



“Life Goes On”¹ – everyday life of children with Down syndrome and their families – selected aspects

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The birth of a child is a major event in family life, which makes parents take on an important role in their lives, characterised by new tasks, chief among which are the care and upbringing of their offspring. Unfortunately, in many families, some factors

¹ “Life Goes On” is not only a phrase that refers to the course of life of children with Down syndrome and their families – something that is often reflected in the statements of parents participating in the study – but also the title of a TV series, which aired in Polish television at the turn of the 1980s and 1990s, which tells the story of the Thatcher family, often brought up by parents. Corky Thatcher is a teenager with Down syndrome. The series enjoyed great popularity and without a shade of doubt it increased public awareness of Down syndrome, functioning and problems of people with this disease. Unfortunately, it also led to children groups adopting the term “corky” as an insult used to describe someone who, generally speaking, understands and knows less than others and who is unable to deal with situations, which are not necessarily considered difficult. Chris Burke himself, who depicted Corky in the show, has become a symbol of people with Down syndrome, the ability to function in a society and concern for the rights of people with disabilities. Today’s television reality mostly creates the image of people with Down syndrome through Maciek’s role in *Klan* aired on Polish Television and the *Down the Road. Zespół w trasie* show on TTV.

emerge that may affect their functioning, disrupt the course of family life, and leave a permanent mark on the family's history. Such a situation can be difficult for many – and many parents find the process of accepting a child with a disability (Down syndrome) and themselves as parents of a child with Down syndrome a long and arduous journey, since taking care of a child, upbringing and supporting their development is an issue in itself, but also a challenge for parents. In many cases, both the child and their parents need support in their daily life, ensuring their high quality of life.

The objective of this study is to outline the functioning of families of children with Down syndrome. Due to the complex nature of the issue at hand, only selected aspects of the functioning of families were diagnosed, showcasing the changes in the family life and its functioning as a result of the birth of children with Down syndrome. The study was based on qualitative methodologies, by analysing individual cases using interview technique and interview dispositions. The research group comprised 10 families of children with intellectual disabilities, and the interviewed group was made up of 10 mothers and 3 fathers in Zielona Góra.

KEY WORDS: Down syndrome, child, family, everyday life

Introduction

The course of human life is determined by numerous and varied situations. Some are expected or even planned, while others emerge unexpectedly. The latter applies to diseases and health problems, which can often be difficult to make sense of. However, they do emerge and leave their marks on people's lives, causing changes for good. This is particularly true in the case of a birth of a child with a disability. The parents of a child face an enormous challenge of accepting the child, accepting themselves as parents of a child with a disability and adapting to a new life situation. Every day of this "new life" will be marked by the child's disability and its consequences, impacting the functioning of the child and the family as a whole.

"Normal life" will seem unattainable and everyday life in such a family will never be associated with the ordinary world of personal and family life² with a fixed order and aspects that form

² M. Dudzikowa, M. Czerepaniak-Walczak, "Codzienność w szkole. Szkoła w codzienności", [in:] *Wychowanie. Pojęcia – Procesy – Konteksty*, M. Dudzikowa,

a description of the everyday world³, with the commonness, ordinariness, or even monotony.⁴ In those cases, parents lose their sense of security, as the element of stability, lack of trouble and predictability of their everyday life disappears. They perceive their situation as uncommon – as an event that breaks down the reality of everyday life, usually independent of the individual’s actions, yet affecting their live.⁵

This particular feeling experienced by parents is amplified by the nature of their child’s disability – genetically conditioned Down syndrome. In spite of knowing the direct cause of the issue, parents do not understand why it occurred. What is more, they are aware that people with Down syndrome – although visible in contemporary society – still evoke strong reactions in people and that they are exposed to “unhealthy” interest, as well as oft-negative social attitudes. The reason for this is a lack of proper knowledge of Down syndrome, people with Down syndrome, their characteristics and consequently their abilities and limitations. The emotions evoked by people with disabilities in the public eye also play an important role. People are often afraid of things that they do not know or understand, and unfortunately this is the case with Down syndrome. The majority of people are not well-acquainted with persons with

M. Czerepaniak-Walczak (eds.), vol. 5, Gdańskie Wydawnictwa Psychologiczne, Gdańsk 2010.

³ M. Kabat, “(Nie) zwykła codzienność nauczyciela – kilka refleksji z teorii i badań”, [in:] *Codziennosc szkoły. Nauczyciel*, J.M. Łukasik, I. Nowosad, M.J. Szymański (eds.), Oficyna Wydawnicza “Impuls”, Kraków 2014.

