What Will Happen Later?)*, Sclera vzw & Iris Visualisaties, <http://sclera.be/resources/pib/tijd/> [accessed on 02 June 2017].

⁴⁰ Due to the lack of certain pictographs we needed to prepare some of the pictures ourselves. It is however possible to use the ready-made sets. I can heartily recommend the elaborate Belgian system *Sclera Symbols*, free to download for personal use only at: www.sclera.be. The system is complete with symbols described in Polish.

meanings. At the same time Krzysztof practised mixing colours and experienced a series of polysensory stimuli⁴¹. To the pictures we attached smaller stickers with particular times in the 6.00 to 22.00 range, in 24-hour system and 15-minute intervals (e.g. 6.00, 6.15, 6.30... etc.). The part of the doorframe closer to bed would hold the A.M. hours, while the P.M. would be stuck on other side, which served to provide a visual distinction between terms such as 'Ante- and Post-Meridieum'. Thus, the basic substructure of our *Day Plan* has been created. Using the ready pictographs and the pictures hand-made by Krzysztof we started to fill the day plan with activities to be completed at particular times - from getting up until the evening toilette.

The parents were tasked with cooperating with their son to create a plan for the following day every evening. Thanks to the watch signalling the passing quarters of an hour, Krzysztof was able to compare the dial with the hours stuck to the *Day Plan* and in this way know that the time for a particular task was imminent. This solution gradually taught him to be systematic and prompt, helped to arrange daily tasks and facilitated the planning and management of 'the family roster', not to mention the positive effect on Krzysztof's self-esteem due to the experience of autonomy. As a result, a greater sense of independence was felt by all of the involved; Krzysztof, his parents and myself as a therapist.

The following stage comprised of conveying the meaning and application of temporal expressions to Krzysztof. Before we started our cooperation, Krzysztof would treat all past events as having happened 'the day before', and any future event as supposed to happen 'on the following day', even though something could be planned a month in advance. He was thus able to discern particular events, as well as past from present, however he could not understand the extent of neither. Thanks to the fact that Krzysztof was relatively adept at counting (or rather counting down), we could

⁴¹ M. Charbicka, *The All-Year-Round Sensory Integration (Integracja sensoryczna przez cały rok)*. Wyd. Difin, Warszawa 2017.

work by making him realise how many days were left until a particular event. At this stage we used a calendar with a date indicator. Firstly, in cooperation with his parents we established when certain events, which were important for the family, such as birthdays, anniversaries, holidays or vacation, would happen. Then Krzysztof would draw a picture to represent each event in the respective box in the calendar. As an example, a cake and a smiling face of a woman with curly hair would indicate his mother's birthday, while flowers and a man's face in glasses would be drawn on his father's name day. Every morning, after waking up, Krzysztof would move the calendar date indicator forward, to mark the present day, and thanks to the drawings at particular events to come we could practice counting down the days left until any of them, which also served as an exercise in counting as such. Moreover, during our sessions we would reach back to past events, where questions such as 'what happened three days ago?' or 'what holiday was on last Monday?' proved to be very practical, forcing him not only to actively use the calendar but also to browse his memory for past events.

At a further stage we were able to benefit from an auxiliary *timeline*, a simple graphic representation of the chronological sequence of events, both past and present, which is a widely suggested tool to practice the arrangement of information within the time continuum (such as historical events, but not limited to these) and thus to gain knowledge in a certain field as well as to broaden the comprehension of time as such. A personal diary can also be regarded as a type of a timeline, even though I should mention that the English-language context would differentiate the above two into a *timeline* and a *timetable*⁴². However, both remain useful in the 'time workshop'. A calendar with a date indicator(s), as was the case with Krzysztof, can serve as an introduction to working with both a diary (a *timetable*) and a *timeline*.

Consolidating the practised skills is where ready-made tools are quite useful, here it was the Think-Arrange-Check (PUS) set of

⁴² Cf. <https://en.wiktionary.org/wiki/timeline> [accessed on 14 August 2017].

teaching aids. Using a set of building blocks and the booklet *Concrete Mathematics. Part 2, the Clock and the Calendar*⁴³, Krzysztof was able to check his own efficiency in a self-reliant fashion and in a playful form, with the added benefit of the encouragement for Krzysztof to read books and making him realise that learning does not necessarily have to be unpleasant. The PUS series is a wide range of teaching aids in multiple topics, ready to use in developing various skills, when the beneficiary is familiar with how to use them and how to see for themselves if a task had been completed correctly.

The results of the ‘time workshop’ within the case study

The first changes in Krzysztof’s behaviour were visible after roughly three weeks; he began to complete minor household tasks and take his medication without the need to be reminded, he was also actively using the calendar with indicator and the day plan, which helped him compose himself and relax, as the scheduled tasks had introduced a degree of routine and predictability into his life. The main goals of the ‘time training’ have been reached after roughly five weeks; Krzysztof developed a habit of taking his medication and cleaning his teeth and became willing to participate in minor household tasks. This in turn prompted his parents to modify the cork board and contract as they saw fit, adding new tasks and rewards. Thanks to the above his training (with later modifications) has been underway constantly for the past three years, by the decision of Krzysztof himself and his parents. Consequently, this activity ceased to be a training as such, but rather a manner of planning and management of everyday life in the family. Working with the PUS system encouraged Krzysztof to try other puzzle books and to solve the problems presented by his parents. The use of the calendar

⁴³ D. Pyrgies, *Concrete Mathematics. Part 2 The Clock and the Calendar (Matematyka konkretna, Część 2. Zegar i kalendarz)*, PUS Series, Wydawnictwo Epideixis, Lublin 2012.

with date indicator helped him develop his vocabulary by introducing expressions such as 'later' (instead of only 'tomorrow') or 'some day' instead of 'yesterday'. However, a more concrete cognition of time (as in 'last Monday'/'in four days'/'in July') remains out of his grasp due to the impaired abstract thinking. It is doubtful whether it will be ever possible, however, the expressions such as above are constantly addressed to him and visualised whenever possible.

Krzysztof learnt to use temporal expressions when speaking about matters of importance to him, e.g. *'During vacation, when it was warm, i was in the mountains with the "community"'*, which made understanding what time he refers to much easier for the listener. What it also suggests, is that Krzysztof has started to develop the need to arrange various events on a timeline. His calendar helped him systematise a number of activities as well as understand that certain events are inevitable, simply coming to pass with time. The pictographs with time captions have also had an unexpected and surprising effect, when Krzysztof started to read whole words. The parents welcome their son's new accomplishments with joy and affection, which additionally strengthens his existing reinforcers. All of the above facts demonstrate the value and significance of the long-term efforts in training with a person with a moderate intellectual disability.

In order to acquire sufficiently objective data on the research results, in January 2015, six months after the project had been launched, I repeated Krzysztof's diagnosis using the same *P-A-C 1 Chart* which was used for the initial diagnosis. The results comparison supported the conclusion, that the systematic and consistent cooperation allowed Krzysztof to progress in his social development. Not only did he retain all of the previous skills, but his range of independence was broadened in a number of areas, which obviously was the result of the conducted 'time training'. There were also improvements in other areas, which can be traced back to a better insight into Krzysztof's needs and capabilities - a result of the greater educational awareness of his parents. It is especially worth to note the following:

- Krzysztof started to take the initiative in self-help activities and household tasks;
- Krzysztof began to explore his home town on his own, even though he still requires support in crossing the street. As there were no traffic lights in close proximity and the traffic itself was quite heavy, we resigned from teaching this particular skill for safety reasons;
- To reduce the level of stress and avoid any kind of humiliation, Krzysztof started using shoes where the problematic shoelaces were substituted with Velcro. As a result, he is now capable of dressing in full by himself.;
- Thanks to the pictographs with time captions on the *Day Plan* Krzysztof started to read whole words;
- Krzysztof became more familiar with his digital watch and uses temporal expressions in a correct way when speaking;
- The augmented sense of autonomy resulted in better self-esteem, which in turn encouraged him to participate in group activities more often.

The six months of regular training and the thoughtful 'time training' helped to eliminate the difficulties which had previously been insuperable to Krzysztof's family. As a result, not only Krzysztof became a more socially adapted individual, but his whole family could function every day with greater level of comfort. The accomplished project served to prove that it is quite possible, and definitely worth the effort, to work to compensate the lacking social skills among persons with intellectual disabilities, even when they had already reached an adult age. The above is equally true with regards to time comprehension and management training.

Conclusion

As is evident from the above case study, time comprehension and management are competences which lie perfectly within the capabilities of persons with moderate intellectual disabilities. Using

a very limited budget and a set of ideas embedded in the daily routine it is quite possible to create space for cooperation for the whole family and, more importantly, to train positive habits and systematicity as well as to make temporal arrangements for the beneficiary's daily life. However, none of the above will be possible without an accurate initial diagnosis of needs, assessment of the situation and existing assets and the systematic cooperation of the whole family. Preparing the pictographic displays and discussing the day plan works not only to deepen the relationships between family members, but also to teach the awareness and respect for other people's personal space and their time. In the case of Krzysztof, the participation on the side of his parents has brought the family closer together and helped them understand the difficulties he experienced in his surroundings. They are now better able to seek further solutions to augment their son's independence and broaden the initial goals of the 'time training'. Krzysztof himself began to understand and appreciate planning and promptness as well as systematicity, resulting in a sense of becoming independent and self-reliant, which in turn has a positive impact on his self-esteem. Consequently, he is more willing to train and undertake further challenges.

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The Polish Dyslexia Association

Dyslexia in adults and depression – in the perspective of a narrative of a participant of pedagogical therapy

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This article presents the problem of adult dyslexia and its emotional-motivational effects – the depressive disorders. It shows the narration of a young man experiencing both types of disorders. The presented quotations provide an image of these disorders, but also ways to deal with them. In spite of serious problems, a high level of aspirations has been maintained, and psycho-pedagogical therapy remains a supportive factor, as well as the experienced success.

KEY WORDS: dyslexia of adults, mood disorders, depression, pedagogical therapy

Introduction

Dyslexia in adulthood is a relatively new and rarely discussed subject in Polish scientific literature¹. This lack is particularly no-

¹ M. Bogdanowicz (ed.), *Dysleksja w wieku dorosłym*, Wyd. Harmonia, Gdańsk 2012; M. Łockiewicz, M.K. Bogdanowicz (2013), *Dysleksja u osób dorosłych*, Impuls, Kraków; Reid A., Szczerbiński M., *Studium przypadku dorosłej osoby z dysleksją rozwo-*

ticeable in comparison with the extremely high interest and numerous studies concerning dyslexia in children and adolescents, conducted mainly in the context of the causes of these specific reading and writing disorders, the risk factors for their occurrence and diagnosis, the functioning of students with dyslexia in schools and the ways to help them, the type and scope of the emerging difficulties, including secondary effects. School and educational issues are clearly dominant in this area, as school is the primary outdoor environment for children and young people, and the core curricula and school programmes, as well as their standards, determine the expectations for educational attainment, including reading and writing. These skills are both autotelic (they constitute the core competences of a literate man, as contrasted with illiteracy which is one of the strongest excluding factors in the era of ubiquitous written language) and instrumental (they are tools for gaining other competences and learning in general).

When describing the secondary effects of dyslexia, the authors underline the consequences of experiencing long-lasting, permanent stress and the experienced failures, mainly educational in nature. Marta Bogdanowicz observes that such are the experiences of dyslexic students in higher classes, when, apart from primary learning difficulties, there appear secondary motivational disorders which become a source of stress and frustration, as well as emotional distress. Among the latter, the author mentions neurotic behaviour, depression, and even suicidal thoughts². If such is the image of a student with dyslexia graduating from school, then an important question arises about the emotional and motivational disorders that will accompany an adult with dyslexia in his/her adult life. To what

jową, A poster at the Conference on Developmental Psychology, PTP, UJ, Kraków 2003; Wszeborowska-Lipińska B., *Dysleksja jako indywidualny wzorzec trudności i zdolności*, [in:] *Dysleksja w wieku dorosłym*, Gdańsk 2012.

² Bogdanowicz M. (2011). *Specyficzne trudności w uczeniu się czytania i pisania – dysleksja, dysortografia, dysgraphia*, [in:] M.B. Pecyna (ed.), *Dysleksja rozwojowa – fakt i tajemnica w diagnostyce psychologiczno-pedagogicznej*, Wyższa Szkoła Zarządzania i Administracji w Opolu, Opole.

extent the opportunity to find a job or even achieve potential career and life success can offset the negative experiences of childhood and adolescence, and to what extent they remain inside the person – in his/her perception of him/herself and self-esteem, emotions and the ability to regulate them, how are they reflected in mood disorders, depression?

The question concerning depressive symptoms in adults with dyslexia and their relationship with this particular disorder in the case of persons experiencing depression, was the main reason for this study. I present a case study of a young man with dyslexia, which he himself identifies (self-determination through the experience of dyslexia), who participated in pedagogical therapy for several years. For reasons of therapeutic ethics, I shall not disclose the details, as dyslexia therapy is not the subject of these considerations. At times, the man referred to in the case study, who is in his early adulthood, refers to this experience himself. I wanted to show the phenomenon of experiencing depression by an adult with dyslexia through fragments of a unique correspondence with a patient participating in my therapy. I omitted many autobiographical topics from the passages, which, although extremely interesting, could allow for the identification of the man and would constitute a violation of his personal data, including sensitive data.

