

Educational and Therapeutic Intervention in the Context of the Profile of Characteristics of Children with Down Syndrome

Interwencja edukacyjno-terapeutyczna w kontekście profilu cech dzieci z zespołem Downa

Renata Biernat

The Mazovian Academy in Plock,
Poland

r.biernat@mazowiecka.edu.pl

ORCID: <https://orcid.org/0009-0008-1536-1542>

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Abstract: This article addresses issues concerning the nature of the most common chromosomal disorder. It indicates the causes, characteristics, behaviours and problems that make up trisomy of chromosome 21. The learning and functioning process of people with Down syndrome (DS) is not determined solely by an extra chromosome. The need to identify the factors and conditions that need to be considered in the process of activating individuals burdened with an extra chromosome seems therefore legitimate. Theoretical inquiries into the similarities and differences of children affected by Down syndrome have important implications in the areas of education and rehabilitation. The cooperation of parents with the school promotes the dynamization of the child's development in both environmental contexts. The choice of the form of special education (in an inclusive, integrative or segregated stream) should be an expression of a thoughtful decision by parents, considering a number of factors, such as: the profile of the characteristics of the child with DS, the effects of previous support for his development, parental involvement and expectations, and the availability and conditions offered by a particular school. As more and more pupils with Down syndrome are being placed in mainstream institutions, it seems that the need to promote knowledge of their development and how to take educational and therapeutic measures is still relevant.

Keywords: Down syndrome (DS), pupil, education, therapy, special education, parents

Abstrakt: Artykuł podejmuje zagadnienia dotyczące istoty najczęstszego zaburzenia chromosomalnego. Wskazuje przyczyny, cechy, zachowania i problemy składające się na trisomię chromosomu 21. O procesie uczenia się i funkcjonowania osób z zespołem Downa (ZD) nie decyduje jedynie dodatkowy chromosom. Potrzeba określenia czynników i warunków, które należy uwzględnić w procesie aktywizowania jednostek obarczonych dodatkowym chromosomem wydaje się zatem zasadna. Teoretyczne dociekania dotyczące podobieństw i różnic dzieci dotkniętych zespołem Downa mają istotne następstwa w obszarach edukacji i rehabilitacji. Współpraca rodziców ze szkołą sprzyja dynamizowaniu rozwoju dziecka w obu kontekstach środowiskowych. Wybór formy kształcenia specjalnego (w nurcie inkluzyjnym, integracyjnym czy segregacyjnym) powinien być wyrazem przemyślanej decyzji rodziców, uwzględniającej szereg czynników, np.: profilu cech dziecka z ZD, efektów dotychczasowego wspomagania jego rozwoju, zaangażowania i oczekiwań rodziców oraz dostępności i warunków oferowanych przez konkretną szkołę. Ponieważ coraz częściej uczniowie z zespołem Downa trafiają do placówek ogólnodostępnych, wydaje się, iż potrzeba propagowania wiedzy na temat ich rozwoju oraz sposobów podejmowania działań edukacyjnych i terapeutycznych jest ciągle aktualna.

Słowa kluczowe: zespół Downa (ZD), uczeń, edukacja, terapia, kształcenie specjalne, rodzice



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INTRODUCTION

The selection of characteristics of people with Down syndrome (DS) was contributed by the classification of races by Johann F. Blumenbach, who in the 19th century identified the following races: Mongolian, Aztec, Caucasian, Malay, and Ethiopian. In 1866, John Langdon Down identified the characteristics of individuals belonging to the Mongolian race. Until 1961, the term “mongolism” was used. In the early 1960s, a group of geneticists coined the term “L. Down syndrome,” which caught on and is still used today (Bolińska 2015, 41).

DS is one of the most common chromosomal abnormalities. Three types can be distinguished: simple trisomy (95% of cases), translocation trisomy (3-5%), and mosaicism (1-3%) (Sadowska et al. 2009, 9-10).

