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My adult son, my adult daughter – reflections of mothers of children with profound intellectual disabilities

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Everyone has the right to participate in society, regardless of his or her current personal situation, level of psychosocial functioning or experience. No reason can justify marginalisation or exclusion of people from social life at any stage of their lives. The aim of the article is an attempt to characterise the adulthood of people with profound intellectual disabilities on the basis of subjective assessment of their mothers. The methodology applied was that of a qualitative research, where the main research technique was narrative interviews. The results of the research demonstrate that adulthood is the stage of life when people with profound intellectual disabilities and their caregivers require special support in mental, spiritual, social, societal and educational dimensions.

KEY WORDS: person, adult, society, profound intellectual disability

Introduction

Discussion over the adulthood of the people with intellectual disabilities have only recently appeared in the literature¹, the adult-

¹ J. Lausch-Żuk, *Terapia czy wychowanie?*, [in:] *Wczesna diagnoza i terapia dzieci z utrudnieniami w rozwoju. Interdyscyplinarne problemy*, ed. J. Kruk-Lasocka, M. Seku-

hood of the people with profound intellectual disabilities being rather seldom the subject matter of scientific research.² Marginalisation or even exclusion from scientific and social discourse of the group of adults with profound intellectual disabilities can be caused, for instance, by: (1) small group size (thus incurring low interest); (2) inhomogeneity of the group (coexistence of other disabilities, giving rise to a new often unique individual requiring an individual approach); (3) difficulty in understanding specific characteristics of development and its consequences demonstrated by a particular psychosocial functioning of such person (social stereotype of an *adult – eternal child*); (4) difficulty in conducting research resulting from the necessity to apply an individual approach to every person (lack of proper techniques and research tools) and time-consuming nature. It should be emphasized that the adulthood of the people with profound intellectual disabilities is the result of the development process, influenced by both internal and external factors (see diagram 1). Peculiarity of functioning of adults with profound intellectual disabilities is demonstrated, for instance, in a considerable diversity of their functioning in various areas: intellectual (attention, memory, thinking, perception); social (establishing interactions, maintaining interactions, relations); emotional (express-

łowicz, Dolnośląska Szkoła Wyższa Edukacji Towarzystwa Wiedzy Powszechnej, Wrocław 2004, pp. 422–423; I. Lindyberg, *O jednym z kontekstów dorosłości osób z głębszą niepełnosprawnością intelektualną, czyli w poszukiwaniu sposobu „wyjścia z szafy”*, [in:] *Dorosłość, niepełnosprawność, czas współczesny. Na pograniczach pedagogiki specjalnej*, ed. K.D. Rzedzicka, A. Kobyłańska, Oficyna Wydawnicza „Impuls”, Kraków 2003, pp. 279–284; K. Wiater, B. Basa, *Losy uczniów warszawskich „szkół życia”*, „Szkoła Specjalna” 1981, No. 1, pp. 52–57.

² D. Kopeć, *Rzeczywistość (nie)edukacyjna osoby z głęboką niepełnosprawnością intelektualną. Zbiorowe instrumentalne studium przypadku*, Wydawnictwo Naukowe Uniwersytetu im. Adama Mickiewicza, Poznań 2003; B. Marcinkowska, *Model kompetencji komunikacyjnych osób z głębszą niepełnosprawnością intelektualną – poszukiwaniu wzajemności i współpracy*, Wydawnictwo Akademii Pedagogiki Specjalnej, Warszawa 2013, pp. 59–64; D. Wolska, *Stymulowanie rozwoju psychofizycznego osób dorosłych z głęboką wieloraką niepełnosprawnością*, [in:] *Annales Universitatis Paedagogicae Cracoviensis, Studia Paedagogica II*, ed. D. Wolska, A. Mikrut, Wydawnictwo Naukowe Uniwersytetu Pedagogicznego, Kraków 2012, pp. 392–399.

ing and controlling emotions); physical (controlling one's body) – as follows from the research it was quite significant in the process of shaping motherhood of the female respondents (mothers of the adult people with profound intellectual disabilities) over the years. Such people often reach physical maturity (including sexual one), whereas their intellectual and social functioning is comparable to the functioning of: 2–3 and 4–5 –years old child³ respectively – which quite frequently conditions the social reception of the adulthood period of individuals with profound intellectual disabilities.