Key concepts: dyslexia and depression in theoretical terms

Dyslexia is one of the most commonly diagnosed and recognized developmental disorders in school-age children, which does not mean that our knowledge of the subject is free of stereotypes or even myths. Writing and reading are complex, multi-level neuropsychological processes, and therefore dyslexia is a complex disorder, characterised by multiple aspects and a varying range of impact on the lives and mental health of different individuals. The concept of „dyslexia” and „developmental dyslexia” was intro-

duced in Polish literature by Marta Bogdanowicz, a precursor of the study of this problem, to identify the specific difficulties and disorders in the process of learning to read and write.³ Dyslexia, within the meaning of the International Dyslexia Association (IDA) and the European Dyslexia Association (EDA), is defined as: *„a specific neurobiological disorder in learning. It is characterized by difficulties in correct and/or fluid word recognition and poor decoding and writing skills. These difficulties are usually due to a deficiency in the phonological aspect of the language, often disproportionate to other cognitive abilities and effective teaching methods used in school. Secondary problems may appear related to reading comprehension and contact with the written word, which may limit the development of vocabulary and general knowledge”*⁴. Dyslexia is explained by a number of scientific theories, including, the hypothesis of temporal processing, the theory of phonological deficit, multicellular theory, deficiency of automation (cerebellar), two-independent deficiencies: phonological processing and speed in naming, procedural and declarative learning deficits, and recently the more and more popular theory of mirror neurons. I shall not discuss them in this paper, as such descriptions are available in Polish literature⁵. However, in the further part of the article, I will present the hypothetical pathomechanism of dyslexia within the meaning used by Marta Bogdanowicz, as it will help to explain the relationship between dyslexia and depression.

It is important to note that in the diagnostic classifications of ICD and DSM, the term dyslexia has a rather complex representation. The ICD-10 classification (in force in Poland) consists of the

³ See: Bogdanowicz, M. (2002). Dysleksja i paradoksy. „Forum Nauczycieli. Nauczanie Zintegrowane”, No 1, pp. 5-10; Bogdanowicz, M. (2005). Ryzyko dysleksji. Problem i diagnozowanie, Wydawnictwo Harmonia, Gdańsk.

⁴ *Ibid.*

⁵ See: G. Krasowicz-Kupis (ed.) (2006), Dysleksja rozwojowa. Perspektywa psychologiczna, Gdańsk: Wydawnictwo Harmonia.2006; M. Rusiniak, M. Lewandowska, Przegląd wybranych koncepcji dysleksji rozwojowej- perspektywa genetyczna, neuropsychologiczna i lingwistyczna, „Nowa Audiofonologia”, 3(1) 2014, p. 10 and other.

category labelled R 48 *Dyslexia and other perceived disorders not classified elsewhere*. The classification also includes the category F81: *Specific disorders in the development of school skills*, which also includes the symptoms of dyslexia, namely:

- F.81.0 specific reading disorders,
- F.81.1 specific spelling disorders,
- F.81.2 specific arithmetic skills disorders,
- F.81.3 mixed school skills disorders,
- F.81.8 specific writing expression disorders,
- F.81.9 non-specific developmental school skills disorders⁶.

The American classification DSM-IV mentions “learning disorders”, and its latest version DSM-5 includes „specific learning disorders.”⁷ Thus, in the DSM-IV version we find the category labelled 315.2, which includes:

- Reading disorders,
- Disorders of communication in writing.

In the DSM-5 version, the problem of dyslexia (which is not named as such) refers to the following categories:

- 315.00 Specific learning disorder with reading impairment.
- 315.1 Specific learning disorder with impaired numeracy skills: understanding numbers, memorizing arithmetic rules. The accuracy or fluidity of accounts and accuracy of mathematical inference.
- 315.2 Specific learning disorder with writing impairment with particular focus on the accuracy of spelling, grammar, punctuation, clarity and organization of the written text.⁸

Unfortunately, when studying dyslexia among adults, it is difficult to rely on any of these classifications, as not all adults, who experienced very serious learning difficulties in the area of reading

⁶ ICD-10. *International Statistical Classification of Diseases and Health Problems*, X Revision, Vol. I, (2008), WHO, Geneva.

⁷ P. Gałeczki, Ł. Świącicki (ed.) (2015), *Kryteria diagnostyczne z DSM-5*, Wyd. ELSEVIER URBAN & PARTNER

⁸ J. Wciórka (ed.) (2008), *Kryteria diagnostyczne według DSM-IV-TR*. Wyd. American Psychiatric Association, Wrocław.

and writing skills, have been diagnosed due to a limited knowledge of dyslexia in the past. In addition, the changing diagnostic criteria for dyslexia may also interfere with this image. It is not possible to reconstruct the scale and extent of the disorders in these individuals. With that in mind, the team under the supervision of Marta Bogdanowicz developed an interesting diagnostic tool: the Adult Dyslexia Questionnaire (KDD), developed by K. Bogdanowicz, M. Łockiewicz, K. Karasiewicz and M. Bogdanowicz.⁹

According to Marta Bogdanowicz, people with dyslexia, including adults, are characterized by a unique profile of cognitive ability, which may be called psychoeducational. This is reflected in the low results achieved by such persons in subtests: Arithmetic, Encoding, Messages and Numbers Repetition. According to the author, these results reveal: a low attention span, poor short-term memory, working and sequential memory, as well as long-term memory, the speed of visual-motor learning and visual-motor coordination, linguistic functioning (e.g. slow recollection of names, sequence of words). Not all of the indicated problems are revealed in every dyslexic person¹⁰. It is important to emphasize that sometimes the diagnosis of dyslexia in adult life confirms their suspicions concerning undiagnosed problems in the school period. From my own therapeutic experience I know that even a late diagnosis of dyslexia allows adults not only to master useful compensatory strategies, which may help them in their present life, but it also has a therapeutic effect. This is caused by a better understanding of the reasons of their own failures, which allows them, in line with the assumptions of practical use of Aaron Antonovsky's salutogenic theory, to regain control over their own lives, controllability, use of resources in specific situations.¹¹ According to this theory, this is how we gain

⁹ See: *Adult Dyslexia Questionnaire* (KDD) developed by K. Bogdanowicz, M. Łockiewicz, K. Karasiewicz and M. Bogdanowicz, [in:] M. Bogdanowicz (ed.) (2012), *Dysleksja w wieku dorosłym*, Wyd. Harmonia, Gdańsk, pp. 116-119.

¹⁰ *Ibid.*, p. 108

¹¹ D. Podgórska-Jachnik (2014), *Praca socjalna z osobami z niepełnosprawnością i ich rodzinami*, CRZL, Warsaw, pp. 146-148.

a sense of coherence, i.e. cognitive-emotional-motivational coherence, which allows for effective adaptation in the world.¹² This mechanism also includes the diagnosis of dyslexia in adults who have not been diagnosed yet, but who experience various types of reading and writing difficulties.

The scale of dyslexia, defined as a specific difficulty in mastering reading and writing, is estimated at approx. 10% of the population, with a different range of indicators in different countries: from 0.98%¹³ to 10%-20% in Poland and other European countries. It seems that socio-cultural factors and other criterion references used in the diagnosis, may have a large impact on this diversity.¹⁴ These are not permanent indicators, as evidenced by the number of dyslexic students entering the state examination for sixth grade students of primary schools: 8.96% of students in Poland in 2007, with 13.1% in 2015¹⁵. I shall not discuss the causes of the observed differences and changes, as indicators show that this is a relatively common phenomenon, and therefore affects a large population of children and adolescents, and then adults. The scale of dyslexia in adulthood is difficult to estimate because of the lack of studies concerning reading and writing skills referring to their school years. Some „dyslexic students” are likely to melt into society, choosing occupations where their problems do not constitute a career barrier,

¹² K. Kirenko (2006), *Globalna orientacja życiowa osób niepełnosprawnych aktywnych i biernych zawodowo*, „Aktywizacja Zawodowa Osób Niepełnosprawnych” No 3-4 (7-8), pp. 216-224.

¹³ R.I. Łalajewa (1997), *Definicje, ujęcie i rozpowszechnienie zaburzeń czytania u dzieci w wieku szkolnym*, [in:] Ł.S. Wołkow, W.I. Sieliworstow (ed.), *Chrestmatia Logopedii*, Vol. II, Włados, Moscow, p. 483.

¹⁴ Probably as in the diagnosis of ADHD-type disorders diagnosed in 3-5% of Europe’s population and 11% in the USA, see: Vallée M. (2009), *ADHD: Biological Disease or Psychosocial Disorder? Accounting for the French-American Divergence in Ritalin Consumption*, University of California, Berkeley, [online] <http://www.irl.berkeley.edu/culture/papers/vallee09.pdf> [access: 15.03.2017].

¹⁵ T. Wejner-Jaworska (2016), *Uczniowie z dysleksją rozwojową pod koniec szkoły podstawowej w roku 2015*, *Kultura i Wychowanie*, No 11 (1), 2016.

others benefit from technological support, or simply learn to function with fragmentary dysfunction that can often be compensated for otherwise – and often is. This is based on the assumption that dyslexia is a functional difference, which does not exclude a different capability profile, sometimes quite outstanding. Thus, for example, the dissemination of Davis's and Braun's extremely accurate, stereotype-breaking approach based on the deficit of the term "the gift of dyslexia", because in certain circumstances a „tamed”, specific way of cognitive functioning may be seen as an attribute.¹⁶

The second key term analysed in the article is depression. This is a serious mental disorder that is manifested by low mood, sadness, loss of interests and pleasures (anhedonia), but also a feeling of guilt, low self-esteem, sleep and appetite disorders, fatigue and decreased concentration. Depression significantly reduces the patients' quality of life, as well as their ability to function in all areas of life, both socially and professionally. Depression is recognized by the World Health Organization (WHO) as the fourth most serious health problem in the world and it continues to grow: by 2020, it is estimated to be the second most common cause of disability resulting from the state of global health.¹⁷

There are several theoretical models explaining the mechanism of depression, however, from the point of view of the discussed subject, the causal model that is part of the paradigm of environmental psychiatry, developed by Tom K.J. Craig¹⁸, adapted to the problem of disability and popularised in Poland by Dorota Podgórska-Jachnik¹⁹, seems most adequate. The author also pre-

¹⁶ Davis R.D., Braun E.M., *Dar dysleksji*, Poznań 2001.

¹⁷ *Depresja – podstawowe informacje* (2014), <http://forumprzeciwdepresji.pl/index.php/932/depresja-podstawowe-informacje.html> [access: 10.07.2017].

¹⁸ T.K.J. Craig (2010), *Depression* [in:] Morgan C., Bhurga D. (ed.), *Principles of Social Psychiatry*, 2nd Ed., Wiley-Bleckwell, Oxford, USA, p. 219.

¹⁹ D. Podgórska-Jachnik (2017) *Problem depresji wśród osób niesłyszących i niewidzących*. W: A. Orzechowska, P. Gałęcki, T. Pietras (ed.), *Nawracające zaburzenia depresyjne: etiologia, diagnoza i terapia*. Wydawnictwo Continuo, Wrocław.

sents it as a developmental model, which is explained by a tendency to accumulate experiences relevant in the genesis of depressive disorders²⁰. Craig's model includes two primary causes of depression: one is biological susceptibility, the other includes negative childhood experiences. Both can occur more frequently in the case of people with dyslexia. As far as the first area is concerned, it would be useful to take into account the various disorders of the central nervous system that could explain the so-called co-morbidity of depression and dyslexia.²¹ I would like to emphasise that I have not reached any research that confirms such a relationship, but I do show their hypothetical co-occurrence. In the second area, Craig gives examples of neglect, violence, but does not close the catalogue of these experiences. Literature provides numerous examples of other negative experiences related to dyslexia, especially related to the functioning of children and adolescents in schools, which can be included in this model: e.g. permanent uncertainty, anxiety, marginalization, humiliation, exclusion, rejection due to insufficient achievements, etc. According to Craig, factors associated with the first area lead to low self-esteem, whereas those from the second one – to difficulties in interpersonal relationships. In the Craig model, negative childhood experiences lead to risky, interpersonal (also sexual) relations and risky relationships. This may be related to, for example, compensation in the search for acceptance, however, it is difficult to speculate in this regard, as there are no studies in this field concerning people with dyslexia. An important element of the genesis of depression are individual serious events (e.g. serious school failures, failure to complete a year, failure to pass examinations decisive about the future, closing the road to study the subject of one's dreams or a perform a dream job), which my patients, who are seeking help due to the experienced trauma, often complain about. Following the assumptions of Podgórska-Jachnik, who refers

²⁰ Ibidem.

²¹ Although depression cannot be regarded as a disease, such a concept in medicine denotes the coexistence of various disorders.

