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Therapeutic Issues in Work with the Intellectually Disabled – Building Linguistic, Communicative and Cognitive Competencies

SUMMARY

People with intellectual disability constitute a group of considerable size, requiring speech therapy from the earliest stages of development. The conduct of such activity must take into account enormous variances among this section of the general population, resulting from various intellectual abilities, aetiology, noted accompanying disorders (e.g. sensory or motor), the state of health, and the environment in which the child grows up. In this article, the authors have distinguished a few sub-groups of the intellectually disabled, which from the point of view of speech therapy require various therapeutic approaches, methods and work techniques, with varying prognoses.

Key words: Intellectual disability, speech therapy, degrees of intellectual disability, aetiology of intellectual disability, accompanying disorders

People with intellectual disability (ID[1]) constitute a considerably large group. As noted by Krystyna Szymańska and Elżbieta Szczepanik (2017: 50-–51), "on the basis of meta-analysis taking in 52 surveys, the estimated rate of appearance of ID is 10/1000 people"[2]. At the same time it is emphasized that this rate takes

[1] For the reader's convenience, this article will use the abbreviation ID to indicate intellectual disability.

[2] Unfortunately, in Poland there is a lack of data concerning the epidemiology of ID. This results partly from the fact that ID is one of the forms of disability. The most frequently given definition of the WHO is that the group of the disabled includes people with long-term reduced physical, mental, intellectual and sensory ability, which in interaction with various barriers may restrict their full and effective participation in social life on an equal level with other citizens. In Poland the generality of disabled people is divided into three basic groups, i.e. people: legally and biologically

on various values depending on the place of survey, the age group surveyed, the socio-economic level, research method, etc. ID is most often noted among children between the ages of 12 and 14 (the rate is 2–3%)[3], as the school system is more demanding, while the lowest rate is among adults (around 1%) (Wald 1987; Komender 2002; Bobkowicz-Lewartowska 2011; Pietras et al, 2012a; Carson, Butcher, Mineka 2003)[4].

It would seem a truism to state that all children with ID have some sort of communicative and/or linguistic deficits (Merrill 1993: 694; McGregor 2009; Griffer 2012: 240). In the definition of ID, presented in the DSM-5 classification (2015), in criterion B, concerning deficits in adjustment, the occurrence of considerable difficulties in communication is emphasized. The *American Association on Intellectual and Developmental Disabilities* (AAIDD) even claims that deficits in the area of one of the components of adaptive behaviours are visible in the whole group of people with intellectual disabilities. This is in fact communicative disability (Griffer 2012: 240–241). However, descriptions of the communicative capabilities of the group with ID are full of contradictions. As Mona Griffer notes, researchers concerned with these people reach the highest agreement in stating that the results of studies conducted so far are incompatible (2022: 241). Controversy arises partly due to the terminology used to characterize the speech of this group, as well as the percentage data concerning the occurrence of speech impairments. In descriptions of the communicative disorders of people with ID in Polish literature on the subject, use is usually made of the terms oligophasia and dyslogia, which in spite of their firm place in logopaedic classifications cannot be considered unambiguous.[5]

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disabled, only legally disabled and only biologically disabled. Depending on the accepted criteria of biological disability, the population of disabled people in Poland may number from 4.9 to 7.7 million people (State of health of the Polish population in 2014, 2016: p. 105–106). However, there is a lack of data concerning ID itself. In the report "The rights of people with intellectual disability: Access to education and employment. Poland 2005", it is stated that "A survey conducted in 2000 indicates merely that people with intellectual disability in the age of 15 years and older constitute 3% of all people with a declared disability" (ibid: 37). It is therefore estimated, though with a considerable margin of error, that in 2002 in Poland there were approximately 130 thousand people with intellectual disability at the age of 16 years and older, living in their own homes.

[3] According to some authors, it is even higher in this age group. Krystyna Komosińska (2012: 259) claims that the frequency of occurrence of this form of disability in the population of children and youth is 2–5%.

[4] Certain authors provide somewhat higher data. For example, according to Maciej Pilecki (2007: 214) mental disability is diagnosed in 4% of cases to sixteen years of age, while among adults this rate is 2% (cf. Strelau 1997). For comparison, in Australian surveys it was claimed that the frequency of occurrence of ID in the age of group of 6–15 years was 14.3/1000, whereas in the age of 25–50 years - only 3.3/1000 (Szymańska, Szczepanik 2017: 51).