The mother’s age, and also the father’s age, is a factor contributing to the birth of a child with Down syndrome. The importance of environmental factors is not excluded. According to the current state of knowledge, the lifestyle of parents, medications they are on, or the diet they follow do not have an impact on the occurrence of trisomy in a child (Chowaniec-Rylke 2016, 95). Very rarely is DS hereditary (Roźnowska 2007, 34).

It remains unexplained how the extra copy of chromosome 21 leads to brain disorders, causing cognitive, language, and motor dysfunctions. It is unclear why some children with Down syndrome develop relatively well, while others are less capable (Jędrzejowska 2017, 18).

1. OVERVIEW OF CHARACTERISTICS OF INDIVIDUALS WITH DOWN SYNDROME

DS is usually diagnosed immediately after birth, as the child has characteristic facial features. Typical external symptoms include a small and short head with a flattened occiput and small low-set rounded ears. Narrow and slanted palpebral fissures, epicanthal folds, and small discolored spots on the iris of the eye are characteristic. The lips and tongue are thick, and the protruding tongue (due to a high-arched palate) is wide, furrowed, with numerous grooves. Most individuals have a defective bite and a

high propensity for caries and periodontal disease. The nose is flat and short. The chest is sometimes flattened. The upper and lower limbs are short, with wide, fleshy, and red hands and feet. The characteristic palm and sandal gaps are present. Individuals with Down syndrome have dry, rough skin and sparse, coarse hair. From the age of 4, they are significantly shorter and lighter in weight (Zasępa 2012, 13-14). With the development of research on people with Down syndrome, two clinical variants have been identified: the pituitary and thyroid types. Children of the thyroid type are short, often obese, and their speech development is weaker. They are cheerful and open. Children representing the second type are usually thin, restless, better at speaking, but also more stubborn and rigid in their behavior (Sokołowska and Kociubińska 2022, 177).

Certain typical behaviors have been noted in people with Down syndrome. For example, infants are usually calm, cry little, and sleep through the night. Older children (2-9 years old) are less emotional and aggressive, less demanding, more pleasant, and affectionate compared to healthy children. There is considerable variability in temperament among children with Down syndrome, ranging from quiet and attentive to impulsive and active. It is also noted that a mild temperament and emotionality are more characteristic of older children. A correlation between temperament traits and the level of intellectual development has been demonstrated. Less capable children are more impulsive and energetic, while the more capable ones are quieter but more restless and moody (Zasępa 2012, 71).

Individuals with Down syndrome are characterized by central nervous system (CNS) structural abnormalities and defects in other systems and organs. Compared to the brains of children with a normal karyotype, the brains of children with Down syndrome achieve smaller volumes and masses (Popowska 2020, 384). Mental illnesses are less common in individuals with Down syndrome than in other cases of intellectual disability. Studies report that 2 to 10% of individuals with this syndrome meet the diagnostic criteria for autism. These individuals are characterized by hypotonia, contributing to postural defects (Żyta 2011, 36).

The same regularities are observed in mental development as in the development of all other children. Differences mainly concern the final outcomes and the time required to achieve them (Grzybowska 2014, 184). Most individuals in the discussed group have mild or moderate intellectual

disability. IQ decreases with age. Intellectual disability is accompanied by thought process and attention disorders, as well as poorer self-control and memory (Minczakiewicz 2001, 20). Problems often arise with speech fluency, tone and quality of produced sounds, articulation, and the ability to pronounce sounds in the correct order (Jankowska 2019, 295). The language of people with Down syndrome is largely telegraphic. Their utterances contain fewer adjectives, adverbs, and abstract concepts. However, word order in short and simple utterances is usually correct (Jędrzejowska 2017, 42).

The strengths of most people with Down syndrome are in emotional and social development. Zasepa (2012, 109), characterizing the development of social competence, notes that: a) the level of adaptive behavior development is higher than the level of intellectual functioning; b) the best results are in the areas of socialization, responsibility, and contacts; c) there is more focus on positive than negative emotions. Jankowska (2019, 297-298) adds that most children with Down syndrome are interested in their surroundings and enjoy the company of other children.