⁴ H. Zgólkowa (ed.), *Praktyczny słownik współczesnej polszczyzny*. Wydawnictwo KURPISZ, Poznań 1996.

⁵ D. Mroczkowska, Ł. Rogowski, R. Skrobacki, “Codzienność niecodzienna/niecodzienność codzienna – spojrzenie na dylematy socjologii życia codziennego”, [in:] *Spółczesność i codzienność. W stronę nowej socjologii*, S. Rudnicki, J. Stypińska, K. Wojnicka (eds.), Wydawnictwo Akademickie i Profesjonalne, Warsaw 2009. Cf. J. Lipińska-Lokś, “Codzienność dziecka z niepełnosprawnością i jego rodziny – wybrane aspekty”, [in:] *Pedagogika specjalna. Nowe obszary teorii i praktyki*, T. Żółkowska, I. Ramik-Mażewska (eds.), Wydawnictwo Uniwersytetu Szczecińskiego, Szczecin 2017.

Down syndrome, and the only image they know is based on the media (usually biased and one-sided).

In order to alleviate the situation and improve the functioning of people with disabilities and their families, it seems necessary to provide social support, also by raising social awareness in the area of developmental disorders such as Down syndrome, showing the characteristics and functioning of people with Down syndrome, presenting the everyday life of families of children with Down syndrome, which is typical and as ordinary as possible, despite being marked with their child's disability.

This paper constitutes an attempt to outline the everyday life of children with Down syndrome and their families, to present the selected aspects of Down syndrome itself and people living in contact with the disease.

Down syndrome and people with Down syndrome – selected aspects

Down syndrome⁶ has been a part of our society for centuries, but despite this, knowledge about this disease is far from complete. People with Down syndrome arouse interest (which – in many cases – can be also unhealthy), as well as a lot of fears resulting mainly from the lack of reliable knowledge about the disorder itself and the functioning of people with this syndrome. The fact that people with Down syndrome are often perceived as different, alien and inferior is not without its significance. Only by raising public awareness in the area of genetic disorders will it be possible to bring closer the

⁶ The term “syndrome” which is used in the nomenclature of diseases, concerns set of similar morphological and clinical characteristics, which occur in people with a similarly altered genetic record. People with Down syndrome undoubtedly have common features of appearance and are characterised by similar behaviour. However, it is important to keep in mind the individual characteristics of each of these people due to the traits inherited from their parents and their personal features. The name Down syndrome has been in use since 1961.

issue of diseases and the functioning of people affected by them, as well as to shape the desired social attitudes and thus improve the quality of life of people with Down syndrome. Therefore, it seems valid to present a compendium concerning Down syndrome itself as well as people who live with this syndrome. Of course, due to the framework of this study, only selected aspects will be outlined.

In the past, Down syndrome was referred to as mongolism. Many other terms were also used, including mongoloidism, Mongolian imbecility, Kalmyk idiocy and mongoloid idiocy. It is also known as Down disease, congenital acromicria, trisomy 21, trisomy G. Some sources also describe people with this syndrome as underdeveloped.⁷

This former name – mongolism – is owed to the first description of 12 characteristics of people, whom an English doctor John Langdon Haydon Down found interesting. In his deliberations, Down sought a connection between the people he studied and the people of the East – the Mongols, precisely because of their specific physical characteristics, in particular their slanting eyes. It is also worth pointing out the fact that the people examined at that time and the Mongolian race of different ethnicity were put on the lower rung of the ladder of human evolution. Of course, the two presented aspects indicate errors of reasoning of the researcher(s) in the past. Changes in the views on the essence of Down syndrome resulted from scientific discoveries, concerning mostly genetics. In 1932, Petrus Johannes Waardenburg put forward the hypothesis that Down syndrome is the result of a chromosome mutation. It was confirmed in 1959 by the French geneticist Jérôme Lejeune (together with his doctoral student M. Gutier) as they discovered that the disease is caused by an additional chromosome in pair 21, hence the term trisomy 21 (tri – "three", soma – "body")⁸, This additional chromosome, which

⁷ A. Maciarz, *Mały Leksykon Pedagoga Specjalnego*, Oficyna Wydawnicza "Impuls", Kraków 2005. Cf. A. Jędrzejowska, *Wspomaganie rozwoju społecznego dziecka z zespołem Downa w przedszkolnej grupie rówieśniczej*, Oficyna Wydawnicza ATUT – Wrocławskie Wydawnictwo Oświatowe, Wrocław 2017.

