



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

Part 2

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

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

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

Due to the extensiveness of the issues raised, the issues discussed are presented in two parts. The present text considers the third of these dimensions and the final reflections formulated on the basis of the conducted analysis.

KEY WORDS: mild intellectual disability, educational disability, cultural and economic capital

Introduction

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

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

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

The first two issues were presented in the first part of the study², with the last one making up the subject of analyses included in the present text. It must be noted that the content discussed by us is variedly assessed within subject literature. We do not aim at eliminating the ambiguities that emerge, but we hope to expose the existing differences, and we even make an attempt at questioning attitudes, which, due to them having been repeated over and over again, took on the form of statements being accepted as the truth. We see in this mode of progress the possibility of thoughtful reflection on reality. Hence, during our analysis concerning persons with

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

² This part was published in issue 26/2019 of the publication „Interdisciplinary contexts of special pedagogy”.

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

Properties of selected components of the mesosystemu of persons with mild intellectual disability

Disability is the result of violation of the balance between the individual dispositions of an individual, their conditions of life and activity and requirements set out by their environment³. The environment and its subsystems can thus be treated as a significant component in course of emergence of disability. Its activity in this regard shines through both in situations and under conditions negatively diverging from the norm, which, according to Heinz Bach⁴, can be described as forms of injury, as well as in expectations formulated with respect to a particular person. Due to the intensity and time of influence, a particular role in the emergence of disability is assigned to two components of the mesosystem: the family environment and the school environment, as well as the relations between the two.

The cultural and economic capital of the family environment

A comparison of resources of the family environment of persons with mild intellectual disability with those of the the general population comes out to the disadvantage of the former.

Low levels of cultural and economic capital, or even a specific “culture of poverty”⁵, characterise the majority of families of pupils

³ H. Bach 1999, as quoted in: G. Szumski, *Integracyjne kształcenie niepełnosprawnych*, Wydawnictwo APS, Wydawnictwo Naukowe PWN, Warszawa 2009, pp. 110–111.

⁴ Ibidem, p. 111.

⁵ Conf. O. Lewis, *Dzieci Sanchez*, transl. by A. Olędzka-Frybesowa, Wydawnictwo Bona, Warszawa 2011

with mild intellectual disability. Among the properties of the family environment of this group of people, researchers⁶ indicate living conditions that hinder development, such as: a disturbed family structure; high number of children; low level of education of parents, frequently related to lack of professional activity or low professional status; economic poverty; difficult living conditions; intellectual disability of the parents or their experience of long-term illness; signs of social pathology, for instance, crime, alcohol abuse. A further property that frequently shines through in families of pupils with mild intellectual disability is an unfavourable upbringing system, which shines through in the form of insufficient care, lack of interest in the affairs of the child or in excess or insufficient requirements or tough penalties for transgressions. A further component characteristic for the discussed families are emotional conditions prevailing in the family that hinder the development of the child: no emotional cohesion between the parents, excess emotional distance from the child, enmity or passivity of parents expressed with respect to the child.

⁶ A. Ostrowska, A. Firkowska-Mankiewicz, *Spoleczne uwarunkowania lekkiego upośledzenia umysłowego*, [in:] *O integrację społeczną młodocianych i dorosłych upośledzonych umysłowo*, ed. by I. Wald, WSiP, Warszawa 1978; M. Kościelska, *Upośledzenie umysłowe a rozwój społeczny. Badania uczniów szkół specjalnych*, PWN, Warszawa 1984; A. Giryński, *Środowisko rodzinne a formy niedostosowania społecznego osób niepełnosprawnych umysłowo*, „Szkola Specjalna” 1985, no. 4–5; F. Wojciechowski, *Dziecko umysłowo upośledzone w rodzinie*, WSiP, Warszawa 1990; T. Żółkowska, *Rodzina a funkcjonowanie w klasie szkolnej ucznia upośledzonego umysłowo w stopniu lekkim*, Wydawnictwo Naukowe US, Szczecin 1994; H. Borzyszkowska, *Isolacja społeczna rodzin mających dziecko upośledzone umysłowo w stopniu lekkim*, Wydawnictwo UG, Gdańsk 1997; J. Głodkowska, *Poznanie ucznia szkoły specjalnej*, WSiP, Warszawa 1999; A. Kozubaska, *Opieka i wychowanie w rodzinie dziecka upośledzonego umysłowo w stopniu lekkim*, Wydawnictwo Uczelniane Akademii Bydgoskiej, Bydgoszcz 2000; Z. Kazanowski, *Środowisko rodzinne młodzieży niepełnosprawnej intelektualnie w stopniu lekkim*, Wydawnictwo UMCS, Lublin 2003; Z. Gajdzica, *Edukacyjne konteksty bezradności społecznej osób z lekkim upośledzeniem umysłowym*, Wydawnictwo UŚ, Katowice 2007; I. Ramik-Mażewska, *Jakość życia absolwentów zasadniczych szkół zawodowych dla młodzieży niepełnosprawnej intelektualnie. Analiza porównawcza*, Wydawnictwo Naukowe US, Szczecin 2011.