Given the significant intragroup differences in the area of relations with others, individuals with Down syndrome can be identified as sociable, kind, affectionate, with good relational skills and a tendency to smile, as well as stubborn, not adapting to social partners. About 8-15% of people with Down syndrome exhibit behavior and personality disorders. According to Zasepa (2003b, 40), children with Down syndrome are more withdrawn, with more motor stereotypes and strange movements, and deviant sexual behaviors.

Literature analysis allows identifying several strengths and weaknesses of children with Down syndrome in other areas of functioning. For example, a strength is the ability to learn signs, gestures, reading, and writing (Jankowska 2017, 298). These children find it easier to reason when task content relates to everyday situations and contains concrete concepts (Zasepa 2003a, 162).

On the other hand, weaknesses of a child with Down syndrome include (Jankowska 2017, 298): problems with auditory perception and memory, shorter attention span, increased fatigue, quick discouragement from more demanding tasks, poor tolerance for failure, and difficulties in generalizing, abstract thinking, and weaker mathematical skills. Children with Down syndrome are accompanied by sensory, balance, motor coordination, and visual-motor integration disorders. There is also slower

activity execution, especially those requiring precision, and difficulties in adjusting muscle strength to the task. Particularly poorly developed in children with Down syndrome are abilities to sequence, classify, and count with understanding (Zasępa 2003a, 157).

Undoubtedly, the course of each person's development is individually variable. The psychological and social situation of individuals with Down syndrome can be diverse (Sadowska, Mysłek-Prucnal and Gruna-Ożarowska 2014, 51). Genetic factors and additional defects and diseases do not define the child as a person but are accompanying disorders.

2. THERAPY AND EDUCATION OF PUPILS WITH DOWN SYNDROME

A child with Down syndrome undergoes medical, psychological, speech, and pedagogical diagnosis from the first days of life. In the child's development, identifying the zone of proximal development is also required, as understanding the range of the child's capabilities will enable surpassing current cognitive abilities (Skrzetuska 2020, 212).

Identifying developmental difficulties requires immediate initiation of therapy — a comprehensive work with the child. According to Wolska-Długosz (2007, 645), therapy is a process of organizing educational-therapeutic situations planned according to diagnosis, influencing the child primarily through pedagogical methods and means. According to Skałbania and Gretkowski (2018,12), therapy is understood as supporting the child's psychomotor and emotional development, correcting developmental delays and disorders. If psychomotor functions are not improved, there is a risk of worsening deficits.

Children with Down syndrome especially require motor improvement and manual stimulation. The therapist should consider several recommendations to enhance the effectiveness of the intervention. Work on balance, postural control, movement planning, and precision is needed. Exercises reinforcing body schema knowledge and self-care activities are expected. Manual tasks should be preceded by providing the child with a large dose of proprioceptive stimuli (Jankowska 2019, 300).

Given the multitude of defects accompanying Down syndrome, systematic repetition of individual exercises, provoking questions, and discussing new information in various ways is essential. Memory processes should be stimulated not only during educational or therapeutic activities at school but also at home. Therefore, from the first days after the child's birth, parents should receive specialist support and learn proper therapeutic work methods, especially speech stimulation aimed at preparing the articulatory apparatus (Kuśnierz and Orłowska-Popek 2019, 352).

In working with a child with Down syndrome, multisensory psychomotor and social stimulation and association methods are particularly recommended (Jędrzejowska 2017, 37). Unquestionable therapeutic values have methods such as: Veronica Sherborne's Developmental Movement, Marianna and Christopher Knill's Activity Program, Marta Bogdanowicz's Good Start Program (Łoś and Wrońska 2014, 212-214). To stimulate the oral-facial area, the Castillo Morales method is used in working with a child with Down syndrome. Kinesiotaping is gaining increasing popularity as a solution supporting and maintaining the work and function of the muscle area subjected to taping (Dubiel-Zielińska and Zieliński 2017, 175). Sensory integration, especially linear vestibular system stimulation, has fundamental importance for the development of a child with Down syndrome (due to the hypotonia present in this group). Determining the optimal level of tolerance for each child in terms of the time dimension of activities, speed of movements, and postures developing balance reactions is required (Uyanik and Kayihan 2010).