⁸ Cf. A. Jędrzejowska, *Wspomaganie rozwoju społecznego dziecka z zespołem Downa w przedszkolnej grupie rówieśniczej*, Oficyna Wydawnicza ATUT – Wrocławskie Wydawnictwo Oświatowe, Wrocław 2017.

results in a cell with this mutation having 47 chromosomes instead of standard 46, is a correct and valid chromosome, which can come from both mother and father. It may appear at different times of chromosome division, hence the three karyotypes causing Down syndrome can be distinguished:

- a) simple trisomy 21, which occurs when an additional 21 chromosome is present in the sperm or egg cell or appears during the first division of the cell, causing each newly formed cell to have a trisomy in the 21st chromosome pair. Studies have shown that this form of disorder is diagnosed in 90–95% of all cases of Down syndrome;
- b) Mosaic form of trisomy 21, when normal cells are present in the body alongside those with trisomy. This situation may occur in the case of a nondisjunction of chromosomes in pair 21 in the second division or subsequent divisions of a fertilized egg, as well as in the cases where an additional chromosome is eliminated in one of the subsequent divisions of a fertilised original trisomic egg. The percentage share of trisomic cells may vary, depending on which of the subsequent divisions of the fertilised egg did not result in the disjunction of the chromosomes of pair 21. Mosaic trisomy 21 may result in a milder form of the syndrome, visible in less-pronounced or less-numerous physical features of Down syndrome, slightly better intellectual performance and better speech development compared to children with simple trisomy 21. However, these differences are hardly significant – combined with the fact that the mosaic form of trisomy 21 is relatively rare (2–5% of children with Down syndrome) does not allow us to point out a clear link between the form of Down syndrome and the level of developmental capabilities of those affected by it.
- c) Trisomy 21 with translocation, when an additional chromosome of pair 21 is connected by its longer arm to the chromosome of another pair, usually 13, 14 or 15. This specific translocation of the additional chromosome 21 affects 3–5% of children and adults with Down syndrome. Despite the relative rarity of this

form of Down syndrome, it is particularly noteworthy due to the fact that it is the only form of this disorder that can be inherited, familial and increases the risk of recurrence in the family. Inheriting the disease occurs when one of the parents is the so-called translocation carrier, which means that they do have the correct amount of genetic material and two chromosomes 21, but one of them is attached to the chromosome in another pair. Despite having this atypical karyotype, such a person does not exhibit any clinical features of the Down syndrome. However, it may (in one case out of 100) result in trisomy 21 with translocation in the offspring when the carrier chromosomes, both the translocated one and the second chromosome 21, find their way to the egg or sperm, causing the fertilised egg to have three chromosomes 21 – two standard ones and one translocated one. Studies have shown that trisomy 21 with translocation is more prevalent in children born to parents under 30 years of age and that the risk of giving birth to a child with Down syndrome is lower if the father is the translocation carrier.⁹

Down syndrome is a well-known genetic syndrome. People with Down syndrome are the most numerous group of people with developmental disorders, the causes of which need to be sought in genetics and damaged genetic code. About 60,000 of people with Down syndrome live in Poland alone. The frequency of live births of children with Down syndrome is on average 1 in 600–700, with 20% among stillbirths. The ratio of men with Down syndrome to women with trisomy 21 is 3 : 2.¹⁰

⁹ E.M. Minczakiewicz, *Jak pomóc w rozwoju dziecka z zespołem Downa. Poradnik dla rodziców i wychowawców*, Wydawnictwo Naukowe Akademii Pedagogicznej, Kraków, 2001. Cf. T. Kaczan, R. Śmigiel, “Wspomaganie rozwoju dzieci z zespołem Downa”, [in:] *Wczesna interwencja i wspomaganie rozwoju dzieci z chorobami genetycznymi*, T. Kaczan, R. Śmigiel (eds.), Oficyna Wydawnicza “Impuls”, Kraków 2012. Cf. C. Cunningham, *Dzieci z zespołem Downa. Poradnik dla rodziców*, Wydawnictwa Szkolne i Pedagogiczne, Warszawa 1994.

¹⁰ A. Jędrzejowska, *Wspomaganie rozwoju społecznego dziecka z zespołem Downa w przedszkolnej grupie rówieśniczej*, Oficyna Wydawnicza ATUT – Wrocławskie Wydawnictwo Oświatowe, Wrocław 2017.