Craig's model to disability, it can be said that, in general, *the factors of depression are the same in the case of these people as in the general population, but their intensification or ease of arising in a given situation [here: associated with dyslexia – annotation by T.W.J.] increase the risk of the disease.*²²

It is worth adding that at a functional level we can talk about several categories of behaviours observed in people experiencing mood disorders that may indicate depression and prove critical in its diagnosis. The case I want to describe includes most of them. According to Neil Glickman, these are: concentration problems, depressive thoughts, thoughts about death, depressive moods, loss of hope, neglect or abandonment of certain activities, loss of interest, withdrawal, and physiological symptoms, such as loss of appetite or, on the contrary, excessive appetite, lack of energy, difficulty in falling asleep and sleeping or sleeping all day, laziness, a slow pace of movement²³. In practice, patients in therapy also talk about the problem with beginning any kind of work, creating arrears, and failing to overcome this resistance, despite the prospect of future problems caused by delay. Some of them, and this group includes some well-read individuals, who consciously seek the causes and mechanisms of their own problems, speak about the auto-diagnosis of procrastination. This term has recently become very popular, however, it is interesting to observe that it is used particularly often by dyslexic people in therapy. Certainly it is a signal of disturbance, or at least serious difficulty, in the emotional-motivational sphere.

In order to explain the possible relationship between dyslexia and depression, I reached for the theoretical model of dyslexia in the view of Marta Bogdanowicz. The author distinguishes three levels: biological, cognitive-motor and emotional-motivational, which confirms that such a theoretical approach is able to explain the analysed problem.

²² D. D. Podgórska-Jachnik (2017), *Problem depresji...*, *op. cit.*

²³ N. Glickman (2009), *Cognitive-Behavioural Therapy for Deaf and Hearing Persons With Language and Learning Challenges*. Routledge, Taylor & Francis Group, New York.

At the biological level, the author goes very deep, as far as the factors that act before fertilization (e.g. abnormalities in genes 1, 6 and 15), during the prenatal period (e.g. over-production of testosterone, malnutrition or hypoxia) and the perinatal period (e.g. premature birth, low birth weight, hypoxia, perinatal injuries). These pathogenic factors translate into abnormalities in the central nervous system structure, as well as its functioning. Bogdanowicz locates these effects on a cognitive-motor level, emphasizing the psychomotor unity of activities, such as reading and writing. On this level, she mentions primary cognitive and motor disorders, as well as perceptual-motor integration disorders (visual-spatial and auditory-linguistic-motor), as well as isolated reading and writing difficulties in the younger classes. The third level, emotional-motivational, includes secondary emotional-motivational disorders, such as anxiety because of school or reluctance to learn. Bogdanowicz's theoretical model concerns dyslexia of children and adolescents. However, it is possible to transpose these problems to out-of-school experiences, including adult life (e.g. fear of working with a written text in connection with performing a job, reluctance to read, etc.). In approx. the 4th grade (around the age of 10), secondary disorders create a kind of „vicious circle” mechanism, which is characterised by a general sense of school failure and secondary neurotic and behavioural disorders. In addition, a „spiral mechanism” is launched, which results in the extension of these experiences (disorders) to the sphere of personality development. According to Bogdanowicz, at this level of dyslexia the effects may include, and most often do: low self-esteem, depression discussed in this article, learned helplessness, school phobia, suicidal thoughts and actions.²⁴ Most of these problems can also affect the adult life of a person with dyslexia. The described pathomechanism of dyslexia explains very precisely, why dyslexic patients suffer from anxiety, depression, mood disorders requiring the intervention of a clinician.

²⁴ Bogdanowicz M. (2011), *Specyficzne trudności w uczeniu się...*, op. cit., p. 24.

Experience of depression by an adult with dyslexia in the light of a case study

Despite the existence of a theoretical basis associating dyslexia and depression, it is difficult to find empirical studies that illustrate this relationship in scientific literature. Therefore, I would like to present an individual case study of a young man in his early adulthood who experiences both kinds of disorders.²⁵ He was diagnosed with dyslexia in primary school. Throughout the course of his studies, he had therapeutic support that allowed him to finish school, and even to study, but the therapy was not well suited to his needs, as it did not prevent the secondary effects of dyslexia. As a boy, the man often received unstable evaluations of his own abilities: on the one hand, he was told he had high intellectual capacities; on the other hand, he experienced typical school problems, as described in the previous section, which showed his school incompetence. He experienced negative reactions of both teachers and peers, which confirms the chain of events described in the Craig model leading to depression. Dyslexia and the resulting failures led to an emotional crises of a young, intelligent, sensitive boy, with elements of anxiety and depression, diagnosed as a school phobia. For the most part of his school years, the boy had individual teaching. Despite difficulty in reading and writing, he graduated from secondary school and began studying, he chose exact sciences. The use of IT technology was crucial for him. He set up his own company offering services in this field. He won a prestigious international competition, confirming a high level of professional competence and creativity. Unfortunately, this did not prevent him from experiencing self-doubt and depression, which he is struggling with under the care of a physician. At the same time, he constantly seeks psycho-pedagogical

²⁵ In the characteristics I omit, due to therapist ethics and the protection of personal data, details that could facilitate the identification of the man. They are also not important to highlight the main problem of the article, therefore I remain at the level of general characteristics.

support, which demonstrates, on the one hand, a high level of self-awareness concerning the (still-experienced) emotional and social problems, and on the other hand, a task approach to dealing with depression.

I decided to reveal a part of our correspondence, since the narratives contained therein are a living proof of the experience of depression resulting from dyslexia. On the other hand, I would like to show a high level of linguistic competence, which does not prove that the limitations related to dyslexia have been eliminated, but it shows well-developed skills of dealing with them in everyday life.

The diagnosis of dyslexia in adulthood was confirmed in the case of the examined man by the KDD questionnaire by K. Bogdanowicz, M. Łockiewicz, K. Karasiewicz and M. Bogdanowicz, described in the theoretical part of the article. It is interesting to note that the study was significant for the examined person himself, which may confirm the theoretical view on the role of such a diagnosis in adults in the recovery of a sense of understanding, self-control and coherence. This is how he refers to the diagnosis of the problems with dyslexia himself (I quote the original statements): *Frankly, I have thought about that organizational meeting for a long time, and to be more specific about one of its aspects – when I was doing the exercise to find the differences in the said words and I couldn't do it. I looked at myself and my environment, and in fact it is a problem that I haven't even realised, or rather I blamed the conditions and the environment. I really have a problem with understanding people's voices, both at the time of speaking (my general practitioner has a speech impairment, and I'm not really able to understand a word he says – when I asked my mum about that, he is also her doctor, she said she didn't have a problem with understanding the doctor), and in telephone conversations (which are even worse, it's like when people are visually impaired and try to overcome the problem by squinting their eyes, I don't understand people on the phone and try to listen as attentively as possible). Frankly speaking, there are situations when someone calls and I have to blame the cracks in the ether, because I don't understand them or ask them to send me an e-mail... I must admit that I experienced this problem also during our last telephone*

conversation, which I didn't understand much (especially the second part). I wonder if it is related to a physical hearing problem (although this is unlikely, as I can hear quiet sounds coming from another room through a closed door) or to dyslexia (and I have no clue, as I have no idea if this is a dyslexic symptom – until I took the test of the Polish Dyslexia Association, I never associated the problems with understanding speech with any dyslexic disorder). And I also wonder if it could be associated with the neuroleptic drugs, and I'll definitely talk about it with my doctor tomorrow.

Most of the following passages do not seem to reveal serious dyslexic problems in writing. There is a rich vocabulary, an advanced level of use of the language. There are no spelling errors in the text (this is, to a large extent, a result of using a text editor, which dyslexic people use in their work nowadays), there are relatively few language errors, many phrases with emoticons, characteristic of the style of communication on the Internet. The sentences are reflective, complex, reveal that the person is well-read and has a broad knowledge. The only problem here is punctuation (the quoted texts were not corrected). To show that the man participating in therapy really experiences dyslexia in everyday life, it is worth to quote his own words: *When are you coming back to Poland? I am asking in the context of therapy. Unfortunately, reading is still a problem, what's more, it is very expansive, developing. I have come to such absurdities in this field that I am not able to make corrections to the text I wrote a while ago (writing is much easier!), or read a mathematical task with comprehension, it just does not impress itself deep enough in my memory; when I'm solving a task, I often guess what I have to do based on the provided data. The experience I gained in the competitions is paying and I'm doing ok in my studies, but I have to admit that I am beginning to be scared of the situation. I still cling to the idea that I may have a problem with my sight, I'm going to an ophthalmologist tomorrow, glasses are still new to me and I do not quite understand when I should replace them.*

The correspondence is filled with information about recurrent mood disorders. His answer to the question about his present state of mind leaves no doubt as to the nature and severity of the symp-

toms: *Ehm, it is certainly a bad question in the present situation :-)* When I wrote in December that I have a recurrence of depression, well I have it to this day, only much more intense, to the degree in which I have withdrawn from any activity because the pain is just too strong. I am under constant medical care, but the drugs are still not working and I may need a change (which means another 5 weeks of illness). I just do not know what to do with my studies. The thesis about depression as a motivational barrier and a factor jeopardizing plans is confirmed by the words expressed in another e-mail: *Frankly speaking, I have to withdraw from my original commitment, at least for now. On the one hand, I have a recurrence of clinical depression which has eaten my desire to engage in anything (although I admit that this obstacle will probably resolve in a few weeks, I have already received the right medicine from the doctor, I just need some time), and on the other hand, I would like to focus on my own business, as soon as I feel better; as for now, the disease is really giving me a hard time and has caused enough delay ... there is a serious delay in my schedule, which I will try to catch up with, if possible, unfortunately at the expense of (...) additional activities.*

The man is signalling how much he needs therapeutic support in these conditions. The e-mail includes many questions about the possibility of a meeting, continuing therapy. At the same time, we see that the need to treat depression, as well as dyslexia, is also very important to him²⁶. Moreover, he sees where both problems overlap, and he can distinguish between them: *The question is: do you have any ideas for possible exercises, therapy or other form of support with the problem of dyslexia? It will be at least two weeks before the drugs I'm taking have a chance to work, so it is not a very urgent matter, in this state I would certainly not take a trip to Mars, ups, a typo, I wanted to write to the city centre. However, I would be happy to have some options, because what I'm doing right now is a technique known to programmers as a brutal force, that is, trying to force myself to read, regardless of the emotional and effort costs. It helps to some extent, only the price is too high ... Other*

²⁶ Apart from seeing a therapist-educator, the man also used the help of a psychologist and a psychiatrist.

fragments prove the cyclical nature of emerging depressive disorders, the awareness of the disease and therapeutic cycle and the necessity take this into account in one's personal and professional life. In this context, there appears the idea of self-employment:

Unfortunately, today the disease has won with me, I feel a lot worse and I have cancelled my visit to the ophthalmologist, as I was unable to force myself to go. I will try to make another appointment.

Fortunately, another change of medication, which I was so afraid of, may prove unnecessary, because I have felt much better for a week and I've started to dig myself out of my little black hole. And there are a lot of things to do! I have to catch up with my studies, but with a little luck and some intelligent talk I may not lose my scholarship for the next academic year. I completed the previous semester with a record grade average of 5.0 in all subjects, so I have a margin of error (to keep the scholarship at the current level, the average for the entire year must exceed 4.5).

My life is slowly starting to settle down. I know that because of the recurrences of the illness, I will never be as productive as a healthy person, but maybe I won't have to. It's hard to convince the boss that I need a week or even a month of lighter work on more self-rewarding projects. That I have to multiply schedules by four which just annoys me because I would like to work faster, but unfortunately it is not possible. But I work well. And this has a chance to succeed, when I become my own boss.

It is worth pointing out how significant it is for the young man to verify and implement the findings resulting from the therapy and the related self-reflection: *Your advice concerning depression in the form of smiling to the mirror (for the mirror neurons to note) has been working exceptionally well and gives the much needed feeling of relief. I have to present this idea to my doctor during my next visit, so that other patients can also benefit :-).*

The man also reveals cognitive-motivational limitations. It is interesting to quote these words because they contradict the stereotype that a person with dyslexia avoids writing. On the contrary, we see that while being aware of the difficulties, he does not give up, although he is very strict in evaluating his own progress in this area:

And unfortunately I haven't been writing a lot recently, paradoxically not because I have no time, I try to have free weekends to deal with my workaholicism. The problem is that I have a small literary art-block; I tried to continue [something I started – annotation by T.W.J.] to write a few years ago (...). The problem is that my words do not connect, particular themes become empty, and the characters are not alive and do not speak in their own voice. Well, maybe it will get better. I have already had such breaks and nothing indicates that it will be different this time, i.e. they will not pass without any interference. Fortunately, it is possible to overcome the blockade, with full awareness of the essence of the double problem: As for the main problem, it is dyslexia ... It was a very strange holiday. On the one hand, I read 2 books which is a big step forward in comparison to spring, but on the other hand, reading is still a struggle for me and I have to force my mind to focus on the words. Especially recently I have a lot of problems with concentration, although I must admit that the most probable reason is depression, I'm not able to program (generally, I'm not able to do anything, it is too painful...)