Arranging situations where children can choose activities is valuable, making them more motivated. Interventions should be based on positive reinforcement (Jankowska 2017, 299). Children with Down syndrome learn most easily through imitation (Właźnik 2019, 48).

According to Żyta (2016, 278), effective learning strategies for children with Down syndrome include using visual support (photos, pictograms), teaching aids, aids (e.g., calculators), and picture-word instruction for taught skills. Children with Down syndrome better remember information provided through different channels (Zasępa 2003a, 158).

Sandy Alton (Żyta 2011, 46-47) developed several guidelines for teaching children with Down syndrome. Due to hypotonia, she recommends: activities strengthening hand and finger dexterity,

occupational therapy, supporting independence in self-care activities, and physical education exercises. The author sees the necessity of supporting speech with visual elements and using printed words to aid language and speech development. She emphasizes the effectiveness of supporting the child in using language in social situations by: a) encouraging loud statements in class, b) using a diary to record experiences; c) creating opportunities for interaction with other children without adult involvement. Alton advocates for exercises related to classifying objects, pictures, and using memory games. The author highlights the importance of breaking activities into short segments and switching to a different activity when the child shows signs of fatigue. Daily attention to the strengths of pupils with Down syndrome helps increase their self-awareness of having abilities, positively affecting their self-esteem (Popowska 2020, 387).

In the process of mastering reading and writing skills by pupils with Down syndrome, the role of strong motivation and the application of an appropriate teaching method is emphasized. Grzybowska (2014, 187) provides arguments for considering global methods in the education of children with Down syndrome because: 1) visual functions, compared to auditory ones, are better developed in them, and 2) global reading promotes better comprehension. This is important as most pupils with Down syndrome do not understand what they read (Brynard 2014, 1889). If learning to read produces little effect, teaching children “functional reading,” such as using a phone, is worthwhile. If “functional reading” is also impossible to master, children should be taught to recognize basic signs (e.g., the word “PHARMACY”) (Właźnik 2019, 48).

Successful rehabilitation involves actions that engage pupils, strengthen the need for self-realization, and create conditions for increasing self-esteem (Głodkowska 2014, 90). Supporting pupils with Down syndrome should be combined with providing them with conditions to: 1) communicate on the basis of individually selected communication systems; 2) make decisions in various areas; 3) communicate their choices; 4) participate in social life, have a say in matters concerning themselves and other people (Żyta 2016, 278).

Comprehensive therapeutic intervention places particular importance on parents, especially the impact of their psychological well-being on the emotional development of the child with Down

syndrome. Therefore, ensuring parents receive appropriate assistance and counseling should result in proper problem-solving, which will, in turn, affect the mental health of their child (Danielewicz 2011, 76).

3. SPECIAL EDUCATION FOR PUPILS WITH DOWN SYNDROME

In Poland, children with Down syndrome are covered by special education within inclusive, integrative, and special education systems. Ultimately, the choice of special education form is made by parents. Choosing the appropriate school (kindergarten) is usually not easy for them. Some pupils with Down syndrome attend special schools. These are usually pupils with moderate, rarely severe intellectual disabilities. These pupils follow a different curriculum than their able-bodied (or with mild intellectual disability) peers.

Integrative education, as an intermediate form of education, fills the gap between mainstream and special schooling (Gajdzica 2014, 57). Currently, it is one of the most popular forms of non-segregated education for pupils with disabilities in our country. However, Grzyb (2013, 32) signals the disappointment with integrative education expressed by many parents of disabled children. Reasons for their dissatisfaction include programmatic and organizational flaws, applied methods, and educational outcomes. Integrative efforts often lead to prejudices, reinforce negative stereotypes, and become sources of social exclusion.