The birth of a child with Down syndrome need not be linked to parents' race or skin colour, the climate in which they live, their culture or environmental conditions. However, the risk of giving birth to a child with Down syndrome increases with the age of the parents, in particular the mother (in the case of a 20-year-old mother the risk is 1:2000, 30-year-old – 1:1000, 35-year-old – 1:500, 40-year-old – 1:80, 45-year-old – 1:17; in mothers over 46 years of age there is a decrease in the incidence of Down syndrome in their children referred to as levelling off, which is due to the inability of older mothers to keep a pregnancy), as well as with the age of the father (after 55 years of age).

Modern dysmorphological taxonomy clearly establishes Down syndrome as a malformation syndrome, indicating that the physical and mental anomalies are caused by organ/tissue morphogenesis disorders during incomplete embryogenesis.¹¹

Down syndrome is a result of an occurrence of an additional chromosome in pair 21. This chromosome holds many genes taking part in important processes linked to the development and functioning of the organism.

Down syndrome is a congenital syndrome of symptoms and characteristics that can be diagnosed in a child at birth (fully confirmed by a cytogenetic exam which analyses the karyotype of a person). In many cases, the way the face looks enables a proper diagnosis of the disease. The most characteristic features, also referred to as cardinal, in Down syndrome are: brachycephaly and moderate microcephalia, lack of hair, flat face profile, slanted eyelids, epicanthal folds, Brushfield spots (light spots on the iris), a small nose with a flat base and a wide back, dysplastic ears, protruding and wrinkled tongue, loose skin on the neck, dysplastic

T. Kaczan, R. Śmigiel, "Wspomaganie rozwoju dzieci z zespołem Downa", [in:] *Wczesna interwencja i wspomaganie rozwoju dzieci z chorobami genetycznymi*, T. Kaczan, R. Śmigiel (eds.), Oficyna Wydawnicza "Impuls", Kraków 2012.

¹¹ A. Jędrzejowska, *Wspomaganie rozwoju społecznego dziecka z zespołem Downa w przedszkolnej grupie rówieśniczej*, Oficyna Wydawnicza ATUT – Wrocławskie Wydawnictwo Oświatowe, Wrocław 2017.

middle phalanx of the fifth finger, transverse groove on the palm, dysplastic pelvis. “Most babies at birth have weak muscle tension (hypotonia) and seem limp. They also have limp joints, which results in a generalised limpness of the body”.¹²

“Clinical observations of the symptoms of Down syndrome led to the distinction of two types of this disease – thyroid form (based on the symptoms of hypothyroidism) and pituitary gland form”.¹³ Among the most important features of the Down syndrome associated with thyroid disorders are stunted growth, a massive, thick-boned body, short and misshapen limbs, hard, yellowish skin, straw hair, large and wrinkled tongue, rough, hoarse voice, mild disposition in contact with others, prevalent apathy. The disorder associated with pituitary gland is characterised by lower body weight, thin subcutaneous tissue, leaner body, slender limbs, thin hair with a tendency to alopecia, rough, rather high and penetrating voice, as well as destructive and undesirable behaviours in contacts with other people.¹⁴

Many children with Down syndrome also experience numerous additional congenital defects, most often heart and digestive system disorders (duodenal atresia, Hirschsprung’s disease, oesophageal atresia), as well as urinary and skeletal system disorders. Children with Down syndrome are much more likely to develop various health problems, autoimmune diseases (such as thyroid diseases), epilepsy, cataracts.

Down syndrome is always accompanied by intellectual disabilities. “Most children with Down syndrome have mild to moderate

¹² C. Cunningham, *Dzieci z zespołem Downa. Poradnik dla rodziców*, Wydawnictwa Szkolne i Pedagogiczne, Warsaw, 1994, p. 109. Cf. E.M. Minczakiewicz, *Jak pomóc w rozwoju dziecka z zespołem Downa. Poradnik dla rodziców i wychowawców*, Wydawnictwo Naukowe Akademii Pedagogicznej, Kraków 2001.

¹³ A. Jędrzejowska, *Wspomaganie rozwoju społecznego dziecka z zespołem Downa w przedszkolnej grupie rówieśniczej*, Oficyna Wydawnicza ATUT – Wrocławskie Wydawnictwo Oświatowe, Wrocław 2017.