The descriptions are interwoven with ups and downs, hopes and doubts. His determination to pursue self-employment, as a way of coping with life under constrained conditions, is strengthened by a sense of success, however, it is not enough to overcome the emotional and motivational blockade: *I have just set up my own business, so far a single person business. I went through the process of certification as a partner [of a significant global company – hidden data; annotation by T.W.J.], I have received the green light [here the description of the project – annotation by T.W.J.], (...) this may take some time though, because after the first wave of „Oh my God, I've just realised one of the biggest dreams of my life!“ I smoothly went to „Oh no, I feel terrible again for no reason, and again it is because of the sick chemistry of neurotransmitters in my brain“, but still there isn't much more work to do. I am definitely more happy, though my mind does not agree with this. I would like to focus on the last sentence, as it shows a dual approach: both cognitive and emotional, to the evaluation of events happening in his life. This type of control is a form of adaptive strategy for a man fighting with depression. The man describes his great success in an*

international IT competition, but at the same time he also complains about the psychological costs of taking the challenge while undergoing pharmacotherapy of depressive disorders: *Generally, it would be really great if not for my health. I was hoping it would be ok (and it was ok!), but I had to change my medication again because of the side effects. Standard changes: nightmares and nausea, plus two to three weeks of total mental disintegration. Fortunately, I am up to date with all my responsibilities, so I won't fail in anything. I can afford a weaker period :-).*

The achieved success pays a clearly self-regulating role, it is crucial in coping with depression at a cognitive level, although it is not a remedy for all the ailments. However, the man is perfectly aware of the further dynamics of the illness, but also how to cope with it: *I received the Dean's scholarship, and it's higher (the grade average (...) above 4.5, more precisely 4.92), and because I had some extra cash before the holidays I went to my favourite antique shop with fantasy books to hunt for some unique books that I always wanted to have (...). Besides, the antidepressants are finally starting to help (though not as much as I would expect), so I am living without psychological pain, although I am still demotivated to do anything. But it is better and it will get even better! :-)*

The fragments describing a successful recruitment procedure for prestigious foreign studies, with a scholarship and an attractive multi-year contract, are particularly interesting (the final decision is to be made after the completion of his current studies in Poland). The man achieved one of the highest scores in the country. Regrettably, I cannot present this particularly interesting part of our correspondence as it contains too many identification details. However, I will describe the meaning of such a successes for a person with dyslexia: *It's funny, because just two weeks ago I told my psychologist in therapy that I haven't not had much success lately (due to the illness) and I need some external confirmation of my intellectual value. I mean, I know that I am capable and have great opportunities, but when less gifted friends achieve something and I do not, my self-esteem starts to fall. Now, I completely believe in myself again :-)* This is not the only achievement in the recent weeks [here a description of another international success – annotation by T.W.J.]. *However, it was not as inspirational (...).*

The current state of the patient and his situation should be assessed positively. And that is how the man evaluates the situation himself, emphasizing the periodic convergence of a better mental condition with experiencing fewer problems related to dyslexia: *Oh really, a lot of positive things are happening! :-)* I have just started my own business, [here the description of the project – annotation by T.W.J.], *I got an average of 5.0 at university again and finally – FINALLY- just a few days ago I got rid of (clinical) depression, which I had been treating since the beginning of December with serotonin drugs. A real torment, but this is an example of contrast law. In contrast to the greyness, the world is now warmer, more lively, wider; literally better. And with such an attitude, I'm catching up with all the backlog, and there's quite a lot of that after spending almost 2.5 months in bed... :-)* I even have the impression that I'm doing better on the dyslectic front, because I'm catching up on my reading and it's going quite well, better than the last time. I think I'm just starting a better part of my life and it would be good to use it in a sensible way :-).

Finally, I would like to present a sample of the man's writing ability, which is also his view on the suffering caused by the disease. This is just a fragment of a longer story dedicated to depression. However, I find it very significant, especially when the tool of expression and auto-therapy is the text itself, the creation of which brings the man clear relief, but the reception (reading) of which is sometimes a cause of suffering, perhaps even the root cause of other experienced mental suffering (depression). Let the young man's words speak about depression:

The mobile phone showed half past one a.m. I was practically a human wreck, a half-dead shred of my old self. I howled with pain, mental pain, which burned more effectively than real fire, twisted the bowels, shattered the will. I looked around like a vulture torn to shreds, looking for a bit of relief from the suffering that had consumed me in the middle. I could of course go to sleep. Lay down and bid farewell to the suffering of the day, greet the dawn of another day with a bit of relief. It was just slightly easier than climbing K2 in the winter. I ate some dark chocolate, the one I always liked. It's an extremely weak antidepressant if you consider the chemistry, but the best I have.

Although I had the impression that I could be using a thimble to bring water to extinguish the fire of thousands of hectares of forest with equal efficiency. The pain was tearing me apart, biting into my soul, burning me with cold fire. Hah, these words are so weak, pale, empty. They are not even close to what I felt. But I realized that I would feel a lasting relief in a few weeks at the earliest, assuming that the drugs would quickly kick in. Oh, what a joyous prospect, nothing but jump from a skyscraper. Fortunately, there were no skyscrapers nearby. I finished the chocolate. So much for its effectiveness (...).

As I wrote, it is just a fragment of the text, in which the man says: *This is the essence of depression. It does not change the world, it changes you. It drains your strength and mood.* This is true, but there is someone in the story who wants to help and shows the way towards transformation. The story is about change, positive change. The author finishes it with the following words: *I was sitting in my room again, alone. I was looking at the monitor, my soul was once again burning with unbearable pain, going to sleep would be a heroic effort. But I did not want to lie down. I was trying to do something different, something that would help me ...* I believe that my hero will make this heroic effort ...

Summary

In this article I have presented a narrative of a young man who is actively beginning his early adulthood with a baggage of experiences related to dyslexia, but also burdened with clinical depression. In the light of the above theories, it is highly probable that dyslexia and the resulting learning difficulties, including school phobia, have contributed to the onset of depressive disorders. At the same time, neither of the disorders jeopardize the chance for self-fulfilment, accomplishment in a dreamed profession or the achievement of an objective successes.

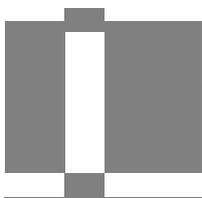
A characteristic feature of the presented case is a high awareness of one's own limitations, but also ways of coping with them. The disorders resulting from dyslexia and depression are related to each

other, which the man is aware of, and seem to be mutually conditioned by periodic or situational fluctuations. It can be said that in the presented case **dyslexia „poses challenges”, while depression shapes sensitivity to the world of one’s own experiences, whereas both shape not only emotionality, but also cognitive functioning and the man’s identity.** In my personal judgment, the young man has provided me with a very valuable material for portraying oneself and the experienced problems. As there is not much literature on the relationship between dyslexia and depression and their impact on adult life, I thought it would be a waste to keep these texts only for myself. Depression is a recurrent disorder, but a person may be prepared for the recurrence based on experiences from the previous phases of the disease and its remission. He may become stronger and more effective. In this case, despite serious problems concerning the emotional and motivational sphere, a high level of aspiration has been maintained and pedagogical therapy remained a supportive factor. This is a clear indication of the direction of therapeutic and support work aimed at personal development of adults with dyslexia and its secondary effects.

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The work of people with deeper intellectual disability as a source of emancipation in the context of personal fulfilment

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Issues of normalisation, autonomy and self-determination of people with intellectual disabilities in special education have already taken their fixed place. The consequence of this continuing discourse is the personal nature of disability, international, timeless declarations and modifications of already established rights. Recently, the emancipatory trend is gaining in importance in this discourse. It remains in close correlation with the primary objective of educating people with intellectual disabilities, which is comprehensive preparation for life. It is a form of conscious self-reliance, self-knowledge and the capacity to take autonomous action. One of the areas of development of self-reliance is work. The resulting interpersonal and intrapersonal experiences can become the path to emancipation. Sometimes one that goes beyond the standards of rehabilitation.

KEY WORDS: disability, work, emancipation

Introduction

Issues of normalisation, autonomy and self-determination of people with intellectual disabilities in special education have already taken their fixed place. The consequence of this continuing dis-

course is the personal nature of disability expressed by the description "Person with disability", as well as international, timeless declarations and modifications of already established rights. Recently, the emancipatory trend is gaining in importance in this discourse¹. With respect to special education, the assumption of the paradigm of emancipation denotes full acceptance of the practical consequences of the meaning of the term "emancipation". It constitutes "liberation from under the rule of social dominance and dependence (...) towards the free expression of one's own, authentic needs, the equality of chances, almost towards self-determination, self-regulation, to an upbringing free of violence, reinforcing the strength of the I"². The structure of the I is related to perceiving oneself as a unique person, the construction of an internal hierarchy of objectives. Its content is composed of individual convictions, interests, needs, values³. Their shaped is determined by the experienced process of socialisation, the environments of significance for this process, and the personal experiences of the person expressed through their knowledge of themselves, and their actions. A consequence of the feeling of independence is the shaping in the person of the structure of the Us, *expressed by the cognitive relations of the person with other people, and identification with their objectives, values and rules of conduct*⁴. From the perspective of social psychology and identity psychology, the mutual relations between the person and their social environment *shine through in changes in life, interests and goals, which are named variously, for instance, "personal struggles", "personal plans"*⁵. The struggles and the plans are activities stemming

¹ C. Barens, G. Mercer, *Niepełnosprawność*, Wydawnictwo Sic!, Warszawa 2008, p. 29.

² B. Śliwerski, *Współczesne teorie i nurty wychowania*, Impuls, Kraków 2005, p. 267.

³ Ł. Grzelak, M. Jarymowicz, *Tożsamość i współzależność*, [in:] Strelau J. (ed.) *Psychologia. Podręcznik Akademicki. Tom 3*, Gdańskie Wydawnictwo Psychologiczne, Gdańsk 2002, p. 107.

⁴ A. Brzezińska, *Spółeczna psychologia rozwoju*, Wydawnictwo Naukowe Scholar, Poznań 2007, p. 239.

⁵ C. Sedikides, L. Gaertner, *Ja społeczne – poszukiwanie tożsamości a prymat motywacyjny Ja Indywidualnego*, [in:] J.P. Forgas, K.D. Williams, L. Wheeler (ed.), *Umysł Społeczny*, Gdańskie Wydawnictwo Psychologiczne, Gdańsk 2005, p. 130.

from emotional, intellectual and social maturity. They are the road towards emancipation. The rule of *nothing about us without us*⁶, constituting the basic dimension of the process of emancipation of disabled people, is reflected for instance in the multitude of documents governing the social functioning of these. What is particularly important is that the emerging provisions are the result of direct contacts, talks and discussions with disabled people. Emancipation in this context is a sign of conscious attempts at changing one's own life, raising its quality, or may even constitute the source of the meaning of life⁷. Authors referring to emancipation pedagogy stress that to experience emancipation is not only to "be independent" but foremost to "be autonomous", meaning, to understand oneself in the structure of the "I" and to be able to distinguish the structure of the "Us"⁸. Comparing and identification with others leads to shaping of the image of oneself within one. Oneself as different from others, and as belonging to a specific community. We are thus considering here an adult who struggles to change their situation or position, and who themselves can decide of their fate and make choices independently. This is doubtless related to the relational model of independence, but also to ever more conscious treatment of disabled persons as a separate entity in the ontological, epistemological and axiological categories. A disabled person is a unique phenomenon that is not described by a specific definition once and for all, but undergoes constant cognition. A phenomenon making relations with other entities, and constituting a value in itself. Considered must also be the possibility of self-actualisation of the individual, which never occurs in solitude. And even though its level is conditioned by one's personal intellectual, emotional and social potential, then if it occurs, it causes the determination of

⁶ D. Podgórska -Jachnik, *Pedagogika emancypacyjna a pedagogika specjalna*, [in:] *Konteksty Interdyscyplinarne Konteksty Pedagogiki Specjalnej*, Wydawnictwo UAM, 2015, p. 23.

⁷ J. Konarska, *Emancypacja jako nowy nurt rehabilitacji*, [in:] *Interdyscyplinarne Konteksty Pedagogiki Specjalnej*, Wydawnictwo UAM, 2015, p. 61.

⁸ B. Śliwerski, *Współczesne teorie i nurty wychowania*, Impuls, Kraków 2005; A. Krause, *Współczesne paradygmaty pedagogiki specjalnej*, Impuls, Kraków 2010.

a further goal. The difficulty of self-improvement allows the experience of personal satisfaction, teaches resistance against failure, raises one's self-assessment. It strengthens one in their daily struggle. It becomes the basis to liberate one from the pressure of "disability". And, as much as this is possible, it shapes the individual "consciousness of freedom". Self-improvement is the vantage point for the emancipation process, *which through a critical negation of compulsion and limitations leads to rational freedom and conscious actions*⁹. Subjective modes of perception of reality by persons with disabilities gain on meaning. Statements, discussions, one's life record, the interpretations, the personal experiences of the researcher and the studied subject uncover a common fate. In many instances they enable *a rediscovery of the meaning of local and global economic, political and cultural forces in the maintenance of the oppressive attitude towards disability, as well as the development of abilities to upset those forces*¹⁰.