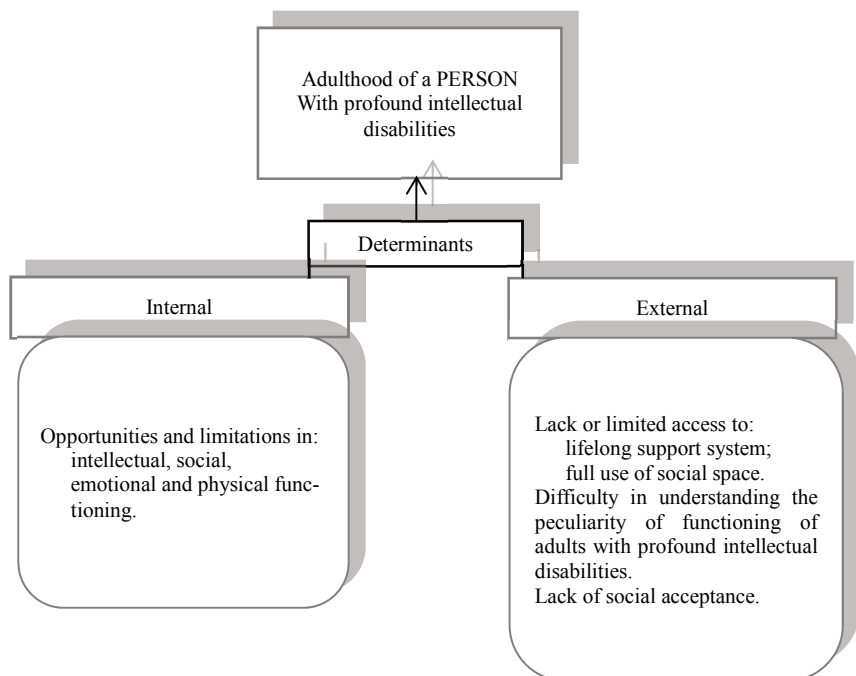


Diagram 1. Determinants of adulthood of people with profound intellectual disabilities

Source: own elaboration.

³ J. Kostrzewski, *Charakterystyka osób upośledzonych umysłowo*, [in:] *Upośledzenie umysłowe. Pedagogika*, red. K. Kirejczyk, Wydawnictwo Naukowe PWN, Warszawa 1981, pp. 110–114.

Living within a society is based on reciprocity and requires cooperation of numerous individuals. Development of a person takes place within the context of his/her mutual relationship with the environment.⁴ A human being is not only influenced by the environment, but also exercises some impact on it. The adoption of such a thesis leads to a reflection on the role of particular individuals (including people with profound intellectual disabilities) in creating a social space that is accessible to everyone. It should be assumed that every human being is part of a complex social system. He/she is a participant in social life and a co-creator of it at the same time. Basic elements that constitute such system are: the person, his/her close and distant relatives, peer environment and local environment, as well as the state and its policy.⁵ It seems appropriate to undertake theoretical and empirical research and analyses, covering the issues of the process of shaping adulthood of people with profound intellectual disabilities and its internal and external determinants (see diagram 1). The results of such analyses can be used to construct effective support systems for people with this type and degree of disability.

⁴ Ecological concepts of development and education indicate the relationships between social environments (ecosystems). (Bronfenbrenner, 1979 as cited in: A. Brzezińska, *Spoleczna psychologia rozwoju*, Wydawnictwo Naukowe Scholar, Warszawa 2007, pp. 187–188). In ecological concepts, the social development environment is understood as a system of interdependent systems, in which every human being will find his or her special place, regardless of abilities, prowess or limitations.