¹⁴ C. Cunningham, *Dzieci z zespołem Downa. Poradnik dla rodziców*, Wydawnictwa Szkolne i Pedagogiczne, Warszawa 1994.

intellectual disabilities. Some children experience more issues, while others have an almost normal level of intelligence. However, there is a constant decrease in IQ with age".¹⁵ It is worth adding that "the intellectual development of children with Down syndrome is individually variable and may vary depending on the support and acceptance of family and loved ones, appropriate psychological and pedagogical support, as well as the possibility of contact with peers, but it is always delayed, which is a constant characteristic of people with Down syndrome".¹⁶

People with Down syndrome also exhibit varying deviations from the norm in terms of strength, mobility and balance of neurodynamic processes, as well as the resulting behaviours. The characteristic features of these issues made it possible to distinguish three groups of children with intellectual disabilities that characterise Down syndrome, namely:

- a) erethic children, also referred to as unbalanced and unstable, characterised by the over-abundance of arousal processes, resulting in: excessive mobility, emotional lability, irritability, impulsivity, affectivity, problems with focus and perseverance;
- b) apathetic children, who – as a result of the predominance of nervous processes – are characterised by poor motivation, lack of self-confidence, shyness, passivity, with a simultaneous slow reaction time, as well as slow movements;
- c) relatively balanced children, in the case of whom – as the name suggests – there are no major behavioural problems, although one particularly noteworthy one is the inertia of nervous processes.¹⁷

¹⁵ L. Sadowska, A. Gruna-Ożarowska, M. Myslek-Prucnal, "Medyczne podstawy zaburzeń struktury i funkcji u dzieci z zespołem Downa", [in:] *Wspomaganie rozwoju dzieci z zespołem Downa – teoria i praktyka*, ed. B. Kaczmarek, Oficyna Wydawnicza "Impuls" Kraków 2008.

¹⁶ T. Kaczan, R. Śmigiel, "Wspomaganie rozwoju dzieci z zespołem Downa", [in:] *Wczesna interwencja i wspomaganie rozwoju dzieci z chorobami genetycznymi*, T. Kaczan, R. Śmigiel (eds.), Oficyna Wydawnicza "Impuls", Kraków 2012, p. 38.

¹⁷ A. Maciarz, *Wybrane zagadnienia pedagogiki specjalnej. Materiały dla studentów kierunków pedagogicznych*, Wydawnictwo WSP w Zielonej Górze, Zielona Góra 1989.

In addition to the characteristics of people with Down syndrome, it is worth noting the life expectancy of patients with this disease. Much depends on the comorbidities associated with Down syndrome, as well as the rehabilitation and treatment. “Currently, people with Down syndrome (...) live to see the age of 60–70 years. However, they age faster and develop Alzheimer’s disease more often”.¹⁸

The features of the children outlined in this paper enable us to see the general category of people with Down syndrome as particularly diverse. In spite of the common characteristics resulting from trisomy 21, these persons have both individual characteristics resulting from being the children of their parents and from living in the given environmental conditions.

“The Down syndrome label gives rise to the tendency to notice mainly flaws and deviations from the norm; however, apart from the areas concerning dysfunctions or disabilities, they are also capable of functioning normally in a variety of areas”.¹⁹ Their life goes on one day at a time, although the everyday life of their families is marked by the issues connected with experiencing Down syndrome.

Methodological basis of author’s own research

The study was based on qualitative methodologies, by analysing individual cases using interview technique and interview dispositions.

Its aim was to diagnose the functioning and everyday life of children with Down syndrome and their families.

Due to the extensive nature of the issues, only selected aspects of this everyday life were presented.

¹⁸ T. Kaczan, R. Śmigiel, “Wspomaganie rozwoju dzieci z zespołem Downa”, [in:] *Wczesna interwencja i wspomaganie rozwoju dzieci z chorobami genetycznymi*, T. Kaczan, R. Śmigiel (eds.), Oficyna Wydawnicza “Impuls”, Kraków 2012, p. 38. Cf. C. Cunningham, *Dzieci z zespołem Downa. Poradnik dla rodziców*, Wydawnictwa Szkolne i Pedagogiczne, Warszawa 1994.

¹⁹ M. Kościelska, *Dzieci z zespołem Downa, One są wśród nas*, CMPPP MEN, Warszawa, pp. 7–8.

The study problem posed was formulated as a question: What characterises the everyday life of a child with Down syndrome? Such a way to formulate this enabled the identification of specific issues, resulting in an accurate diagnosis of the problem at hand. These issues concerned the subsequent questions of how parents received information about their child's Down syndrome and how they reacted to it. The subsequent detailed and more specific issues were aimed at diagnosing the changes in the functioning of the family after the birth of a child with Down syndrome (changes in the financial status and living situation of the family, career changes in the case of the parents, family relations, social situation of the family) and the impact of the child's disability on the everyday life of the child and their family, the daily rhythm of which is determined by taking care of the child, as well as their upbringing, education and therapy.