Work as an area of emancipation

The present article concerns the social situation of three men with deeper intellectual disability, who after several years of courses in occupational therapy had participated in a scheme simplifying the entry into the open job market. They had undergone a half-year professional internship at a social cooperative in Poland's Kamień Pomorski¹¹, and subsequently, having completed it, returned nei-

⁹ M. Czerepaniak-Walczak, *Między dostosowaniem a zmianą. Elementy emancypacyjnej teorii edukacji*, Wydawnictwo Uniwersytetu Szczecińskiego, Szczecin 2005, p. 45.

¹⁰ C. Barnes, A. Sheldon, "Emancipatory" *Disability Research and Special Educational Needs*, [in:] *The Sage Handbook of Special Education*, ed. by L. Florian, Sage, London, 2007, p. 242.

¹¹ The formation meeting of the "Warcisław" social cooperative in Kamień Pomorski took place on August 25th, 2009. Its main goal was the support of people threatened by social exclusion. The cooperative operates based on cooperation with the commune of Kamień Pomorski, the social aid institution in Kamień Pomorski and the county employment agency of Kamień Pomorski. As part of its activities,

ther to workshops, nor did they undertake any employment. This short information serves to introduce the reader into the research area of this article, to be described in more detail later on.

The movement towards reflections on work doubtless requires a short description of it. Work is one of the basic activities of man, most important during adulthood, it is the defining factor of civilisational development, including the development of every man and the society, in which they are raised. It influences the physical and psychological development of man, releases creativity, initiative, provides satisfaction, happiness and the feeling of being useful¹². It lets one participate in the process of shaping one's own environment, the conditions of one's own life, culture, and the person themselves¹³. It is the kind of activity that becomes the social binder, as it allows the experience of human integration, it is a source of income, and also determines the socio-professional position of one¹⁴. In literature on the subject, work is considered not only as an economic and sociological category, but also as a paedagogical category. Indeed, it is believed that work has additional properties. It is a system of separate and repeatable activities, constitutes a source of income and requires special vocational preparation¹⁵, whereby the profession for the most part determines not only the place of work, but one's position in the social process of work. From the perspective of special education, work is considered in terms of rehabilitation, because work secures for the disabled person the fulfilment of their economic needs, markedly improving their disturbed functions. It permits the confirmation of one's social effectiveness and usefulness, which as a consequence prevents defrustration and

it had made possible an internship of seven persons in social and useful work, who were participants of occupational therapy workshops at the Polish society for the intellectually disabled in Kamień Pomorski.

¹² Z. Wiatrowski, *Podstawy pedagogiki pracy*, Bydgoszcz 2005, p. 78.

¹³ A. Bogaj, *Człowiek w środowisku pracy*, [in:] S.M. Kwiatkowski, A. Bogaj, B. Baniak, *Pedagogika pracy*, Warszawa 2007, p. 23.

¹⁴ Z. Wiatrowski..., *op. cit.*, p. 99.

¹⁵ Z. Wiatrowski..., *op. cit.*, p. 101.

leads to professional as well as social integration¹⁶. Sadly, disability in many cases forms the basis of one being stripped of maturity typical for an adult living in a particular culture. Achieving gainful employment, especially on the open job market is very difficult for disabled persons. Becoming unemployed, they take on, in many instances, the roles of beneficiaries of social aid institutions for the rest of their lives. Considered subjectively, unemployment is a condition of professional inactivity of persons able to work and announcing readiness to undertake it, the basis for the existence of whom is income from work¹⁷. Work leads to psychological resistance, optimism in life, activity of one, and its lack gives rise to passivity, distress and resignation. All the negative effects of unemployment stem foremost from the inability of satisfying of hidden needs, meaning, the psychological functions of work¹⁸. It is believed that certain elements of the work environment such as the possibility of control, a valued social position, variety, the ability to use one's qualifications, interpersonal contacts, are required for psychological health, the feeling of threat or the ability to foresee one's future. This last aspect in particular causes one's own plans and strategies to shatter, it causes social isolation and financial troubles. Great importance is ascribed to the content of the executed tasks, assigning them the role of the determinant of autonomy (independence), the possibility of to express themselves and develop. It is only then that one becomes fully mature and responsible. In losing employment, they lose the ability to express themselves in authentic activity, and at the same time, they lose the ability to develop a mature personality. The main effect of unemployment are financial hardships, which significantly influence the reduction of the standard of life. Lack of income strips the unemployed from the possibility of

¹⁶ H. Borzyszkowska, *Przygotowanie dzieci niepełnosprawnych do pracy w rodzinie i szkole* [in:] A. Hulek (ed.) *Praca ludzi niepełnosprawnych-zadania pedagoga*. Wrocław-Warszawa-Kraków-Gdańsk-Łódź 1985, p. 80.

¹⁷ K. Mlonek, *Tradycja badań bezrobocia w Polsce – zagadnienia metodologiczne*, *Wiadomości Statystyczne* no. 6, 1992, p. 1.

¹⁸ A. Bańka, *Bezrobocie, Podręcznik Pomocy Psychologicznej*, [in:] N. Chmiel, *Psychologia pracy i organizacji*, GWP, Gdańsk 2003, p. 74.

purchasing goods that are status symbols. It also leads to the reduction of one's self-evaluation concerning one's own social position. As unemployment progresses, social isolation and simultaneous reduction of activity deepens. It is the result of either relaxation of ties with former colleagues, or of voluntary reduction of social relations by the unemployed because they do not want to publicly show off their difficult situation. A weakening of the feeling of a community of interests with the employed takes place, with a simultaneous lack of bond with groups that are employed. A breakdown of the structure of time is observed, because the time plan of activities is no longer determined by one's working hours, and this causes difficulty in organising and using one's time. A rule is that preoccupation with time, its amount, the inability to use it, and the feeling of killing time, becomes obsessive. This impacts one's emotions and one's behaviour. It causes discouragement, and even a slowing of one's motions. The ever-deepening hardships, social isolation, the inability to find new employment, dependence on others, humiliations, the feeling of a reduction of status and shutting oneself home¹⁹.

The present struggles towards employing intellectually disabled persons on the open job market are a sign of the mature perception of society on this group of Differents. The offers of the job market apply to the open market, to professional activity centres or social cooperatives. Subject literature broadly describes the positive effects of work of this group of people. Noticeable in particular are the interpersonal and intrapersonal consequences of work as seen in one's daily experiences.

Reflections from research

Calling social cooperatives into existence remains in close relationship with the idea of social work understood holistically as *engagement, responsibility of all global and local entities able to influence*

¹⁹ I. Reszke, *Wobec bezrobocia: opinie i stereotypy*, Wyd. Naukowe Śląsk, Katowice 1999; F. Znaniecki, *Socjologia bezrobotnych*, „Kultura i Społeczeństwo” no. 1, 1992.

*the quality of life of the inhabitants of the entire Earth with consideration for the issues of social changes, human rights, equality before the law and liberation of peoples*²⁰. Among the many goals of social work in the context of the present article, two need to be stressed. The compensation objective struggling to fulfil individual needs that the individuals cannot fulfil on their own, and the promotional objective, meaning, support in the solution of life's hardships in order to help individuals and groups reach a more satisfying level of life. From the point of view of intellectual disability, both these goals are so important as the first one is related to the real possibility of employment, and the second is of significance for the improvement of the quality of life and the experience of multi-context aspects of freedom.

A social cooperative is a unique form of a working cooperative. The subject of its operation is foremost running a common business enterprise based on the personal labour of its members for the purpose of their social and professional reintegration. A social cooperative conducts business activity, but the profit from this activity is not the objective in itself, but a resource used for the implementation of its stated goals. The appreciable purposes of a cooperative are the creation of interpersonal bonds, maintaining the ability to participate in the life of the local community in the members of the cooperative, and shaping the ability to independently provide work on the job market. The purpose of a cooperative is also conducting social and educational as well as cultural activity for the benefit of its members and the local community, as well as activity that is socially useful in the sphere of public activities as described in the Polish act on non-profit activity and on volunteering (Pl. Ustawa o działalności pożytku publicznego i o wolontariacie)²¹.

Such were also the goals that the social cooperative "Warcisław" of Kamień Pomorski²² set for itself. The tasks stated by the coopera-

²⁰ R. Szafenberg, *Nierówności i ubóstwo a uczestnictwo Polski w Unii Europejskiej*, Wyd. Instytut Polityki Społecznej, Uniwersytet Warszawski, Warszawa, 2015, p. 3.

²¹ Polish Journal of Laws no. 96 of May 29th, 2003, item 873.

²² The cooperative operates based on the Polish act of April 27th, 2006., on social cooperatives (Pl. Ustawa o spółdzielniach socjalnych), Polish Journal of Laws of

tive²³ were related to the maintenance of cleanliness and orderliness in the town of Kamień Pomorski and concerned foremost: mowing, raking and removal of grass, planted flowers and trees in public spaces, cleaning and running maintenance of green spaces, maintenance of order and cleanliness in the streets, pavements and parking lots, maintenance of pavements in winter, comprehensive services for town-organised events in terms of maintenance of cleanliness and order. The scope of activities permits one to state that the members of the cooperative were responsible for a very important sphere of the city aesthetics, which certainly was not unimportant to the moods of the inhabitants of Kamień Pomorski. In implementing specific tasks, they foremost became a visible professional group. They specialised in various forms of professional activity. They learned about their tools of the trade and their uses. Work in such a broad scope was the source of many interpersonal (being among other people doing specific work, experiencing various levels of communication, learning the understanding of relations related to the personal structure at work) and intrapersonal experiences (awareness of oneself, of one's abilities, discovering new possibilities, learning and mastering things, that is, new knowledge, placing oneself within the structure of the team and within the social structure). Another significant aspect of such work causes the "visualisation of a person" with their difficulties, as an employee, meaning someone who, despite their limitations, is able to operate independently. For the social image of disabled people, in particular intellectually-disabled people, this has profound importance as it shatters stereotypes, prejudice, in many cases lifting the stigma.

Such an idea of socialisation was the guiding light for the "Warcisław" social cooperative, which implemented, with the participation of the Office of the Marshall of the Voivodeship of Western Pomerania, a programme for the countering of social exclusion of

2006, no. 94, item 651, the Polish act of September 16th, 1982, the cooperative law (Pl. Prawo spółdzielcze), unified text – Journal of Laws of 2003, no. 188, item 1848.

²³ The bylaws of the "Warcisław" social cooperative in Kamień Pomorski.

persons threatened by exclusion. In the programme participated persons indicated by the local employment agency, the county agency for family aid, as well as seven participants of the occupational therapy workshops at the Polish society for the intellectually disabled in Kamień Pomorski. The cooperation programme with the social cooperative covered a six-month internship which as a consequence could fruit in permanent employment of the intellectually disabled. Participants in the programme had prior to that undergone appropriate training in OHS and spanning specific activities related to the undertaken internship. The programme concluded in the year 2015. Sadly, none of the participants of the occupational therapy workshops was willing to commence employment after the programme. Four persons returned to the workshops, with the remaining three²⁴, those under research, did not undertake any activity. And here arose an emancipational dilemma. Why, having such rich experience, these people preferred returning home to do nothing? Why did they make such choices? Were these independent choices, or were the decisions made for them? Assuming that work is one of the pillars of rehabilitation, it should fall within the area of interest of the intellectually disabled themselves, as well as their families. This was not the case, however. These questions formed the basis of my research. An attempt at answering them was sought in the statements of the caretaker therapist, the statements of the people who did not commence employment, and the representatives of their family environments.

The therapist, the person who participated in this programme, seeks the causes of failure to undertake employment within the attitudes of the unemployed themselves.

...they did not always show up for work, sometimes we had to bring them in because they overslept or simply did not feel like coming...(...)...the wheelbarrow was a cause of a dispute or insult (...) it was like that there, probably who

²⁴ The interviewees are males aged 29, 34 and 36, inhabitants of Kamień Pomorski, remaining under family care. Their internships at the social cooperative were based on prior evaluation of their abilities to make interpersonal contacts, their abilities, and primarily their expressed willingness to work.

had the wheelbarrow, they had the rule, they felt important... (...)...In the beginning they wanted very much, they were important... but when it turned it out that one had to arrive on time and do something specific, they lost interest in this....

The statements of the therapist also permit the conclusion that the work had nobilitating character only in the declaratory layer. In the area of activity, it became a burden and a task requiring control from the outside, which was noticed by the intellectually disabled and not accepted.

...the persons running the work would sometimes bemoaned that they constantly needed to drive those from the workshops... that violent disputes arise... I believe that it was just that others were more able and worked faster.

How is this issue remembered by the intellectually disabled themselves?

M1 (29 years)

...work in the rain, on Sundays.....we were constantly guarded, like in prison...

The person making the statement refers to the work as if it was compulsory, this stems from the fact his view of the work differed from that which he had to provide himself.

M2 (34 years)

...there was no car to drive the equipment, and one would walk across all of the town with these wheelbarrows... it was cold... the manager shouted that we are loafing around, but when it was cold she would quickly retreat to the office.