[5] More on this subject: K. Kaczorowska-Bray 2017a; 2017b; K. Kaczorowska-Bray, S. Milewski, M. Michalik 2018.

Despite the existing disagreements on the level of theory, there is no doubt in the conviction that all children with ID require diagnosis and speech therapy. It seems obvious that in considering these needs, one should determine a program of diagnosis and therapy, and work out a methodological procedure. However, this task is not only difficult but also somewhat daring, taking into consideration the enormous variances among this part of the general population.

The heterogeneity of the group with ID results somewhat from the definition itself. Intellectual disability is not a recognized disease entity[6], so there is no determined cause, similar course or symptoms, nor similar prognoses in all patients. It is usually treated as a symptom (basic, dominating or coinciding) of many illnesses of various aetiology (Komender 2002; Komender 2004) or as a consequential state of various diseases and injuries (Radochoński 2001). Basic problems occurring in this whole group are referred to in the diagnostic criteria included in classifications, e.g. ICD-10 and DSM-5. According to the latter, in order to diagnose ID, three criteria must be fulfilled:

A. the presence of deficits in intellectual functioning, such as making conclusions, solving problems, planning, abstract thinking, evaluating, learning and learning based on experience – attested by clinical evaluation and standardized intelligence tests adjusted to the patient;
B. the occurrence of deficits in adjustment, leading to failure in the realisation of developmental and social-cultural standards, which render it impossible for the study subject to maintain independence and responsibility. Without appropriate support, these deficits restrict functioning in one or many everyday activities, including communication, participation in social life, and independent life, in various environments such as: the home, school, work or the social group;
C. the beginning of intellectual and adaptive deficits in the developmental period (DSM-5 2015: 15).

These criteria allow one to indicate difficulties and deficits which must appear in people in order for a diagnosis of ID to be made. However, even observing that which this group have in common, one may perceive significant variances. For instance, intelligence quotient, which in people with ID of a mild degree is at the level of 50-69 IQ, in the case of profound ID reaches a level below 20 IQ (ICD-10 2000:190-192). The difference in intellectual abilities is therefore enormous. It is similar in the case of criterion B, regarding evaluation of adaptive abilities. People with a mild level of ID often function independently or with a little support of their surroundings. They gain a profession, take on work, start families, and so fulfil themselves in various social roles. The group with profound ID re-

[6] A disease entity according to the Polish Dictionary PWN (http://sjp.pwn.pl) is an illness with determined causes, symptoms and course, officially recognized by a group of specialists.

quires assistance through their whole life, and most often at every level of daily life[7], including the fulfilment of basic physiological needs. Criterion C indicates the time in which symptoms both in the cognitive sphere as well as in adaptive behaviours should appear. It should be pointed out that the expression "developmental age" is not very precise, as this term takes in childhood and adolescence (Morrison 2016: 35). However, most cases of ID arise in the perinatal period or a damaging factor was active before birth (or even before fertilization, e.g. in the case of certain forms of Down's syndrome). In a few cases the child's development followed a normal course for a certain time. James Morrison (2016: 35) states that only about 5% of ID arises as a result of disorders and somatic states acquired in childhood (e.g. lead poisoning, infections or injuries), and ca. 20% is a consequence of environmental factors (e.g. deprivation) or mental disorders (e.g. early-beginning schizophrenia). In accordance with the traditional approach in psychiatry, these would be groups of children with significant variances in functioning. Emil Kraepelin and Jean-Étienne Dominique Esquirol distinguished mental underdevelopment (disorders of general mental development arising early, i.e. acquired in the foetal period or later, of a hereditary or inborn basis) from dementia (general retardation of mental development arising later, as a result of illness). We find a similar approach in the Polish context. An example may be in the opinions of Maria Grzegorzewska (1964) and Ryszard Kościelak (1984, 1989), who make use of the term mental retardation as overriding such terms as oligophrenia and dementia. Oligophrenia would be here seen as mental underdevelopment occurring from birth or earliest childhood (to 3 years of age), brought on by the suspension of brain development and higher nervous activity, while dementia refers to cases which appear later, after 3 years of age, and involve "mental reversing" resulting from some pathological process. In the case of dementia, as Kościelak states (1984: 12), "general mental development has occurred properly until a certain point, and then as a result of damaging factors there occur the decay of full intellectual functions with a tendency to regression".