One should note that the issues raised concerned the life of the child and their family from the date of birth to the present day.

The study group consisted of parents of 10 children with Down syndrome (10 mothers and 3 fathers), who made up a diverse group, characterised by varying age, marital status, education, careers, number of children and place of residence (Zielona Góra and nearby villages). Also the group of children of the parents participating in the study was diverse according to their gender, age, image of Down syndrome, degree of intellectual disability and form of education.

The presented study results constitute a brief fragment of a study into the functioning of a child with disabilities and their families. The study material was collected over the years during the author's professional activity in the local community, as well as in associations working to support children with disabilities and their families.

Living with the Down syndrome – study results

The lives of parents of children with Down syndrome are determined by issues related to caring, educating, upbringing and supporting their children, who – depending on their age – need these

processes to varying degrees. The birth of a child results in an eruption of diagnoses, according to Hania's mother: "diagnosis after diagnosis – it was so tiring and ... we did not understand it completely. (...) we knew that it was Down's... What was it all for? (...) today, after these 5 years, I look at it differently – I know that Down syndrome is one thing, but the condition of the child, the impact of the disease its effects are something else (...) at that time, we were tired, and so was our child, but today I know how important it was for the child and for us too, because it showed us what to do next, how to live". The diagnosis aspect is present in all interviews with parents, who pay particular attention to the moment when they were informed about Down syndrome ("it was a nightmare (...) I thought I was going to die when I heard it, my life was over (...) it was a shock". Their memories are marked with both disbelief and fear due to the thought of having to live with their child's Down syndrome, as well as the fear of other people reacting to the news of this "misfortune", "tragedy", or "punishment". "The doctor kept talking and I listened, but... it was like hearing news about someone else – it could not have been about me, I could not have had a baby like that, because why would I...? I was not old, I was healthy"; "Oh my God – it is over, a tragedy, we are doomed for life"; "What did I do that God punished me so hard?"; "How will I tell my husband about it, (...) how will people look at us?" The parents' statements paint a picture of a comprehensive diagnosis of children with Down syndrome, not only including the genetic tests confirming Down syndrome and its karyotype, but also a number of diagnostic tests to establish the child's condition, the state of their organs, capabilities and developmental limitations. At the stage of the children's diagnosis, parents' experiences varied depending on the availability of proper diagnosis in their immediate environment, time of waiting for the diagnosis, manner in which they were informed about the results and consequences. The latter two aspects that were signalled as an issue: "The doctor said that ant that was it. We had so many questions, and we were left alone with them (...) What does this and that mean?, (...) What do we do next, where do we go for help?"

However, many statements outline good medical practice: "We were terrified, but the doctor explained everything, she directed us and our child, (...) she was so calm and reassured us, she said that it would be difficult, but we will manage, because these days you can live almost a normal life with Down's (...) Today I know that it is 'almost' is really something that matters, and I can also look to the future with hope, like the doctor".

"Diagnosis is one thing, but life goes on..." - This statement by a parent of a 13-year-old boy with Down syndrome shows the course of life - the fact that life simply goes on.

Every small child needs care, and a child with a disability usually requires special care. This fact was also pointed out by parents, who received the diagnosis: "I took care of Bartek like I did with Olcia before, but everything was different in this case, he needed more attention, (...) I was afraid that his heart would act up, (...) that there would be breathing problems (...), I was more vigilant, I conscientiously followed all the recommendations (...). I was responsible for my son's life". Another mother pointed out her enormous fatigue bordering on physical and mental exhaustion while caring for her child, especially in the first months of their life. Another one voiced her helplessness, lack care skills, as well as need for support by her loved ones (husband, mother), but also gratitude to the health care providers (community nurse, paediatrician) for the selfless help and going the extra mile.

This help also concerned the therapy for a child with Down syndrome. The diagnosis determined the way of thinking about the needs of the child, about the care, as well as stimulating and supporting their growth and the much-needed therapeutic interventions. The experience of paediatricians allows to guide parents in this area: "The doctor told me about my child's problems and how to help them (...) thanks to them, I learned about this method..."; "At the clinic, I got referred to a physiotherapist, (...) she was good, she did a lot for Hania (...)".