We are clearly seeing here a dislike for work caused by the working conditions, weather conditions, with simultaneous painful experiences of the freedom of another person who was able to „re-treat“. The next male's expressions had a similar tone, noting the bad conditions of employment. He did not analyse the tempo of his work, perhaps the failure to adjust his behaviour, but his memory retained the experience of „verbal abuse“.

M3 (36 years)

...in the beginning I liked it... but the manager kept complaining... do this... do that... I hated worst that I had to get up early... and outside, outside... it was very cold...

A further area of consideration was the relationship with former occupation, whether they were happy with it, and in this case all three indicated being satisfied.

M 1

I learned a lot about flowers, how to care for them. One could talk, joke around.

I had money, I could buy cake for the family, coffee or something else. (...) I have a friend where I live.

What is impactful in this statement is a completely different approach to money. The man benefits from a monthly pension, but the money gained from work had a different dimension. They placed him in a group able to decide on one's resources. They certainly broadened the perspective of one's self-perception, as someone providing their own, autonomous activity for the home environment.

M 2

I was satisfied, even very satisfied, in the beginning. It was different later, because when those from the agency came, they wanted to show us that they were better, but they loafed around. (...) but sometimes I could choose the task myself, because I know a lot about flowers. Sometimes even our manager would ask what to do so that they don't freeze over.

In this statement clear is the experience of competition, feeling worse in light of others, those Different. This is doubtless a very personal and deep experience. Uncovering the truth about oneself, however, we see here also ascribing a meaning to one's own abilities.

M 3

We would joke around or talk up women. I even had a date with one, I think three times. If one has money, one has women. Now I don't do meetings any

more... When they let us go, we don't meet any more. Do I regret it? I don't know... I think so... but she has someone. Also from the cooperative... but he was from the agency.

In this statement as well, other money is also of importance, money for work, but they are basically a secondary problem in light of the fact of facing the myth of women. Like his colleague, the man experiences Otherness. And even though he does not clearly stress it, the fact that a competitor was from outside the workshop made him, in his view, more valuable for the woman.

Why did the men not take up employment after the completed internships?

The issue is very complex. On the one hand, it was related to the restructuring of the cooperative itself, on the other hand the men could receive references permitting them to get employment anywhere in gardening. Discussions with the men permit the conclusion that they were held back from independent work by fear of whether they would make it? At the cooperative, there was someone who would organise the work, issue orders as to the scope of tasks, control the day from the beginning until the end of work.

M1

...I was told to go to X but the father said that you will not work for him... because he won't pay... here they said that he abuses people...(..) I won't go back to the workshops, no... there is no work for me there (...) what is there to speak about with them...

These fragments of the statement seemed interesting to me for two reasons. First of all, one can get the impression that the man was perhaps ready to start working, were he motivated by the family and if that motivation was maintained. Second of all, he clearly indicated his uniqueness, Difference, maybe even being „better“ than former colleagues. He is thus ready to live in a certain isolation from the environment, so that he would not need, before himself, to identify with the group that he „graduated from“.

M2

I already had enough of the cold... I did not want to ride there. What kind of money that was... now I just get... and I also have money. My sister even sought work for me, but I'm not going back to gardening... rain - work, wind - work... it's not bad... I'm not going anywhere... from the workshops I got colleagues, but they call, call, I would sometimes go... from the cooperative I also have colleagues, but I do not meet them.

The entire attitude of the man is an expression of his unwillingness to work, any discussion on the subject even irritates him. He also does not see himself in any other area of work. He relates work only with unpleasant experiences. In the discussion, the subject of undertaking any other employment does not show up at all. Important are in turn relationships with friends. A certain dichotomy is noticeable here. The workshop activities do not interest the man, but he remains in contact with the persons that remain there. One could make the assumption that the force of the relationships entered into earlier is strong. The completed internship had perhaps become important for the self-assessment of the man, but it did not influence the emergence of new bonds.

M3

...they did not extend it, so there was nothing... I did not want to do the workshops any more, I am too old... I have friends... here, neighbours, a friend from the cooperative comes in, but he also does not go there (to the workshops)... I know something of working in a small garden... I help out my neighbour in his garden...

The interviewee does not understand the fact that he participated in a scheme that opened up for him the route to employment. When the scheme was over, he did not feel the need to continue it. He behaves as if that time in his life was not an important event. The experience of work did not give rise in him to changes in his life. He did not strive to maintain the status of an employee, colleague or co-worker. It is as it is. He lives with his extended family,

receives his social pension. He makes the impression of being satisfied with life.

Among the members of the family, only the sister of one of the men (M2) consented to talk to me

I found him a job in gardening, they were quite satisfied because my brother is strong, one has to carry crates, soil... but what do I say, he got bored with it... once he would go, once he wouldn't... the time I spent encouraging him... he's not one to consider an explanation. he has the pension, but he goes here to do something... I do not understand this, after all, he was satisfied.

In case of this man, the sister's engagement was very strong. What is interesting is that the search for employment was aimed in the direction of former work. The sister was convinced that the man could make it. I believe, however, that other factors weighed in that were not present in the employment. First of all, the man worked alone, he was formerly in a group. Independent work was task-oriented and it was related to making even minor decisions. At the cooperative, the work day, irrespective of the tasks, had its specific beginning and end. It cannot be excluded that one needs also rituals to accept work that were missing from the place of independent work.

Is not undertaking work already a way towards emancipation?

Constructing an emancipational paradigm of special education requires referring to many groups of disabled people. It is thus a process, the birth and the path of which we are observing. One could, however, say with full responsibility, that it assumes as the primary term, the feeling of conscious freedom of man. Freedom that lets one design their own life and live it according to that design. Freedom that liberates one from the oppression of stereotype, exclusion, marginalisation. Why a stereotype? In the introductory portion of this article I have indicated the negative consequences of unemployment. The entanglement in the condition of passivity that degrades one and pushes them to the margins of life. Special education ascribes a great importance to work as emancipating disabled people, and in the global sense this is undoubtedly the case. A disabled person at work, as a colleague, friend, subordinate, etc., is

a great merit of special education. In individual experiences, it shines through that it need not necessarily have this dimension. The undertaken effort, social constructions, determine the common standards, and a departure from them gives rise to disquiet and amazement. There exists the fear of exclusion. The interviewees did not have this feeling, they live in their own worlds, and even though its scope may seem limited, this is where they experience their daily lives that do not seem unpleasant to them. So, we come to marginalisation. It can be perceived in many ways, but in most cases we consider here the unavailability, limitations in the implementation of needs. In my discussions with the evaluated men, I did not notice this, and commencing these, I pondered exactly what needs do they not fulfil. The attitude of passivity, acceptance of reality, the lack of expectations is quite stunning. It would seem that the experience from the workshops, from the social cooperative could awaken the needs, encourage changes. Not every home environment is accompanied by passivity, and yet, despite the struggle, intellectually disabled persons cannot be encouraged to be active, even though they have relevant experiences. The analysed persons do not experience the passage of time, they do not identify themselves as belonging to the group of those who do not work. They do not experience discomfort stemming from non-participation in the activities of any environment. Returning thus to the stated question, whether one could speak of emancipation in terms of these three men? The response is difficult to find. The social model of disability accepts research usability of individual persons, and yet the decisions made by the interviewees stem from the collected experiences, the feeling of difference, of self-assessment. It would seem that despite the varied attitudes of the family environment, these are their own decisions. Every man exhibits emancipation abilities according to their own measure²⁵. The work had released in the interviewees

²⁵ B. Cytowska, *Trudne drogi adaptacji. Wątki emancypacyjne w analizie sytuacji dorosłych osób z niepełnosprawnością intelektualną we współczesnym społeczeństwie polskim*. Oficyna Wydawnicza „Impuls”, Kraków 2012.

the potential to adapt, but at the same time it had also become the basis for the choices that were made. Did they make these choices alone? Their attitudes confirm this. However, disturbing is the unwillingness of the men to undertake any activity. Perhaps they had gained new knowledge of themselves that makes the return to former experiences difficult. This is doubtless an interesting research field.

The process of emancipation is extensive in character, and in most cases constitutes a continuum, from claims through aspirations, to specifically exhibited efforts. If we are ready to assume that it is a competence of intellectually disabled persons to consciously not undertake work, then we see here within the readiness for a change of method. Self-realisation against common and social views can become a measure of emancipation²⁶. The assumption of this measure may become the cause of antagonisation in an environment of professionals, but it can also become a proposition of „critical awareness”, in which the emancipational paradigm of special paedagogy ceases to seem distant.

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²⁶ D. Podgórska-Jachnik, *Pedagogika emancypacyjna a pedagogika specjalna*, [in:] *Konteksty Interdyscyplinarne Konteksty Pedagogiki Specjalnej*, Wydawnictwo UAM, 2015, p. 21.

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CONFERENCE REPORT



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REPORT FROM THE 14th SCIENTIFIC CONFERENCE
from the series
Discourses of Special Education
“Disability versus changes – changes versus disability”

From 10th to 12th of May 2017 in Gdańsk, the 14th Scientific Conference on Discourses of Special Education was held. This time the lectures were focused on the subject: “Disability versus changes – changes versus disability”. The conference was organized by the Department of Special Education, the Institute of Pedagogy, the Faculty of Social Sciences of the University of Gdańsk and the Polish Association of Special Educators. The participants of the conference were accommodated in the charming, sea-front Hotel Nowotel Marina.

The conference was opened by the host of the meeting, prof. zw. dr hab. Amadeusz Krause, who greeted the guests and introduced the main topics of the conference by giving a lecture on “Building knowledge in special education, and on the harmfulness of point parameterization for the development of social and human sciences.” On the same day, two more plenary sessions were held, addressing issues of current and changing disability models, disability studies and examples of changes in the practical approach to people with disabilities. On the first day of the conference speeches were delivered by: prof. dr hab. Andrzej Twardowski (UAM – Adam Mickiewicz University in Poznań) *Is the social disability model still valid?*, dr hab. prof. US Marcin Wlazło (University of Szczecin), *Studies on dis/ability – between the fight for rights and theoretical change*, prof. dr hab. Aniela Korzon (DSW – University of Lower Silesia in Wrocław), *Seniors with Disabilities –*

Discrimination or Integration, prof. dr hab. Anna Nowak (University of Silesia), *Measures to protect the rights of people with disabilities – proposals for changes*, dr hab. prof. UP Grażyna Gunia (UP Kraków – Pedagogical University of Cracow), *Students' readiness for alternative communication in educational and therapeutic activities with people with disabilities*, dr hab. prof. APS Bernadeta Szczupał (APS – The Maria Grzegorzewska Pedagogical University in Warsaw), *The sense of dignity of adult oncologically ill patients in the opinion of volunteers*, dr hab. Dorota Podgórska-Jachnik (UKW Bydgoszcz – Kazimierz Wielki University in Bydgoszcz) *Between “medical” and “medicine-controlled” – questions about the place of medicine in contemporary interdisciplinary studies on disability*, dr hab. Lilianna Konopska (University of Szczecin) *Pre, peri – and early postnatal conditions of speech development of children with desonization*, dr hab. Stanisław Byra together with dr hab. Monika Parchomiuk (UMCS Lublin – Maria Curie-Skłodowska University in Lublin), *Positive changes in the perception of mothers of children with disabilities – structure and conditions*, and the presentation by dr hab. prof. Teresa Żółkowska (University of Szczecin), absent at the conference: *Disability in the neomaterialist discourse*, read by her doctoral student. The fruitful and very interesting first day of the conference ended with a gala dinner and discussions in the lobby.

On the second day of the conference, the session was held at the Faculty of Social Sciences of the University of Gdańsk. In the morning, four plenary sessions were planned. The first speeches were delivered by: dr hab., prof. UR Krystyna Barłóg (University of Rzeszów) *The motivation for rehabilitation and activity of young people with reduced mobility*, Joanna Kulisiak-Kaźmierczak PhD and Joanna Zborowska PhD (DSW in Wrocław), *„Good changes” – a family with a child with disability*, Dorota Prysak PhD (University of Silesia) *The project „Meeting with Dignity” – pedagogical research in action*, Kamila Miler-Zdanowska PhD (APS in Warsaw), *New Perspectives on the functioning of institutions acting on behalf of people with sight disability in the context of changes in the educational and social space*, Marta Mikołajczyk PhD (APS Warsaw), *Change or persistence? Social services on working with homeless people*, Dorota Chemicz PhD (UMCS in Lublin), *Diagnosis of the needs and expectations of environments supporting people with disabilities in the changing social and legal reality*, Monika Gołubiew-Konieczna MA (Psychological-Educational Counselling Centre No. 7 in Gdańsk), *Parents of disabled children from public schools and their teachers – a reflection of the educator / psychologist, practice in process, widely understood change*.

During the second plenary session, speeches were delivered by: Katarzyna Pawelczak PhD (UAM in Poznań), *The (no) presence of a person with intellectual disability in the hybrid space*, Irena Ramik-Mażewska PhD (University of Szczecin), *Social innovations as a factor of changing the image of people with disabilities*, Izabela Belzyt Joanna PhD (University of Gdansk), *„Loneliness in a situation of dual exclusion – disabled people in South Africa (post-workshop reflections)“*, Agnieszka Olechowska PhD (APS in Warsaw) *Change, lack of change and the „third space“ of disability*, Małgorzata Oleniacz PhD (DSW in Wrocław), *Youth with disability in the context of change and coping with change*, Jakub Wolny MA (Special Schools Complex no 4 in Sosnowiec), *The functioning of students with deeper intellectual disability in the digital space*.