In the education of pupils with Down syndrome, the importance of developing inclusive schools is emphasized. Inclusive education is currently one of the increasingly applied forms of education for children with Down syndrome (Żyta and Ćwirynkało 2014, 186). As Chrzanowska (2014, 112) notes: “The path to full inclusion seems to be the only right direction in education.” However, the author simultaneously highlights the “wishful” assumptions of inclusion, namely: 1) as a society, we are ready for inclusion, 2) we have a qualified staff, 3) the educational outcomes of inclusive education for disabled pupils will be better than in other forms.

Inclusive education will be implemented if teachers support its idea (Mudło-Głagolska 2021, 264). It is important for them to believe in the success that children with Down syndrome can achieve in a classroom group. It turns out that the way and frequency with which a teacher reprimands, praises, or encourages a child with Down syndrome affects the type of relationship that will be established between the disabled pupil and their classmates. Therefore, it is necessary to develop inclusive programs that address the issue of interaction between the teacher and pupils in the classroom (Carbone 2023).

An obvious expression of parents' concern for the effective inclusion of a child with Down syndrome into mainstream school will be taking care of building proper relationships with peers (Brynard 2014, 1895). Sobolewska (2002, 203), the mother of a girl with Down syndrome, notes: "The biggest worry is the lack of true partnership in contacts with other children." This problem can result from the child experiencing a lack of acceptance. Such circumstances make parents refrain from communicating sensitive issues about their child, as they may reinforce negative perceptions, and thus inappropriate behavior from peers and teachers towards them (Lipińska-Lokś 2014, 238).

Certainly, every form of education has both advantages and disadvantages. What is optimal for one pupil and their parents may be unacceptable for another. Therefore, it is worth reflecting on this issue and identifying essential elements for the effective functioning of pupils with Down syndrome in school.

Żyta (2016, 227) signals the positives of learning for pupils with Down syndrome in mainstream schools, such as improving language and speech, which positively affects their social and emotional functioning level. The author also sees several other positive effects of children's stay in mainstream schools: better results in reading, writing, and counting skills, and general knowledge.

Extremely interesting data was provided by the results of research conducted in the UK by Johnson (Żyta 2011, 47). The author found that parents of pupils with Down syndrome attending mainstream schools indicate many advantages of this form of education: progress in school skills, better social integration, better speech and language development, greater independence. On the other hand, parents included among the disadvantages: a lack of understanding and appropriate knowledge among some school staff, difficulty obtaining support at subsequent educational stages, too difficult homework, often a lack of additional speech therapy or physiotherapy classes, and a lack of training for teachers. The

inclusion and participation of pupils with Down syndrome in the classroom are hampered by their language and communication problems, which affect all aspects of learning and development, including access to the curriculum, socio-emotional development, and behavior (Boundy 2023).

In other studies, the achievements of teenagers with Down syndrome learning throughout their schooling in mainstream classes and special schools were compared. Regardless of the type of facility, all pupils made progress in speech, language, writing and reading skills, socialization, daily skills, and behavior. Only communication improved solely for pupils in inclusive schools. No significant differences were found in daily skills or socialization. Pupils in mainstream schools had fewer behavioral problems. The only area where special school pupils achieved better results was interpersonal relationships. It was shown that young people in special schools had more opportunities to form friendships with peers of similar functioning and interests. The research indicates that education in mainstream schools does not contribute to better social integration. Daily contact with able-bodied peers at home and school did not result in forming friendships. Teenagers with Down syndrome learning in mainstream schools also had fewer friends among disabled people, were less likely to have crushes, and participated less independently in social life (Żyta 2011, 48).