The ubiquity of prevalence of the indicated properties in the discussed group of families forms the basis for the conclusion that in case of the majority of persons with mild intellectual disability, a sociogenic character of this disability is probable⁷. It is in the environmental neglect that one should seek the direct causes of the dysfunction, a fact that became the basis for the differentiation of the so-called „cultural intellectual disability”⁸.

In families, in which patterns of passivity and low levels of aspirations prevail, and in which parental behaviour is characterised by helplessness or a demanding attitude, or negative attitudes towards the school, there arises the risk that as a result of modelling, the child’s ambitions and aspirations could be diminished, and the process would begin of sinking into the disability. In addition, the risk of repetition of the model of family life, the phenomenon of social inheritance of the cultural capital provokes one to perceive the errors in the functioning of the family as a source of disability for future generations.

At the same time, however, in the discussed families, disability, and, hence, a child with a disability, can acquire acceptance, because, as it should be assumed, these circles treat intellectual disability as something normal that doesn’t give rise to disquiet. In certain instances, the phenomenon of intellectual disability is “tamed” due to the fact that the child is not the only person in the family to experience this dysfunction. The disability expressed by the child does not usually force the family to change its life plans, as there are either no fixed plans in this regard, or intellectual capacity, not be-

⁷ I.G. Sarason, B.R. Sarason 1984, as quoted in: W. Otrębski W., *Osoby z upośledzeniem umysłowym w sytuacji pracy*, Towarzystwo Naukowe KUL, Lublin 2001, p. 24.

⁸ In psychological and paedagogical literature, this phenomenon is defined in various ways (see J. Kostrzewski, *Charakterystyka osób upośledzonych umysłowo*, [in:] *Upośledzenie umysłowe- pedagogika*, ed. by K. Kirejczyk, PWN, Warszawa 1981, p. 127, pp. 97-129; I. Obuchowska, *Dzieci upośledzone umysłowe w stopniu lekkim*, [in:] *Dziecko niepełnosprawne w rodzinie*, ed. by I. Obuchowska, WSiP, Warszawa 1991, p. 212, pp. 199-239; J. Głodkowska, op. cit., pp. 26-27).

ing a value particularly praised by parents, does not form the basis to design one's future on. The described mode of treatment of disability may be considered as a factor facilitating self-acceptance, advantageous for the emotional development of a child experiencing the disability.

Lack of knowledge and skills necessary to fulfil a parental role, or lack of parental responsibility expressed in insufficient interest in the child, in the reluctance to take on parental tasks, result in lack of necessary support activities. Consequences of this shortcoming shine through in diverse life situations, when planning one's education, professional life or in relation to the emergence of school, peer, health and other problems. In addition, parentification may arise⁹, meaning, a situation, in which the child takes over the parents' responsibilities, their tasks, is forced to take care of family members and its economic assets.

Leaving the child alone to cope may result in premature takeover of adult life roles, despite the lack of proper preparation for their fulfilment. "Parents characterised by low socio-cultural status do not provide the children with space for safe experimentation in social roles, they do not encourage them to seek and try themselves out in terms of strengths and abilities, they do not simplify finding out one's own identity, they do not create the required safety zone, which – looking back to Erikson – could be referred to as a psychosocial moratorium"¹⁰.

Consequences of the described situations can arise in the form of failures experienced by the child, yet at the same time, the necessity to take up initiative, take matters into its own hands, forcing activity, independence, triggering life dexterity. One could also notice in this situation the lack of risk of emergence of overbearance by the parents, see an opportunity of unlimited capacity to experience in-

⁹ K. Schier K., *Dorośle dzieci*, Wydawnictwo Naukowe Scholar, Warszawa 2014.

¹⁰ K. Parys, *Przeciwdziałanie petryfikacji nierówności społecznych w procesie edukacji – w kierunku zwiększania szans rozwojowych uczniów z niepełnosprawnością intelektualną w stopniu lekkim*, „Rocznik Komisji Nauk Pedagogicznych” 2017, LXX, p. 71.

dependence. Facing high demands forces the triggering and reinforcement of the child's resources.

A further problem that forms a potential threat for development is the unsatisfied need of closeness, the lack of an emotional bond between the parents and the child. As a result, the child's behaviour may be characterised by emotional viscosity and the drive to seek acceptance outside of the family, in the school or peer environment. There exists the risk that a person or group that forms for the child a source of emotional support would exhibit values that are not acceptable socially, and that contact with it shall form the source of pathologisation of development. At the same time, neglect by the family could cause the school to potentially become an environment, in which the child could compensate for shortcomings of the family environment, satisfy its need of acceptance, strengthen its feeling of coherence.