The interviews with parents show a diverse picture of therapy for children with Down syndrome. The most frequently mentioned

were: physical rehabilitation, intellectual development support, independence training, alternative and supportive communication, speech therapy, as well as specific methods of working with children, such as the Developmental Movement Method, equine-assisted therapy, art therapy, Knill method, Elements method. The level of knowledge of parents about specific methods varied. According to the parents, each of these interventions had clear effects – sometimes significant, sometimes not, but there was always hope for improvement of the child's functioning. Many parents pointed out their own great involvement in helping their child, many pointed out their fatigue and the feeling of discouragement with therapy due to unsatisfactory effects and reluctance of the child, many talked about their therapists. In this area, one of the particularly visible issues is the fact of different quality of therapist-parent cooperation, characterised by different opinions on the knowledge, skills and attitudes of therapists. What the parents have in common, however, is pointing out that the therapist was often the only person who "just listened (...) they often did not say anything, just let us talk (...), and then it was better". "The therapist taught us a lot, she told us how to exercise with our daughter (...) how to love her (...)"

Care and therapy constituted a significant part – but only a part – of the daily lives of children with Down syndrome and their parents. At a certain point, the issue of raising a child becomes more prominent, and this is also an area on which many parents tend to focus. These statements allow the author to distinguish a number of certain parent types:

- a) parents deliberately raising a 'special child' – those who either point out the fact that the family's upbringing functions have given way to the child's therapy, as well as those who turned upbringing into a part of their child's therapy or noted the need to carry out upbringing activities as part of the therapy;
- b) parents bringing up children with Down syndrome like other children in the family, while keeping in mind that each child is different and unique, and that this needs to be taken into account in the process of upbringing, the demands imposed on the child and the use of rewards and punishments;

- c) parents 'raising' a child with Down syndrome, who believe that not much can be done in terms of the upbringing and education of their child because Down syndrome has effectively reduced or even deprived their child of the opportunity to be raised and taught.

The diagnosis made it possible to learn the preferred style of raising children used by parents. It is worth noting that the parents participating in the survey exhibit significant diversity in this aspect. The survey saw one autocratic parent: "Partnership? You are joking, he does not understand anything, I have to (...) - it is obvious", who explains their attitude and actions with their child's developmental limitations. The other is an example of properly implementing a liberal upbringing, although the motivation of the parent to do so may raise some doubts: "I remember about her illness all the time (...) she suffers enough, (...) and I am somehow supposed to demand things and tell her to do something (...)? I know that she decides, (...) I no longer have the strength". Interestingly, in the case of another parent, the awareness of the child's developmental differences triggered a democratic upbringing style: "Disability or not, (...) but we decide on important and less important matters together, (...) we advise (...) we discuss a lot (...) We keep supporting them and we always will (...) even in adulthood (...)" This diversity should not come as a surprise, especially since the most common style is the mixed one.

The parents surveyed unanimously claim that the condition of their children has had a significant impact on their attitudes. Among the right parental attitudes, they value acceptance, cooperation, offering freedom, recognition of rights; they also declare that these attitudes are not alien to them, but they add that: "The extent of freedom I give depends on the age of the child, but above all on their abilities and limitations"; „I do my best to fully accept them we have already been there before, but when new situations emerge, I have problems with this acceptance and I think that it is because of this disability”; "We cooperate - of course, but sometimes it is me who decides and does things, because he cannot

cope". Speaking of inappropriate parental attitudes, the participating parents admit that they do appear, citing examples of rejecting the child, avoiding the child and their problems, making excessive demands on the child despite their limited capabilities, without taking into account their constraints and special needs. Interestingly, they themselves only admit to being overprotective of their children, especially in situations which are difficult for the child due to the disability they live with.

Finally, there is another important aspect to consider, which determines the everyday life of children with Down syndrome and their families – education. Children with Down syndrome, like any other, are subject to compulsory schooling obligation, which can be carried out in a number of ways in different facilities, depending on the health and development of the child. Children who were surveyed as part of the author's study carried out their compulsory schooling by attending special schools, integration classes or inclusive education facilities. Over the years, legal regulations have changed, and parents were more and more empowered in making decisions about their children's educational path; however, there have always been – and will probably always be – parents' dilemmas about their children's school: "I wondered for a long time about a school for her, (...) people advised me to enrol her in a special school, and I heard a lot about an integration class, because my neighbour's son went there – but he was only deaf, and my Anna had Down syndrome and an intellectual disability (...) She did not really do well in integration class, (...) so I moved her to the special school (...) she was doing better at school and she found friends, (...) no one laughed at her behind her back there". Another mother experienced something completely different, when it came to her daughter's school: "We could not have done better, the kids were great, (...) the teacher was amazing – she was a great person as well". Many parents paid attention to the competence of teachers concerning teaching children with problems and their personality traits, believing that these conditioned their children's school success and their satisfaction with the school and cooperation with

teachers. Parents also believe that this cooperation determines how much of the family's everyday life is devoted to school of their child. However, it seems that it is not the nature of the child's problem, but the very fact of its existence that determines the level of family involvement in the child's education.