⁵ J. Głodkowska, *Przestrzeń rehabilitacyjna w otoczeniu osób z niepełnosprawnością intelektualną – ujęcie koncepcyjne*, „Ruch Pedagogiczny”, 2005, No. 5/6, pp. 7–23; B. Marcinkowska, A. Wołowicz, *Wielospecjalistyczna ocena poziomu funkcjonowania i konstruowanie programów dla osób z głębszą niepełnosprawnością intelektualną*, Wydawnictwo Akademii Pedagogiki Specjalnej, Warszawa 2010, p. 9; O. Speck, *Niepełnosprawni w społeczeństwie. Podstawy ortopedagogiki*, tłum. W. Seidler, A. Skrzypek, D. Gącza, D. Szarkowicz, Gdańskie Wydawnictwo Psychologiczne, Gdańsk 2005, pp. 271–308.

Selected prospects of adulthood with respect to profound intellectual disabilities – theoretical findings

As a conceptual category, *adulthood* can be analysed from different perspectives: (1) biological – age, specific physical appearance: weight, height, completion of development of somatic systems; (2) psychological – in other words, “maturity of an individual” characterized by self-determination, autonomy, shaped view of the world; (3) social – fulfilling certain social roles, observance of social norms, participation in social life; (4) cultural – understanding culture and participation in it⁶; (5) medical – taking into account the level of functioning of the individual.⁷ In people whose development is harmonious, individual areas of their functioning are correlated at a similar level. An adult person has specific rights, but also social expectations are formulated towards him/her. In people with profound intellectual disabilities, the development of particular spheres of functioning has different characteristics than in people with proper development.

One of the most common criteria in the definition of adulthood is age – the biological perspective of adulthood considerations.⁸ As an example, we can cite Robert Havighurst’s concept of three stages of adulthood: early adulthood (18–35 years), middle age (35–60 years), late adulthood (60–65 years).⁹ Each of these stages is attributed to expectations, achievements, and a certain image of man is constructed. We note here the connection between the following crite-

⁶ B. Cytowska, *Rodzice wobec dorosłości swoich dzieci z niepełnosprawnością intelektualną*, [in:] *Wychowanie w rodzinie. Rodzin o specjalnych potrzebach*. T. 4, eds, S. Walasek, B. Winczura, Karkonoska Wydawnictwo Państwowej Szkoły Wyższej, Jelenia Góra 2011, pp. 87–107.

⁷ B. Jordan, G. Dunlap, *Construction of Adulthood and Disability*, “Mental Retardation”, 2001, No. 39/4, pp. 286–296.

⁸ O. Czerniawska, *Trendy rozwojowe w zachowaniu ludzi dorosłych*, [in:] *Wprowadzenie do andragogiki*, ed. T. Wujek, Wydawnictwo Naukowe Instytutu Technologii Eksploatacji, Warszawa 1996, pp. 36–46.

⁹ R.J. Havighurst, *Developmental tasks and education*, New York–London, Longman, 1981, as cited in: A. Brzezińska, *Spółeczna psychologia rozwoju*, Wydawnictwo Naukowe Scholar, Warszawa 2000, pp. 231–236.

ria: legal (18 years of age), biological (ability to start a family, procreation), mental and social (a person is mentally mature enough to meet social expectations, has specific rights but also obligations with regard to society and takes responsibility for his/her actions and therefore is considered to be an “adult”).

Therefore, it should be assumed that adulthood of a person with profound intellectual disabilities has a unique characteristics. The consequence of adopting such a thesis is a specific approach to the process of supporting people with profound intellectual disabilities. The process of developing a support procedure should be guided not only by developmental age, but also by life age.¹⁰ An important problem in the support process is the recognition of the right of a person with profound intellectual disabilities (at various stages of development) to autonomy, expressed in the exercise of the right to self-determination. The ability to function independently on a daily basis, as Deborah Smith puts it¹¹, depends on the activities learned and the type of support provided. The problem we face in our reality is the social conviction that there is a need for “continuous and ongoing support” or care. Moreover, this conviction is present not only in public opinion, but also in the conduct of parents and therapists. The most common mistakes made by parents, which can be related to individuals with profound intellectual disabilities, include: lack of conditions and situations to take various actions,

¹⁰ It should be mentioned here that there is a certain “trap” – developmental age is a determinant in the treatment of children with disabilities, it is a point of reference in the selection of forms, methods and means for work, but very often developmental age dominates over the chronological age of people with profound intellectual disabilities. This is also indicated by Jolanta Lausch. – (J. Lausch-Żuk, *Terapia czy wychowanie?*, [in:] *Wczesna diagnoza i terapia dzieci z utrudnieniami w rozwoju. Interdyscyplinarne problemy*, eds. J. Kruk-Lasocka, M. Sekułowicz, Dolnośląska Szkoła Wyższa Edukacji Towarzystwa Wiedzy Powszechnej, Wrocław 2004, pp. 422–423), who mentions: too much emphasis on words, using typical childhood concepts or using diminutive elements in communication with adults with disabilities.