The school environment and the needs and capacities of pupils with mild intellectual disability

Interference between the capacities of the pupil, their conditions of living and activity as well as the requirements set forth by the environment, in particular by the school environment, becomes the factor triggering the phenomenon of mild intellectual disability¹¹. The minimisation of the mentioned disparity should be perceived as one of the tasks of the school. The mode of execution of this task can take on various forms. One could focus on the person of the pupil – making an effort at evening out the shortcomings, at improving their resources and resources of the environment in which they function, without changing the requirements, leaving them as they were. One could also take on a different strategy of progress – focusing attention and activity on requirements. Starting with the

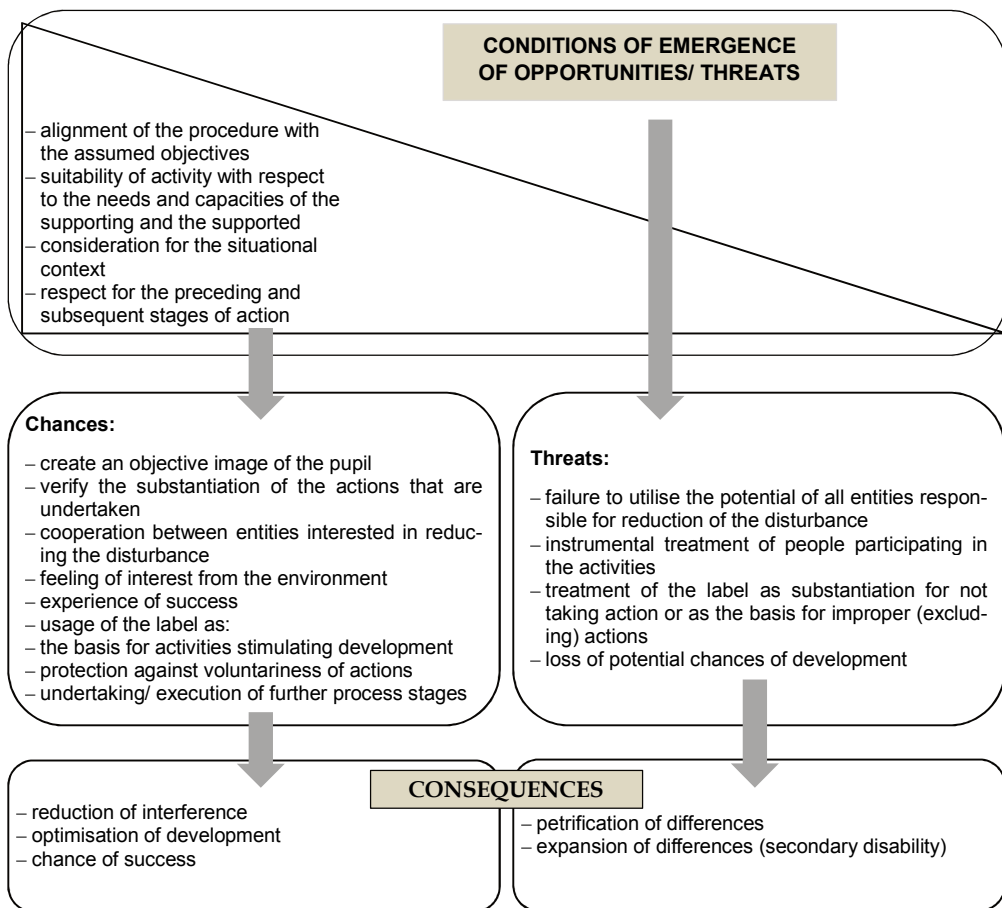
¹¹ H. Bach 1999, as quoted in: G. Szumski, *Integracyjne kształcenie niepełnosprawnych*, Wydawnictwo APS, Wydawnictwo Naukowe PWN, Warszawa 2009, p. 110.

question about the purposefulness of the described expectations, to eliminate some of them or to reduce them in such a way so that they would be adapted to the capacities of the pupil, or it could focus on the mode of execution of requirements, the adaptation of the speed of work or the methods of action to the needs and the capacities of the pupil. Finally, one could influence both the school's requirements, the modes of their execution as well as the resources of the pupil and their environment.

Irrespective of what strategy shall be used in the end, actions aimed at the reduction of discrepancies between the pupil's capacities and the requirements of the environment should take into account three stages: the recognition of needs and resources, the design of education and rehabilitation activities and their implementation along with verification of their effectiveness. During the execution of these stages, specific opportunities and threats for the functioning of all entities included in the process of education of the disabled pupil. The fact that certain opportunities and threats are more closely bound to specific stages does not exclude the possibility of their emergence during the entire procedure. One could hence speak about a specific, universal character of the opportunities and threats indicated in diagram 1.