Ćwirynkało and Żyta (2014, 193-196) found through research that, for some mothers of children with Down syndrome, the primary determinant for choosing a school was its proximity and the belief in the right of disabled children to be educated among healthy peers. Respondents addressed the problem of acceptance of children with Down syndrome by their healthy peers. They see it as the main obstacle to non-segregated education. They fear their child's isolation by able-bodied peers and their poorer well-being due to "always being the worst" in class. Another problem with non-segregated education for a child with a disability may be the burden of responsibilities on the child and the parents themselves. The surveyed mothers expressed favorable opinions about special schools. In their opinion, these facilities offer an educational program tailored to the capabilities of disabled children.

Jędrzejowska (2022, 115), based on research in a kindergarten, found that children with Down syndrome were not attractive partners for their peers, were not considered in various activities, and communication from able-bodied children to those with Down syndrome was exceptionally rare.

According to Kruk-Lasocka (2017, 132), currently, in Poland, the introduction of full-scale inclusive education is not possible. Roźnowska (2007, 82) believes that only 5-10% of children with Down syndrome are suitable for learning in a normal school. Therefore, integrative education is being implemented.

According to Bełza and Prysak (2014, 30), there is a fear that education for a disabled person may be an area of daily functioning where they experience humiliation. The multitude of actions and apparent proposals means that a person with a disability cannot meet the challenges, thus not fully and freely benefiting from various aspects of social life. The authors note that inclusive efforts, aimed at normalizing the lives of disabled people, “are, in reality, further apparent actions with often the opposite effect.” Jędrzejowska (2022, 115) expresses the need to organize groups of pupils with homogeneous disorders (children with Down syndrome alongside peers similar to themselves). The belief in mutual similarity brings people closer, builds a sense of security, and conditions the development of a person in all aspects (Jędrzejowska 2022, 115).

Integrative and inclusive education should not be seen as a panacea for everything. In the name of integration, good special schools are sometimes closed down. However, despite building an atmosphere of understanding and well-being among pupils, even such schools do not protect against stereotypes and do not allow pupils to forget their differences (Bełza and Prysak 2013, 31). According to Żyta (2016, 277-288), special schools offer better conditions for peer contact. However, the author notes that children with Down syndrome, due to the characteristics of the chromosomal disorder, have a chance for success in inclusive education because they present a higher level of social functioning than, for example, their peers with intellectual disabilities (Żyta 2011, 49).

Therefore, it is worth quoting Roźnowska (2007, 119): “Different schools are needed for different children so that each can find a place for optimal, comprehensive development.” It is essential that a new quality in education is expressed by moving away from a focus on knowledge towards the self-realization of the whole person. Working with children with Down syndrome should aim towards active participation in social life and achieving possible independence in every area of functioning. The priority task of education and rehabilitation is to develop life skills and instill a sense of agency, building the

pupil's self-confidence. This is an essential foundation on which a satisfying life of an adult person is built. This requires systematic and often challenging work from teachers, specialists, and parents, guided by a reliable, thoughtful, and interdisciplinary diagnosis, considering the needs, interests, and personal development of the child with Down syndrome (Maciąg 2022, 62).

CONCLUSION

Each individual with Down syndrome undergoes a developmental process that is disharmonious. Fulfilling the role of a pupil is a challenging task for a child with Down syndrome, their parents, and teachers. Supportive and accepting attitudes, mainly presented by the home and school environment, based on a thorough understanding of the pupil and the accompanying disorder, are crucial. Work with the pupil should constitute a maximally adapted proposal for improving and stimulating development. The aspects of working with a child with Down syndrome presented (within the article's limits) can be seen as a base shaping and guiding efforts undertaken at subsequent stages of their development.

Krauze (2009, 14) made an accurate observation, highlighting the need to find a compromise between revalidation and normalcy in the life of a disabled person. Even the best rehabilitation programs, conducive to building competencies in children with Down syndrome, do not guarantee optimal conditions for development. Much more important is the involvement of able-bodied individuals in matters concerning their integration. Development is possible, as Jędrzejowska (2015, 344) argues, only with another person.

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