The diagnosis also confirmed the impact of having a child with Down syndrome on the lives of parents and the whole family, which is visible in practically all spheres of family life, as indicated by specific statements of parents:

- Change in the family's financial situation: "(...) Obviously, bringing up a child costs money, but a child with a disability costs much more than that (...) my wife quit her job, and I picked up a second one (...) we were back to where we started, and where was the extra money for new needs? (...) We learned to cope"; "I was not aware that we had such a social support system (...) it is, but it is not always so obvious, (...) it takes a lot of work, (...) it is hard to ask, but..."; "That is just life - that is how it is and... it is OK";
- Change in the family's housing situation: "We have remodelled our lives, and we started by renovating the apartment (...), we needed to make it easier to move around, to bathe the child"; "It turned out that the apartment was too small(...) we sold our flat and our grandparents' apartments and bought a new big one for all of us (...) it was the idea of our in-laws (...) we will be grateful for their help until the end of our lives";
- Change in the professional situation of the parents (which is undoubtedly related to the change in the financial situation): "I knew I had to stay home, I was a mother and I would take care of him best (...) I was not thinking about the so-called career (...) I had plans before, but ... now I had an obvious plan (...)"; "My job became my way to escape... I could not cope with this thinking about Bartek, about his Down's (...); "I was happy (...) no, not because of the illness, but because I would stay home (...) I did not like my job (...) and so I wanted to change it after my maternity leave (...) I never looked again (...)";

- Change of family relations (in marriage, with parents, with remote family): "There was a child who had to be taken care of and that was our marriage now"; "If it had not been for the support of my husband (...), the understanding (...) of my daughter - I would not have been able to do it (...) this situation brought us closer to each other"; "It is a shame to admit, but now - after many years - we know that we did it wrong. We have neglected our older daughter, since we were busy with our little sick child, (...) today it is different, we know that she has her own life, (...) she will help with her brother if she wants to"; "Remote family? - it varies, but overall it has not changed much";
- Change of social situation: "We were the hot topic in the neighbourhood"; "You discover who your real friends are in a difficult situation and that was exactly what happened to us - only the real ones stuck around"; "Friends - we did not have time (...) they did not insist on keeping in touch either"; "Thanks to Krzyś, we meet many new people (...) we have a lot in common (...) our children and their affairs".

The parents were asked directly to evaluate their family life with Down syndrome. Everyone points out that their life changed when a child with Down syndrome was born, but "it is not worse, nor better - it is just different". And this difference seems to be a challenge for parents, who try to make every day normal, to make life go the most natural way possible, because "in the evening I think that another day is now over, and tomorrow will be the next one, and so, life goes on, day by day in spite of Down syndrome, or maybe... thanks to it?"

Conclusion

The diagnosis made it possible to outline the functioning of children with Down syndrome and their families. Undoubtedly, Down syndrome affects the daily life of children, as well as their

families; nevertheless, this impact is determined by the state of development of a child with Down syndrome, but also by the attitude of the parents towards their child and towards themselves, as well as by the degree of coping with the situation of life with trisomy 21. Several reflections concerning this issue emerge as a conclusion, namely:

- 1) Down syndrome should not be a "sudden event in the life of the child's parents" – prenatal diagnosis may enable parents to prepare to welcome a 'special' child, to get used to a new life situation, which will pose both personal and family challenges;
- 2) receiving information about the diagnosis of Down syndrome should not be a traumatic situation for the parents, in particular the mother of the child – a proper informing procedure with an inseparable psychological support element is crucial.
- 3) parents should not be left to their own devices in this new, difficult situation – formal, transparent and comprehensive support is needed, providing the family with a good place in the system of medical, social and therapeutic services.

Improving the situation of families of children with Down syndrome will improve the quality of life of the people with Down syndrome themselves. There are many issues to take care of, which all take time and effort, but change is possible. It is worth giving this a try.

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