The emergence of opportunities or threats depends on the properties of the procedure: alignment with the assumed objectives, its suitability for the needs and capacities of the persons providing support and being supported, consideration for the context of the situation, as well as for the preceding and subsequent stages of action. The intensity of the described properties will condition just how real the opportunities or threats shall become, will in the end the discrepancy between the capacities of the pupil and the demands of the environment be reduced, or just the opposite – will it expand or will it keep its *status quo*, become petrified. The higher the intensity of the presented properties of procedure, the higher the chances of reduction of the mentioned discrepancies (see diagram 1).

Diagram 1. Opportunities and threats related to the reduction of discrepancies between the capacities of the pupil and the requirements of the environment in the context of conditions of emergence and the consequences



Source: own work.

The execution of activities aimed at the reduction of discrepancies between the capacities of the pupil and the demands of the environment is conditioned upon the readiness and the resources at

the disposal of all entities engaged in the education process. The school has a particular role to play in this regard, as it is characterised by specific resources and needs. The atmosphere of the facility, the school's mission, the tasks set out by it and the mode of control of their execution, the organisation of work, the quality of personnel – preparation, engagement, motivation to work as well as the infrastructure of the facility are factors influencing the taking of, execution and effect of activities aimed at the elimination of excess discrepancies between the requirements of the school environment on the one hand and the needs and capacities of the pupil on the other. It is worth remembering that this discrepancy should not only be considered as a threat. It may be a chance of development, forcing effort, counteracting inertia, encouraging activity, the acquisition of new experiences, the perfection of teacher work. If, however, the described discrepancy would be too big or, if no activity is undertaken to minimise this state – there arises the risk of permanence of the referred discrepancy, or even its expansion.

Closing reflections

The present text constitutes an attempt at attracting attention to the fact that mild intellectual disability is a demanding disability. The arguments substantiating this claim may include:

- a high number of persons diagnosed as suffering from mild intellectual disability,
- the intra-group variety of the population of people with mild intellectual disability,
- the “invisibility” of mild intellectual disability, expressed in hard-to-notice symptoms,
- the limited validity time of the label of mild intellectual disability,
- frequent intermixing of the described disability with the culturally poor family environment which, due to the lack of suitable resources, does not guarantee suitable support,

- the threat by the phenomenon of social inheritance of mild intellectual disability and the “translation” onto further generations.

The referred components, being constitutive for the situation of persons with mild intellectual disability, can bring about developmental opportunities or threats that were indicated and discussed in both parts of the study. The awareness of the situation, in which persons with mild intellectual disability are found, gives rise to the necessity of searching for and undertaking of activities to allow them to utilise the opportunities, at the same time eliminating threats. This is a further argument allowing one to believe that mild intellectual disability should be treated as a demanding disability. Such a perspective of the discussed disability is also forced by conceptual and implementation changes within Polish special education. As time passes and as the discipline develops, the conviction began to be accentuated that positive results of rehabilitation work are achievable by anyone, irrespective of the level of disability that they experience. As a result, beside the activities aimed at persons with mild intellectual disability, ever more advanced work began to be undertaken to facilitate the optimisation of development of persons with deeper or deep intellectual disability. At the same time, an expansion of the scope and a shift of the focus of interest of special education occurred – from mild towards deeper and deep intellectual disability¹², with issues of mild intellectual disability being shifted away or even wholly neglected. This found its expression in:

- the reduction of the number of facilities educating pupils with mild intellectual disability, and along with this, a reduction of the number of these pupils learning at special facilities. One must note that a range of facilities hitherto foreseen exclusively for pupils with mild intellectual activity expands or completely changes its character of operation, turning also or exclusively to people with deeper or deep intellectual disability,

¹² See S. Olszewski, K. Parys, *Wektory zmian zachodzących w polskiej pedagogice specjalnej*, „Niepełnosprawność. Dyskursy Pedagogiki Specjalnej” 2018, no. 32.

- ever more numerous studies and publications concerning people with deeper or deep intellectual ability,
- changes to the proportion of content in study plans and programmes, on the basis of which special educators are prepared to work with intellectually disabled persons. The time foreseen for the teaching of topics concerning issues of persons with deeper or deep intellectual disability dominates over the time spent on issues concerning mild intellectual disability,
- gradual deceleration of development of methods of education of pupils with mild intellectual disability.

The assignment of the status of being a demanding disability to intellectual disability provokes one to search for an answer to the question: "what does this disability demand?" Without a doubt, one needs in this regard to ponder on the situation of persons with mild intellectual disability that would take into account their actual needs and capacities, the historic development of special education, as well as socio-economic conditions. The verification of the solutions developed historically against the backdrop of reality of the contemporary world can allow one to take action that will facilitate the normalisation of life for this group of people.

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