¹¹ D.D. Smith, *Pedagogika specjalna. Podręcznik akademicki*, T. 1, trans. T. Hołówka, A.P. Zakrzewski, Wydawnictwo APS, Wydawnictwo Naukowe PWN, Warszawa 2008, pp. 226–228.

lack of access to people, places; interference in all actions taken; nannying.¹²

Adulthood of people with intellectual disabilities is defined by Stanisław Kowalik as a “lost development zone”.¹³ According to the author, “adulthood is a very long time of a person’s life, in which nothing interesting happens. There are no new skills, mental processes have reached their peak, social relationships in which people function are fully stabilized”.¹⁴ It is reflected in the situation of people with profound intellectual disabilities, who, having attained the age of 25, are no longer obliged to attend remedial classes and thus no longer able to do so. At this point the question arises: what next? This is due to the fact that there is still a shortage of places in institutions such as community self-help homes, while in other institutions such people are not accepted because of their health status. Adulthood of such person is locked in the home and motherhood or fatherhood return to the starting point, to the situation from years ago.

Towards adulthood of people with profound intellectual disabilities – methodological findings

The aim of the research was theoretical, empirical and practical analysis of various aspects of experiencing motherhood in single mothers of adult children with profound intellectual disabilities. The analysis of the research results presented in the text was carried out in accordance with the following research problems:

- (1) How do mothers bringing up children with profound intellectual disabilities perceive their adulthood? Another re-

¹² A. Twardowski, *Oddziaływania rodziców blokujące rozwój autonomii u dzieci upośledzonych umysłowo*, [in:] *Spółczesność wobec autonomii osób niepełnosprawnych. Od diagnozy do prognoz i do działań*, ed. W. Dykcik, Wydawnictwo Eruditus, Poznań 1996, pp. 147–151.

¹³ S. Kowalik, *Dorostłość osób niepełnosprawnych w świetle koncepcji strefy utraconego rozwoju*, [in:] *Dorostłość, niepełnosprawność, czas współczesny. Na pograniczach pedagogiki specjalnej*, eds. K.D. Rzedzicka, A. Kobylańska, Oficyna Wydawnicza „Impuls”, Kraków 2003, pp. 61–78.

¹⁴ *Ibidem*, 2003, p. 61.

search problem was formulated on the basis of the theoretical assumptions presented in Diagram 1.

- (2) What is the significance of internal and external factors in the course and creation of the image of adulthood of people with profound intellectual disabilities in the opinion of their mothers (see Diagram 1)?

34 women from all over Poland were interviewed. The group of respondents included single mothers raising adult children with profound intellectual disabilities (children aged over 25). Out of 34 respondents, only three lived in a full family.

Other characteristic features of the research group are:

- age of women: 55-78 years;
- place of residence - due to the small size of the group of people with profound intellectual disabilities, women from all over Poland were included in the research;
- education - vocational, secondary, rarely tertiary; in the sample group there were both working and non-working women - more of the latter (including retired women). The number of qualitative surveys does not prove the accuracy, unlike in the quantitative methodology. The reliability of qualitative research is confirmed by the uniqueness of each interviewed person.

The research lasted from October 2015 to January 2018. The snowball method applied lead from one woman to others, also through state institutions, charities (foundations, associations), blogs and websites. The basic research technique was individual narrative interview. The respondents were asked to tell a fragment of their life or history of their entire life in the context of experiencing motherhood. The interviews were recorded on a recorder, then transcribed, and the recording procedure made it possible to listen to them repeatedly. The obtained information was analysed within the analytical procedures proposed in the well-established theory (MTU)¹⁵

¹⁵ B.G. Glaser, A.L. Strauss A.L., *The Discovery of Grounded Theory: Strategies for Qualitative Research*, Aldine Publishing, New York 1967. (Polish edition: 2009, *Odkrywanie teorii ugruntowanej: Strategie badania jakościowego*, Kraków, Zakład Wydawniczy Nomos, trans. M. Gorzko).

methodology, taking into account selected definitions of adulthood and disability cited in the theoretical part of the article.