The heterogeneity of the discussed group also results from many other factors than those indicated above. A basic question is of course aetiology. ID may be caused by many various aetiological factors, effective during various points of the developmental period. One of the newer perspectives on the matter of risk factors of intellectual disability is presented by Robert L. Schalock and collabo-

[7] The DSM-4 TR (2008) classification more precisely than DSM-5 indicates areas in which people with ID most often show adaptive problems. These were: communication; personal resourcefulness; household upkeep; social and interpersonal skills; making use of environmental resources; self-determination; learning skills; working; resting; caring for health and safety. People with ID to a mild degree usually show difficulties in the area of learning and in taking on professional work. The more profound the disability, the more the distinguished abilities are affected by disorders.

rators (2010). Significant in this approach is its wide view of social, behavioural and educational factors, particularly important in the case of disability to a mild degree. Researchers have distinguished here three periods of active risk factors:

1. prenatal:
– biomedical factors – chromosomal disorders, monogenic disorders, syndromes, metabolic disorders, dysgenesis, mother's illnesses, age of parents;
– social factors – poverty, mother's malnutrition, lack of access to prenatal care;
– behavioural factors – taking drugs during pregnancy, drinking alcohol during pregnancy, parents smoking cigarettes, immaturity of parents;
– educational factors – cognitive disability of parents not making use of support, lack of preparation for parenthood;
2. perinatal:
– biomedical factors – premature birth, perinatal damage, neonatal disorders;
– social factors – lack of access to prenatal care;
– behavioural factors – parents refusing to provide care, parents abandoning child;
– educational factors – lack of medical referral to early intervention;
3. postnatal:
– biomedical factors – post-accident brain damage, malnutrition, meningitis, epilepsy, degenerative disorders;
– social factors – improper child – caregiver interaction, lack of appropriate stimulation, poverty, chronic illness in the family, institutionalisation;
– behavioural factors – ill treatment and neglect of the child, domestic violence, insufficient protection of the child's safety, social deprivation, difficult behaviour of the child;
– educational factors – parents incapable regarding upbringing, late diagnosis, improper system of early intervention, improper system of special education, inappropriate family support (Schalock et al. 2010; for: Żyta 2014: 21).

Social, behavioural and educational factors constitute the main basis of ID to a mild degree. As Renata Strzyżewska claims: "There are two causes of mental retardation. The first is related to a pathological physical condition. In this case the mental retardation is a consequence of an injury or illness. The second is referred to as cultural-familial retardation and appears as a result of environmental factors – mainly familial (harmful effects on the child of parents' attitudes, the effects of genetic and psycho-social factors as well as inheritance" (Strzyżewska 2005: 68–69; cf. Shapiro and Batshaw 2013: 297). Thus, from the point of view of aetiology, one may distinguish two groups of people in which ID have various bases:

1. people with ID of mild degree, 95% of whom (Gunzburg 1971, p. 371; Wald 1981, s. 94) are from the poorest families, with the lowest education, often with multiple children. Research on the family situation of mentally

retarded children conducted by Ryszard Kościelak (1996), Małgorzata Kościelska (1984) and Krystyna Barłóg (2008) confirm the difficult conditions in which children with ID to this degree are raised. Małgorzata Kościelska even claims that the particular characteristics of mentally retarded children mainly depend on the fact that "as a population they have had considerably worse than average conditions for development in both the biological and social sense" (ibid: 351). The aetiology of ID can in this case be considered to be environmental-cultural. In regards to this type of ID, various terminology is used in subject literature. For example, Stanisław Kowalik (2008: 138–139) has referred to it as social-familial, while Klimasiński as learned or cultural-familial mental retardation (2000: 75; 2002: 73), Mona Griffer calls it ID of a family origin (2012: 234), emphasizing the basis of the disorder.

2. people with ID to a profound degree - in the case of this group, relations between the frequency of the disorder's occurrence and the environment have not been noted. It is emphasized that most cases of retardation to a profound degree have organic causes, which are usually divided into genetic and acquired (Kostrzewski 1981; Wald, Stomma 1981; Obuchowska 1995; Kościelak 1996; Klimasiński 2000; Kozubska 2000; Carson, Butcher, Mineka 2003; Pilecki 2007; Kowalik 2008; Heward 2013).

Mona Griffer (2012: 234) points out the fundamental differences between the distinguished types of intellectual disability. According to the researcher, these groups differ not only in aetiology, but also in the environmental conditions in which they grow up, their state of health, the occurrence of dysmorphic characteristics and anomalies in body structure as well as developmental possibilities.