During the third plenary session, speeches were delivered by: dr hab., prof. UZ, Zdzisława Janiszewska-Niescioruk (University of Zielona Góra), *The socio-educational context of poverty of people with intellectual disability*, Jolanta Gebreselassie PhD (The Jacob of Paradies University in Gorzów Wielkopolski), *Prevention of speech disorders in the case of students with intellectual disabilities in the light of a new model of prevention*, Dorota Krzemińska PhD (University of Gdańsk), *„My case“. The change of meaning of the theater of people with intellectual disability in the context of the category of carnival and borderline by M. Bachtin*, Zofia Redlarska PhD (University of Białystok), *Contexts of children's literature in the artistic world of a disabled child. How do we discover beauty?*, Ewa Gawlik PhD and Sabina Pawlik MA (University of Silesia) *Protected housing as an element of the ecosystem – on the example of the author's concept of a „Perfect World“*, Agnieszka Woynarowska PhD and Jolanta Rzeźnicka- Krupe PhD (University of Gdańsk) *Theatre as a place of work of adults and the team*.

In the last, fourth plenary session, the speeches were delivered by: dr hab. Anna Wojnarska and Katarzyna Korona MA (Maria Curie-Skłodowska University in Lublin), *The sense of loneliness as a factor of victimization*, dr hab. prof. UM Tadeusz Pietras (UM in Łódź), *Change in the understanding of schizophrenia-induced disability in the light of special education paradigms*, Kornelia Czerwińska PhD (APS in Warsaw), *Gradual loss of sight and fulfillment of social roles in adulthood*, Monika Jurewicz PhD (SGGW – Warsaw University of Life Sciences), *The trajectory of suffering in individual biographical experiences in the perspective of F. Schutze*, Agnieszka Wołowicz-Ruszkowska PhD (APS), *Access to reproductive rights of women with intellectual disabilities in Poland*, Buchnat Marzena PhD (UAM in Poznan), *Supporting the social competences of pupils with slight intellectual disability in school*.

After the lunch break, the sessions took place in seven sections divided by themes: The first section: **Education as action**, the speeches were delivered by: Dorota Otapo PhD, Agnieszka Sakowicz-Boboryko PhD, Dorota Wyrzykowska-Koda MA (University of Białystok), Petr Franiok PhD (Ostravska Univerzita Ostrava), Igor Hampl PhD, Renata Kovarova PhD (Ostravska Univerzita Ostrava), Karol Bidziński PhD (Jan Kochanowski University in Kielce), Elżbieta Lubińska-Kościółek PhD (Pedagogical University of Cracow), Jerzy Wolny PhD (Silesian University of Technology), Bełza Małgorzata PhD (University of Silesia), Katarzyna Nadachewicz PhD (University of Białystok), Kasper Sipowicz PhD (APS in Warsaw), Jolanta Maciąg PhD (Pomeranian Academy in Słupsk), Agnieszka Muchacka MA.

In the second section: **The child as the subject of educational and therapeutic activities**, the speeches were delivered by: Szymon Godawa PhD (University of Silesia), Beata Gumienny PhD (University of Rzeszów), Agnieszka Pawluk-Skrzypek PhD (Warsaw University of Life Sciences), Lidia Wawryk PhD (University of Zielona Góra), Aleksandra Mach PhD (University of Rzeszów), Izabella Kucharczyk PhD (APS in Warsaw), Justyna Wojciechowska PhD (University of Bielsko-Biała), Aleksandra Szczesiul, MA.

The third section entitled **Teachers, educators, therapists, curators** gathered the following speakers: Edyta Nieduziak PhD (University of Wrocław), Monika Skura PhD (University of Warsaw), Ewa Grudziewska PhD (APS), Krystyna Moczka PhD (University of Silesia), Anna Karłyk-Ćwik PhD (DSW in Wrocław), Aneta Lew-Koralewicz PhD (University of Rzeszów), Grażyna Walczak PhD (APS), Joanna Skibska PhD (University of Bielsko-Biała), Małgorzata Osieńska MA (Regional Court Lublin-Zachód), Maria Flanczewska-Wolny MA (Silesian University of Technology).

The fourth section devoted to **Family and Disability** was attended by the following speakers: Grażyna Kwaśniewska PhD (PWSTE in Jarosław), Dorota Tomczyszyn PhD (Pope John Paul II State School of Higher Education in Biała Podlaska), Karolina Kaliszewska MA (University of Szczecin), Barbara Czuba PhD (PWSTE in Jarosław), Małgorzata Zaborniak-Sobczak PhD (Univeristy of Rzeszów), Diana Aksamit PhD (APS), Ewa Janion PhD (University of Zielona Góra), Anita Szafrńska PhD (University of Silesia), Patrycja Łaga MA (University of Gdańsk).

The lectures of the fifth section were focused on the subject of **Childhood Support and Therapy**, delivered by: Anna Lis-Zaldivar PhD (The Jacob of Paradies University in Gorzów Wielkopolski), Sylwia Niemiec MA

(UP in Cracow), Ewelina Kłak MA (Lower Silesian Association for the Support of Children and Adolescents "Ostoja"), Aneta Rudzińska-Rogoża PhD (University of Zielona Góra), Małgorzata Bilewicz PhD (University of Białystok), Anna Kobylańska PhD (University of Gdańsk), Magdalena Olempska-Wysocka PhD (UAM in Poznań), Agnieszka Hamerlińska-Latecka PhD (Kazimierz Wielki University in Bydgoszcz), Sara Knapik-Szwed MA (University of Silesia), Karolina Tersa PhD and Joanna Doroszuk PhD (University of Gdańsk).

The sixth section which focused on **Support in Adulthood** began with a lecture by Elżbieta Minczakiewicz PhD, followed by: Iwona Myśliwczyk PhD (UWM - University of Warmia and Mazury in Olsztyn), Agnieszka Ochman MA (Pedagogical University in Cracow), Anna Banasiak, PhD (Jan Długosz Academy in Częstochowa), Monika Dąbkowska PhD (Nicolaus Copernicus University in Toruń), Agnieszka Lewko MA (University of Silesia), Beata Tylewska-Nowak PhD (UAM in Poznań) and Iwona Lindyberg PhD (University of Gdańsk).

The topic of the seventh section: **Around the change in thinking about disability** was presented in eleven speeches delivered by: Agnieszka Buczek PhD and Jacek Sikorski PhD (UP in Cracow), Małgorzata Mozyńska PhD (PWSZ - The State University of Applied Sciences in Elbląg), Izabela Marczykowska PhD (University of Rzeszów), Danuta Grzybowska PhD, Katarzyna Kampert PhD and Katarzyna Materny PhD (University of Gdańsk), Anna Bernacka MA (University of Warmia and Mazury in Olsztyn), Magdalena Bartniczak MA (University of Gdańsk), Anna Wolny MA (Special Schools Complex No. 7 in Gliwice), Justyna Juszcak MA (County Community Self-Help Home), Wioletta Stęczniewska MA (UWM in Olsztyn), Agnieszka Muchacka MA, Ewa Wodka-Natkaniec MA and Anna Steliga PhD (University of Rzeszów).

The issues presented at the plenary sessions and during the discussions in particular sections were very interesting and their number could be an inspiration for both pedagogical practice and research. After an exhausting day, the scientific discussion moved to a more informal seaside area.

On the third day of the Gdańsk conference a debate was held, together with a discussion, under an intriguing title, particularly interesting to the environment of special educators: „Where is special education going?”. The debate included: prof. dr. hab. Iwona Chrzanowska and dr hab. prof. UAM, Beata Jachimczak from the Adam Mickiewicz University in Poznań, dr hab. prof. APS, Grzegorz Szumski from the Maria Grzegorzewska Ped-

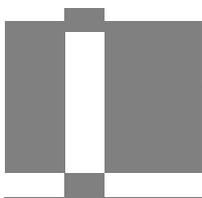
agogical University in Warsaw, prof. dr hab. Bożena Muchacka from the Pedagogical University in Cracow, and prof. dr hab. Marzenna Zaorska – Chairperson of the Special Education Team at the Pedagogical Sciences Committee of the Polish Academy of Sciences, and dr hab. prof. UWM, Sławomir Przybyliński from the University of Warmia and Mazury in Olsztyn, dr hab. prof. UG, Sławomira Sadowska from the University of Gdańsk, dr hab. prof. UW Grażyna Dryżałowska from the University of Warsaw. The discussion was moderated by prof. dr hab. Amadeusz Krause (University of Gdańsk), the organizer of the conference.

The debate focused on finding the answers to the four main questions: 1. What kind of learning? – the strengths and weaknesses of special education, 2. What kind of school? – the direction of changes in education and their consequences for special educators, 3. What kind of education? – who will educate special educators in 20 years and how, 4. What kind of studies? – directions of activities strengthening special education

Voices from the audience were also added to the debate. It was impossible to exhaust such extensive and important issues concerning contemporary special education in the prescribed time frame. It is likely that the discussion will take place long after the end of the conference in the particular environments of special educators. The 14th scientific conference from the series: Discourses of Special Education ended on Friday, May 12 at noon. The numerous groups of special educators, educators, representatives of other scientific disciplines and practitioners gathered at the conference prove the need to exchange thoughts and experiences, as well as reflections on the direction of activities and the condition of special education. We would like to thank the organizers, being aware of their great effort in preparing the conference, and we look forward to the 15th edition.



REVIEW



JUSTYNA SOCHA

University of Lodz

**Review of Barbara Winczura's book entitled
"Emocje dzieci i młodzieży z trudnościami w rozwoju
i zachowaniu", Oficyna Wydawnicza "Impuls",
Kraków 2017**

"Emocje dzieci i młodzieży z trudnościami w rozwoju i zachowaniu" ("Emotions of Children and Youth with Difficulties in Development and Behaviour") is the most recent publication edited by Barbara Winczura. The book is a collection of articles pertaining to the period of adolescence, taking various types of difficulties into account. Childhood, as well as puberty, are associated with happiness and light-heartedness. Unfortunately, for many children and young people this is a difficult time, when they experience a lot of negative emotions. Authors of articles compiled in the publication draw attention to risk factors that may result in development difficulties.

The book was divided into two parts. The first part contains scientific articles pertaining to negative experiences in the life of children and youth which may result in emotional disorders. The article opening this part is entitled "Emocje, temperament i przywiązanie a procesy rozwoju zaburzeń psychicznych u dzieci" ("Emotions, Temper and Attachment vs. Processes of Development of Mental Disorders in Children") was written by Hanna Kubiak. The author presents, in an interesting manner, the way in which habits and emotional traits are created in children. Kubiak shows the way in which social experiences shape their temper. She discusses issues that are of vital importance for the development processes of the brain, such as the early experiences determining the manner in which the person will experience and understand the world surrounding him/ her.

Another important aspect that is discussed in the above-mentioned publication, penned by Urszula Bartnikowska, is entitled "Doświadczenia wczesnego dzieciństwa a zaburzenia regulacji emocji u dziecka" ("Early Childhood Experiences and Emotion Regulation Disorders in Children"). The author lists medical procedures (i.e. situations in which a child is subjected to operations or stays in hospital) as the most traumatising events. Other negative experiences include participation in a catastrophe or being a witness to such incident. Events that are highly damaging for children include situations when a person who is close to them betrayed them, i.e. neglected or abandoned them. In her article, the author distinguishes trauma resulting from a one-time incident (e.g. a car accident) from situations that recur over time (e.g. abuse by a parent). She also draws attention to the fact that a young person whose emotional traits are only being shaped, experiences negative incidents much more intensely than an adult person.

The next problem discussed in the book is "Emocjonalne oblicza zespołu stresu pourazowego u dzieci i młodzieży" ("Emotional Manifestations of Post-Traumatic Stress Disorder in Children and Youth") written by Małgorzata Przepióra. The clinical image of this disorder is presented here, along with its' potential sources. The author discusses her own studies, which are very interesting, including specific statements of children who survived a catastrophe, were beaten by parents or sexually abused. These statements are a unique source of knowledge for the readers with respect to emotions experienced by abused children and youth. Once again, attention was attracted to the fact that children whose cognitive structures are not yet mature, find it much more difficult to become reconciled with a negative experience, as well as handle stress related to it for a long time after the event.

A very interesting issue presented in the publication is the phenomenon of depression. Małgorzata Cichecka-Wilk has described it in her article entitled "Zaburzenia emocjonalne w przebiegu depresji u dzieci i młodzieży" ("Emotional Disorders in the Course of Depression in Children and Youth"). Depression is associated mainly with adult people; nevertheless, the author draws attention to the fact that even children who are younger than three years' of age can suffer from it. Cichecka-Wilk describes the clinical image of depression in various periods of life of a growing person. She divided them to a period up to 3 years' of age, pre-school period (3-6 years), early and middle childhood period (7-11 years), a quite similar period of early adolescence (10-12 years), youth in middle puberty stage (13-16 years) and

a period when depression appears most often, i.e. the period of late adolescence (17-19 years). In this division prepared by the author, the specific traits of depression at various stages of development are clearly perceptible. Subsequently, the author discusses the consequences that are carried by the state of depression and the factor that contribute to it.