Adult maturity – the perspective of the possibility or „coming full circle” – in the light of the results of own research

Age is one of the most common categories used to formulate a definition of adulthood, which is also demonstrated in the interviews. Mothers very often referred to the age of their children, emphasizing it as one of the important factors of their motherhood and determinants of their children's adulthood.

She's 38 years old, and I keep thinking how it went. She's grown up now, even though it is what it is [Ms Barbara]

She's 39 years old, not particularly independent, to be honest, dressing, washing... well, everything. But she is 39 years old and she is unlikely to learn more. But I don't force many things anymore, I let it go, because she's already grown up. I can see that she is also getting older, she is getting more and more tired and she doesn't feel like doing this or that, just like all of us. There is no verbal contact with her, but now that she is 39 years old, she can show what she wants. [Ms Agnieszka]

She's 40 years old and we threw her a real 40th birthday party... Because I wanted to invite her friends first of all. They came from all over Poland. [Ms Iza]

It is the age that determined the course of action and care. It encouraged women to notice and recognise the needs and choices of their children. This has a significant impact on the psychological and social functioning of people with profound intellectual disabilities. For years, the issue of adulthood of people with intellectual disabilities has been ignored or limited to solutions for young children: for pre-school and school age groups. The question arises:

what proposals do we have today for rehabilitation and education of adults with profound intellectual disabilities? Such dilemmas have appeared in the statements of women.

In the past, everyone cut themselves off from small children, from our children... And we didn't know what to do with them, because they didn't go to kindergarten, didn't go to school... Today it's different again. There are a lot of different therapies for children, even kindergartens, schools, and again there is nothing for adults. Just as for us, there is nothing. Maybe somewhere in Warsaw or in another big city... but there's nothing here... You know, as if we've come full circle. [Ms Agnieszka]

There is simply no life for our kids... Because the school ends and it seems like we start from scratch... Because once we lived a normal life, kids used to go to kindergarten, I used to go to work, but with time diseases started to appear, seizures, emotional problems, which most centres do not cope with. [Ms Zofia]

The concept of Stanislaw Kowalik's adulthood as a "zone of lost development"¹⁶ is reflected in the reality in which adults with profound intellectual disabilities function. As mothers emphasize, childhood is a period when a parent can benefit from many proposals of the educational and care sector. However, adulthood is a period when they have to return to their starting point, when what has been developed is subject to degradation.

The older he gets, the more trouble you get. I will not hide it. [Ms Nela]

If she doesn't want something, there is aggression. I learned how to deal with it, but now it's different. She is an adult, she has more strength, and sometimes I get the impression that I'm getting weaker and weaker. [Ms Agnieszka]

He's a grown man, it's not like Antoś would stay with his grandmother anymore. Now his grandmother is simply afraid of him sometimes, because he is quite strong. [Ms Jolanta]

¹⁶ S. Kowalik, op. cit., 2003, pp. 61-78.

I can't go out, because if she has a seizure, you have to give her medication, and not everyone is allowed and can do it properly, and she doesn't always accept it. [Ms Zofia]

Women emphasized that during the adulthood of their children, they experience different difficulties than before when they were younger. They pointed to the need for a different kind of support from what is available and offered to them.