This type of division, based on aetiological criteria, is significant from the viewpoint of therapy. The two distinguished groups present different patterns of speech development; therefore, in their speech therapy different goals are set and the choice of methods and work techniques is also different. Children with ID of a mild degree go through the same stages in speech development as those of typical development, though they do so at a slower pace and with decreasing dynamics. Their course may also be characteristic, as "among the mentally retarded, these stages are generally unfinished and fragmentary. The developmental mechanism is slower and less efficient" (Tarkowski 2005: 565). As time passes, the differences between children with intellectual disability and in the norm not only do not disappear, but become increasingly distinct, especially in the area of the syntactic and lexical-semantic systems. Children with more profound ID present an atypical pattern of speech development, which results partly from biological dysfunctions occurring in this group. In the case of part of this group, speech development is impossible, which may result from profound cognitive limitations

and/or anatomical anomalies in the area of systems enabling this form communication. Therefore, while in conducting therapy of a child with mild ID, a therapist may formulate goals close to those set for a child of typical development (e.g. evoking unrealised speech sounds or attaining proper articulation with deformation present), in the case of patients with more profound developmental problems this is normally impossible.

What causes particular difficulty for therapists working with this group of people is undoubtedly the multiplicity and variety of noted disorders accompanying ID. Among the most commonly occurring are sensory impairments. It has been indicated that around 60% of the population with ID demonstrate some form of these. These include visual and hearing impairments, which are of particular interest for speech therapists. In as many as 40%–50% of the group, significant hearing impairments are diagnosed (Barr et al. 1999: 1486; Carvill 2001: 471; Levy 2009: 147; Barron, Winn 2009, p. 3). It is possible to indicate people particularly at risk of this type of problem, e.g. with Down's syndrome, in whom the risk of occurrence of sensory disorders increases to 80% (Barron, Winn 2009, s. 3). It is noted that in nearly 30%–70% of people with ID, considerable problems in functioning of the visual organ are diagnosed, i.e. from 8.5 to 200 times more often than in the general population. The influence of visual impairments on speech development has not been well recognized (see Kaczorowska-Bray 2014; Milewski, Kaczorowska-Bray 2015; Kaczorowska-Bray, Milewski 2016; Kaczorowska-Bray, Milewski 2017). However, many researchers draw attention to the fact that damaged vision existing in the early developmental period may result in poor communicative skills. This obviously hinders the baby's observation of the care-giver's face and perception of the articulatory system typical for a given speech sound. Visual contact with the speaker is also of great importance for creating the conversational situation itself and taking on the alternating roles of listener and speaker. Damage to the visual organ also cuts off the speaker from non-verbal sources: making it impossible to observe facial expressions, direction of vision and gestures or bodily movements (Levy 2009: 150).

Intellectual disability is a state of overall delayed pace of psycho-motor development in the form of severe and extensive disorders (Szmigiel 2010: 89), in which disorders of mental ability are often accompanied by motor impairments, as well as physical deformations. In the case of children with mild ID, the development of particular motor skills may be delayed by up to three years; with more profound forms of ID – four years or more. These delays have a qualitative as well as quantitative character. Differences between the group with ID and children of typical development become more significant with age (Payne, Yan, Block 2010: 18; Block 2012: 448)[8]. In the case of more profound disability whose cause is

[8] This may be confirmed by the research of Jiabei Zhang (2005), conducted with a group of

neurological damage or syndromes of genetic defects, there is noted a considerably higher risk of occurrence of anatomical anomalies and a generally poor state of health, which further hinder the child's motor development (ibid).

In each person with ID, accompanying disorders, their type and strength, may create a unique combination which the speech therapy must take under consideration in conducting therapy. Stimulation of some deficits should be included by the therapist in a program of therapy, e.g. exercises of visual and aural perception, vision-movement coordination. Since the child with ID, especially to a profound degree, is also under the care of other specialists, e.g. physiotherapists or sensory integration therapists, cooperation is necessary within a multi-specialized team, which ensures cohesion of activities and increases effectiveness.