The first part of the book also includes the issue of sexual harassment. The author, Anna Gulczyńska, presents an article entitled "Zaburzenia emocjonalne u dzieci po traumie molestowania seksualnego" ("Emotional Disorder in Children Suffering from the Trauma of Sexual Harassment"), where she shows detailed statistics pertaining to this phenomenon which occurred during childhood. She also describes mental and physical syndromes that are manifested in the victim. Gulczyńska presents a child that experienced harassment. She signals the child's negative experiences and, most importantly, a sudden drop in the feeling of security. Gulczyńska describes a situation where children are not mature enough to be able to evaluate the negative experiences in a realistic manner. They succumb to the lies of their harassers who say that what they do is good and normal. In reality, sexual harassment is never good and normal. The author presents syndromes appearing in a harmed child. To this aim, she uses a graph presenting psychical and somatic syndromes. The article was provided with numerous statements of patients, which allows for better understanding of the discussed issue.

Another issue tackled in the book, this time by two authors, bears the title "Parentyfikacja i jej rola w genezie zaburzeń obrazu własnego ciała w przebiegu anoreksji u dzieci i młodzieży" ("Parentification and Its' Role in Genesis of Own Body Image Disorders In the Course of Anorexia in Children and Youth"). The first term refers to the situation where the obligations of parents (or their part) are taken-over by children, i.e. an exchange of roles. The authors, i.e. Dorota Ryżanowska and Anna Siwec, present the dependency of these two phenomena, which seemingly have nothing to do with each other, in a comprehensible manner. The authors claim that nutrition disorders, including anorexia, are frequently the result of parentification. They describe a mental disorder such as anorexia and its causes and syndromes. They also show the correct prevention of nutrition disorders. The authors argue that parentification exerts a significant psychological burden on the child and has negative impact on the child's development, manifested in a significant degree of malnourishment and irregularities in building the image of own body.

The last issue tackled in this part of the book pertains to “Zaburzenia eksternalizacyjne w kontekście regulacji zachowania” (“Externalisation Disorders in the Context of Behaviour Regulation”). The author, Piotr Kwiatkowski, focuses attention on disturbed personality of children which, according to him, is the main cause for the absence of emotion regulation. Kwiatkowski describes the medical aspect, i.e. the operation of cerebral structures which are impacted both by negative and positive experiences. He believes that externalisation disorders, i.e., e.g. anger, hostility towards the environment, aggression, lies, etc., are responsible for the lack of proper regulation of emotions. Kwiatkowski also refers to three most important factors that influence self-regulation, and which were created by R.F. Baumeister and his colleagues. These are: awareness of the state of affairs that one wishes to accomplish, monitoring the standard with the actual status and energy resources located in the brain.

The second part of the publication contains a collection of articles on emotional disorders in children and young people suffering from chronic diseases or intellectual disabilities. These articles refer to the issue of emotional disorders caused by external factors, to which children and young people are exposed in a social environment. The second part tackles the issue of emotions in sick children, who suffer from disabilities.

The first author, Jolanta Lipińska-Lokś describes “Zaburzenia emocjonalne u dzieci z chorobą przewlekłą” (“Emotional Disorders in Children with Chronic Diseases”). In her article, the author presents examples of diseases which are considered chronic. They include cerebral palsy, cancer, skin allergies, diabetes and obesity. Furthermore, the author lists the main features of diseases that are classified as chronic. They include, first of all, the duration of the disease that exceeds three months. She draws the readers’ attention to the fact that only from 10% to 18% of children and young people show full psycho-physical fitness. The article shows two highly different approaches to the phenomenon of disease: these are the biomedical and holistic models. Joanna Lipińska-Lokś emphasises the fact that a somatic disease may carry, in consequence, emotional functioning disorders, especially in case when a disease damages the nervous system. She stresses the fact that a child who is chronically ill is daily accompanied by negative emotions, i.e. fear. Dysfunction causes changes in the child’s functioning in the society; the child cannot participate in all childhood activities and, due to this, feels different from the peers. The author also discusses

basic principles of work with young people who are chronically ill and factors that definitely facilitate their functioning.

The next issue that is tackled in the publication is "Znaczenie wczesnodziecięcych doświadczeń emocjonalnych osób z niepełnosprawnością dla podejmowania wyzwań życiowych" ("Significance of Early-Childhood Emotional Experiences of People with Disabilities in Accepting Life Challenges"). Joanna Konarska presents the concept of development continuum created by J. Liedloff. The author lists the needs the absence of which may lead to disorders in later life of a child. These needs include body contact, sending communications to the child by a person who takes care of the child most often. Konarska describes the beginnings of the child's emotionality and emphasises the significance of original integration, which takes place during the first 12 months of the child's life. She also shows the manner in which relations with parents and children influence the self-assessment and building of self-esteem. The author also presents a very interesting image of the society's control, which observes and unjustly evaluates parents of children with disabilities. She describes pressure exerted on parents who, in consequence, may emotionally encumber their children with own failures. Joanna Konarska presents the situation of children with sight defects who find it difficult to receive emotive stimuli. Deprivation effects of this disorder are visible primarily in development of cognitive processes, orientation in the environment and practical activities of the child. Afterwards, the author presents emotional development of hearing-impaired children which, in the first moments of life, does not differ from development of a healthy child. At the end, the development of a child with physical disability is presented, who is usually accompanied by constant fear of pain caused by rehabilitation or attempts at independent movement. Such fear often transforms into trauma, which adversely impacts the person's attitude to life challenges.

In the second part, Ewa Bartuś presents "Emocje na drodze do adaptacji społecznej dzieci i młodzieży z niepełnosprawnością intelektualną" ("Emotions On the Path to Social Adaptation of Children and Youth with Intellectual Disabilities"). The author emphasises the fact that development of children with intellectual disability is much slower than of healthy children. Bartuś mentions the change of approach to people with disabilities; in the past, main focus was primarily on the medical aspect. In the course of time, this approach evolved to social issues, such as disruption of cooperation of a sick person with the society that rejects such person. In her text, she refers to the term "difference complex" which describes a situation

when young people who suffer from intellectual disability notice the difference between themselves and their peers. Quoting DSM-5, Ewa Bartuś lists three criteria testifying to intellectual disability. The article also contains a description of emotional development during specific degrees of intellectual disability (light, moderate and severe). The problem of hindered development of interactions between the child and the parent is shown, caused exclusively by passive receipt of emotions by the sick person. The author emphasises that development in the area of empathic skills may be hindered on account of long-lasting ego-centrism or lack of understanding of the subjective feelings of other people.

The next article is entitled "Zaburzenia emocjonalne u dzieci niewidomych i słabowidzących" ("Emotional Disorders in Blind and Sight-Impaired Children") written by Joanna Gładyszewska-Cylulko. Similarly to another author of the publication, Gładyszewska-Cylulko pays attention to the emotional difficulties in children with sight deficiency; however, this time the attention is focused exclusively on this disorder. The author lists the causes of emotional disorders which may be searched for among biological and social factors. She emphasises that early diagnosis and rehabilitation may prevent or decrease the intensity of occurrence of emotional disorders. Gładyszewska-Cylulko notes that a vital aspect in development is acceptance on the part of closest environment. A blind or sight-impaired person who has the support of the family has a much greater possibility of developing traits that are conducive to later adaptation. The author lists and describes most frequent emotional disorders affecting people with sight deficit. As the first one, she mentions stress resulting from, e.g., physical threats. As an example, the author provides a walk on the pavement which, for a fully-able person is an ordinary activity, yet for blind people is very stressful. Specific disorders of blind people include sleep disorders or mannerisms, e.g. unjustified hand or head movements. The next emotional disorder that occurs in such people is the fear caused by unexpected situations or changes that appeared in activities that they became acquainted with as children. Fear may also be manifested in the form of shame of revealing own disability before the rest of the society. The author also lists the touching phobia as one of the types of fear manifested in children that are blind or sight-impaired. The article lists four types of various defence mechanisms used by children with this disorder. These are: negation, suppression, projection and rationalisation. Each mechanism is illustrated by a story of a given person presenting a specific situation.

Joanna Kossewska discusses the issue of “Specyfika rozwoju procesów emocjonalnych u dzieci z uszkodzonym słuchem” (“Nature of Development of Emotional Processes in Hearing-Impaired Children”). The author emphasises in the article that hearing-impaired children have a definitely limited participation in communication situations and, in relation to this, their linguistic development is also disrupted. Kossewska refers to the concept of development of emotional competence according to its’ author, C. Saarni. She lists main elements of the concept and afterwards describes them in detail. As the first one, the author mentions the awareness of existence of own emotional states and the ability to recognise emotions in other people based on their mimics and situational context in which they are located. The author also describes the ability for linguistic description of emotions by hearing-impaired children, their predisposition for experiencing empathy and the ability to understand inconsistency between the emotional state and its’ expression by various persons. Subsequently, Kossewska presents the traits of the process of regulation and control of own emotions, describes the awareness of the significance of emotions in relations between a hearing-impaired child and other people. Finally, she discusses the last of the listed elements of the concept of development of emotional competence, i.e. the feeling of own emotional efficiency.

Agnieszka Słopień and Aneta Wojciechowska are the first authors in the publication to draw the readers’ attention to “Funkcjonowanie emocjonalne u dzieci ze spektrum autyzmu” (“Emotional Functioning of Children with Autism Spectrum”). At the beginning, the authors characterise the emotional development of a healthy person and the phenomenon of attachment in small children. Next, they present a theory that disorders from the spectrum of autism encompass a non-uniform group of patients, because the disorder is differently manifested in different people. The authors present the best recognisable features of ASD (autism spectrum disorders, ASD), which include difficulties in social functioning, which appear already in the first year of life of autistic children. The most important traits that were listed include: lack of eye contact, absence of attention sharing behaviour, absence of the need to share interests with the closest environment and no use of gestures to communicate, as well as failure to recognise own feelings and failure to name them. Słopień and Wojciechowska present an interesting comparison of behaviour of patients with highly-functioning autism and patients suffering from Asperger syndrome. Subsequently, they mention the issue of co-occurrence of additional mental

diseases in young people with ASD, which is very common. The authors believe that further studies on emotional problems of patients with autism will probably contribute to development of new forms of therapy, which are going to improve the quality of life of patients.

An important issue tackled by Barbara Winczura is "Rozwój emocji i przywiązania dzieci ze spektrum autyzmu w kontaktach z bliskimi" ("Development of Emotions and Attachment of Children with Autism Spectrum in Contacts with Relatives"). The author indicates that autism is a complex disorder, where development difficulties may occur in various configurations, primarily in the area of social contacts, development of language and various competence. In the picture of the disorder, a great diversification of emotional reactions among patients is visible. Winczura presents the symptoms of autism that appear in the first months of the child's life, due to which the parents become aware of the fact that the infant has difficulties in development and have the possibility of starting therapy early. The article also presents the stance of an autistic child, who prefers contact with a toy rather than close and emotional contact with a living person, e.g. a parent. An autistic person is not looking for and does not need relations with other people. On account of this, Winczura emphasises that contact with the parents, and primarily their sensitivity to emotions shown by the child is highly important and positively influences the child's development. Another important aspect described by Winczura is the recognition and understanding of emotions by autistic people, which is, without doubt, disrupted. In consequence, children show inadequate social behaviour and emotional reactions towards other people. She also emphasises the problem of disrupted ties that are manifested in indifference of an autistic person towards his/ her closest relatives.

The article that ends the publication is "Relacje emocjonalne między dzieckiem a jego rodziną we wczesnej interwencji" ("Emotional Relations Between a Child and His/ Her family in Early Intervention") written by Sylwia Wrona. The author makes an attempt at unequivocal definition of emotions by presenting opinions of different people and describing the elements that make up emotions. Apart from it, Wrona presents an interesting breakdown of six basic emotions along with facial expression accompanying them, physiological reactions and their adaptive functions. The author quotes own study about the circle of trust for children, which constitutes a guidebook for the parents. The article presents problems that parents of a child suffering from developmental disorder have to face.

These are: manners of expressing emotions which may be compromised on account of their improper decoding and lack of harmony in the child's development. A child with development disorders grows up much slower than his/ her peers in the emotional, social and cognitive sphere. At the end, the author tries to show the role and the tasks set before the experts in building correct emotional relations between a disabled child or a child suffering from development disorder and his/ her carers. To this aim, the author presents five most important principles of early intervention.

"*Emocje dzieci i młodzieży z trudnościami w rozwoju i zachowaniu*" is definitely a very interesting publication pertaining to development disorders of children exposed to negative environmental factors or suffering from a disease or disability. A great advantage of the book is the variety of articles collected in it and studies confirming the presented theories. Additionally, I believe that persons who read this publication enrich their knowledge about the proposals and modes of work with children and young people who manifest difficulties in development and behaviour.

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