I used to go out more, I had friends... But now, since my daughter doesn't go to the centre, I know that I've closed myself in. But I don't feel like it anymore, and so the two of us are getting older. [Ms Renata]

I still need support, I need it myself, even though I support these young women every day... Every mother with such a child, she doesn't need to hear: What are you saying? She won't walk? or that this child of yours is a child all her life „... I don't need pity, I just need something positive. [Ms Margaret]

Therefore, it should be concluded that the analysed adulthood requires special support and transforms the functioning of the family. It requires solutions that take into account not only the individuals with intellectual disabilities themselves, but also their carers. In one of her articles, Iwona Lindyberg¹⁷ mentions Stephen Schoen's "Psychotherapy as a sacred area" study¹⁸, in which the author uses the term "presence" written in Las Vegas inside the casino: "You must be present to win." This understanding applies to people with profound intellectual disabilities, especially their carers. This is due to a certain dependence caused by the specificity of profound intellectual disability (see Diagram 1), but it does not exclude the possibility of being treated with the same rights as others at every stage of life – something mothers in particular "fight for" every day. An attempt to analyse the two concepts: adulthood and profound intel-

¹⁷ I. Lindyberg, op. cit., 2003, pp. 279–284.

¹⁸ S. Schoen, *Psychoterapia jako obszar święty*, „Gestalt” 1992, No. 5, pp. 114–125.

lectual disability can be controversial and give rise to dilemmas. This may be due to the way in which these concepts are interpreted. The women respondents place them in a continuum consisting of three approaches: person – adulthood – disability.

She always has a choice, here she has coffee, here she has tea... But I always ask her: coffee or tea? [Ms Małgosia]

My daughter says one word: Mom. Oh, no, she's also argues with me. But lately she has been saying: 'ne you', which means she doesn't want to. [Ms Maria]

Apart from the above mentioned aspects determining adulthood and the factors that constitute it, mothers pointed to the personality traits of their children and included them in a continuum of terms: person-adults-disabilities.

Here's my little girl [...], namely [...] I don't think I should say that, because she's a grown-up woman. [Ms Małgosia]

I used to read to her, but now I prefer to talk to her, we like watching TV, she has her favourite shows, that he likes. [Ms Agnieszka]

She senses a lot, and with age, despite her condition, I know that she feels more and more in her own way. [Ms Jolanta]

As she gets older, she gets more and more huffy, she doesn't notice me if something doesn't go her way, even if I leave her in the best care and I have to leave, then when I come back, I see that she's in a huff with me. [Ms Maria]

It is difficult for people with profound intellectual disabilities to function as adults or to create their own adulthood because of the medical conditions that women have faced over the years.

I always have to be there, because if my daughter gets an epilepsy attack, not everyone knows what to do. But nobody wants to stay, although at the beginning I explained what to do... Because I wouldn't do anything else in such a situation. [Ms Agnieszka]

My daughter has to be monitored all the time, because she bites, pinches, now even throws different objects, sometimes it all gets thrown in the air. [Ms Agnieszka]

Apart from the medical aspects that determine the image of adulthood of people with profound intellectual disabilities, women speakers pointed to conditions resulting from social attitudes and opinions.

Even now I can hear: you better place her [in some institution], you've been toiling all your life. [Ms Grażyna]

I have a son who's 36 years old. But they don't always look at him as if he were a man of his age. Sometimes they talk to him like to a child, he gets nervous then, and so do I. [Ms Barbara]

People always feel sorry for me... I'm a mother, but my child is an adult. It's different, too. [Ms Aleksandra]

Adulthood of people with profound disabilities is a complex concept, conditioned and created by their carers, environment, culture in which they function.

Summary

On the way to respecting the adulthood of people with profound intellectual disabilities, there are many changes ahead of us, not only in the legal and guardianship system, but also in the social awareness. Based on the analysis of the interviews conducted so far, we can conclude that adulthood of people with profound intellectual disabilities in both subjective and objective dimensions (social opinion) is determined by the nature and level of support provided (social, psychological, information). It should be stressed that the (un)received expected support determines the psychological and spiritual condition of mothers as the only carers of adults with profound intellectual disabilities and has an impact on the quality of their lives. Adulthood of people with profound intellectual disabili-

ties in the opinion of their mothers should be considered in two dimensions: individual and community, which are interdependent and conditioned by each other. *Adulthood is a stage available to all people, regardless of the level of support they require. It is created and shaped by their carers, social attitudes, and then by themselves because of the opportunities they have. It is a concept entangled in negative stereotypes, implanted by the medical perception of disability and the medical model of therapy as well as the broadly understood rehabilitation directed to this group of people for years.*

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