From the point of view of the speech therapist, considering differences in the course of speech development as well as the communicative capabilities of people with ID, this group is divided into at least a few subgroups. The basic division distinguishes people with ID to a mild degree. Separating this subgroup is justified by the usually different aetiology and environmental conditions in which the child develops, as well as a different course of speech development itself, compared with children of more profound ID. They usually do not have any neurological damage, and the basis on which their intellectual abilities are formed allows fully communicative speech to develop. Using it, they are able to convey their needs and establish relations with their surroundings. The level of mastering speech allows them to take on work and enter into various social roles as adults. Tasks that the speech therapy has to conduct in therapy of such a patient are similar to those determined for children of typical development. These include care for correct articulation. However, it is obvious that removing numerous speech sound deformations may turn out to be a considerably more difficult and time-consuming task than in the case of a peer who is developing without disorders. The numerous anatomical anomalies in this group, e.g. malocclusion, are often not treated, which may render it impossible to attain proper sounds. Therapy does not always end in success, as people with ID of a mild degree rarely develop the internal motivation which is necessary at the stage of automation of properly made speech sounds. Speech therapists usually cannot count on support and cooperation from the child's closest surroundings. Parents, struggling with material problems, do not have the time to assist the child with its exercises. It also occurs that as a result of their cognitive limitations, they do not perceive the seriousness of the problem.

The next division of the group of people with ID is into those with ID of a mild to moderate degree and the group with extreme or profound ID. In the case

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children with ID of mild degree in the age of 12–15 years, which indicated motor delays between 6–10 years in relation to peers of typical development. The groups were tested with the *Bruininks-Oseretsky Test of Motor Proficiency*.

of the first distinguished subgroup, limitations in the intellectual sphere are not so serious as to make speech development impossible. Therefore, of course allowing for delays in this area, we can expect that children with mild ID will say their first words at around 3 years of age, while the first sentence – around 5 years of age. In the group with moderate disability, these appear later; at school age, however, speech should become their main tool of communication (Bogdanowicz 19891; Błeszyński 2012; Kaczorowska-Bray 2012). If such is not the case, one should look for other causes of such profound delays, as these cannot be explained by intellectual disability alone. In the case of children with more severe ID, speech development is sometimes impossible – the hindrance may be in anomalies in the anatomical structure of speech organs, neurological damage or an excessively low intelligence quotient, making speech too difficult and abstract for them. The task of the speech therapist is early recognition and suggestion as early as possible of an appropriate form of assisted or alternative communication where possible. This selection is a considerably more difficult task than it may seem – the chosen system must not only be adjusted to the child's abilities, considering his motor or sensory deficits, but also must be accepted by the people surrounding them, who in many cases, e.g. systems based on gestures, must learn the system themselves.

The last division to which we draw attention distinguishes the group of people with ID whose cognitive limitations are so profound that not only speech but also alternative communication is impossible to introduce. In such people neurological damage has rendered impossible the intention of communicating. In other words, they are not able to perceive and understand that their behaviour may affect their surroundings and bring about certain changes in them. This is usually described as functioning on a reflexive, preverbal, pre-intentional level or at the level of one-sided non-intentional communication (inter alia Ruiter 2000; Barron and Winn 2009; Baraniewicz and Baraniewicz 2007). People of this group do not behave in an intentional manner nor do they direct their reactions towards a particular recipient. Usually strong limitations of movement are noted in them, though some of these people have developed certain motor skills. The observing care-giver may give meaning to the patient's behaviour, though it remains unclear to a large extent. Therefore, such interpretation is often referred to as "over-interpretation". At this level of communication, attempts to understand and give meaning, undertaken by therapists and care-givers, may be made in response to: shouting, directing vision, smiles, squeals, muscle tension, skin colour, change of voice (volume, tone of sounds), body movements and changes of position, possible changes of distance to a person of the surroundings, etc. (Baraniewicz, Baraniewicz 2007). In the case of the group of such profound disability, the conduct of speech therapy is made particularly difficult – diagnosis as well as therapy require specific skills and wide knowledge of the therapist, but also time which the diagnostician and

therapist must spend on observation of the patient's behaviour, especially that which serves establishing relations with the surroundings.

The more severe intellectual disability is, the less possibilities there are for using methods and work techniques that are considered fundamental in work with people of typical development. Disorder of speech perception, difficulties in focussing attention, problems with movement of speech organs, sensory disorders – these are just some of the difficulties which restrict the active participation of patients in therapy. A person with ID is a patient requiring of the therapist not only profound theoretical knowledge, including logopaedic, medical, psychological and pedagogical issues. Also essential is knowledge of many methods assisting the work of the speech therapist, based on movement, music, rhythm, taking into consideration methods allowing for multisensory stimulation of the patient.

Taking under consideration the particular diagnostic and therapeutic needs of people with ID, it seems necessary to clearly distinguish a sub-discipline of speech therapy, which may be referred to oligophreno-logopaedics. Including the oligophreno-speech therapist on the list of professions would allow a group of therapists to develop, willing to take on the challenge of work with people with ID.

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