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## **Families with a child with ASD and Down syndrome - their attitudes and values**

### **Rodziny z dzieckiem z ASD oraz z zespołem Downa - ich postawy i wartości**

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**Abstract:** We are all called to live and improve the world for ourselves and others. Every person, even if he or she is a person with a disability, and with an impaired ability to perceive and understand, is a fully human subject who has an inalienable right to life and development, a right that belongs to every human being. A human being always has his or her dignity and a particular, unquestionable value. The most complete community for every human being is the family. It is the foundation of a fulfilling life, even for a child with such serious dysfunctions as ASD or Down syndrome. Having a child with ASD, or a child with Down syndrome, undoubtedly causes difficulties for the whole family in many areas. Social and cultural changes can affect how a family with a child with ASD or Down syndrome works. Thus, they may affect difficult parenting: motherhood or difficult fatherhood. At the same time, there is still a lack of research and analysis devoted to such families, to the perceived positive changes in the family system as a whole, and in the families themselves. The aim of this analysis is to try to answer the question of what attitudes and values parents of children with ASD and Down syndrome present. The research used the Attitudes Towards Disabled Persons Scale, the Attitudes Towards Disabled Persons Questionnaire and the Axiological Questionnaire by A. Sękowski. The research conducted using a diagnostic survey confirms that families characterised by a high level of moral and religious values present positive attitudes towards people with disabilities, including children with Down syndrome and ASD. Maximum assistance and support should be provided to families with a child with ASD and Down syndrome, in order to enable optimal development of children with ASD and Down syndrome in psychomotor and intellectual development by accepting and stimulating their subjectivity, and securing a space full of love and empathy.

**Keywords:** ASD, family, Down syndrome, attitudes, values

**Abstrakt:** Wszyscy jesteśmy powołani do tego, aby żyć i doskonalić świat dla siebie i innych. Każda osoba, nawet wówczas, gdy jest osobą z niepełnosprawnością, i z zaburzoną zdolnością do postrzegania i rozumienia, jest w pełni ludzkim podmiotem, który ma niezbywalne prawo do życia i rozwoju, prawo przynależne każdemu człowiekowi. Istota ludzka zawsze ma swoją godność i szczególną, niepodważalną wartość. Najpełniejszą wspólnotą dla każdego człowieka jest rodzina. Jest ona fundamentem realizującego się życia również w sytuacji, gdy jest to dziecko z tak poważnymi dysfunkcjami jak ASD, czy dziecko z zespołem Downa. Posiadanie dziecka z ASD czy dziecka z zespołem Downa niewątpliwie wpływa na trudności w wielu obszarach funkcjonowania całej rodziny. Przemiany społeczne i kulturowe determinują funkcjonowanie rodziny z dzieckiem z ASD, czy z dzieckiem z zespołem Downa. Tym samym mogą wpływać na trudne rodzicielstwo: macierzyństwo czy trudne ojcostwo. Jednocześnie brak jest nadal badań i analiz poświęconych takim rodzinom, dostrzeganym pozytywnym zmianom w całym systemie rodzinnym, i w nich samych. Celem podejmowanej analizy jest próba odpowiedzi na pytanie, jakie postawy i wartości prezentują rodzice dzieci z ASD i z zespołem Downa. W badaniach wykorzystano Skalę Postaw Wobec Osób

Niepełnosprawnych, Kwestionariusz Postaw Wobec Osób Niepełnosprawnych oraz Kwestionariusz Aksjologiczny A. Sękowskiego. Prowadzone badania z wykorzystaniem sondażu diagnostycznego potwierdzają, że rodziny charakteryzujące się wysokim poziomem wartości moralnych, religijnych prezentują pozytywne postawy wobec osób niepełnosprawnych, w tym dzieci z zespołem Downa i z ASD. Należy zabezpieczyć rodzinom z dzieckiem z ASD i zespołem Downa maksymalną pomoc i wsparcie, tak, aby jednocześnie umożliwić optymalny rozwój dzieciom z ASD oraz z zespołem Downa w rozwoju psychomotorycznym i intelektualnym poprzez przyjęcie i stymulowanie ich podmiotowości, i zabezpieczenie przestrzeni pełnej miłości i empatii.

**Słowa kluczowe:** ASD, zespół Downa, rodzina, postawy, wartości

## Introduction

The most perfect community for every human being is the family. The family is the space of love, the space of life, attitudes, but also development. Each family is a special space of life for the child, and the first interactions always take place within the family. As a unique and individual space for its members, the family influences the child with its unique interaction. The family is therefore a fundamental and special value for every child (Kiliszek, 2019). The experiences of parents of children with ASD and Down syndrome are particularly difficult (Kostiukov, Strzelecki, Poniewierski, Samborski, 2019). Despite the advances in knowledge on this topic that have been made in recent years and the change in approaches to the problems faced by parents of such children, there is still no unified theory on this issue (Drabata, 2019). As early as at the time of diagnosis, parents experience a great deal of negative experiences, feel hurt and rejected, and are unable to cope with such a difficult challenge. In such families, therefore, a difficult process of shock, breakdown, disbelief, rejection of the situation and escape from the problem begins. Parents often isolate themselves and enter a trajectory of suffering. The escalation of negative emotions occurs especially in the first year of diagnosis but also in the following years, and it happens that, over time, the number of negative experiences decreases in favour of the satisfaction of contact with the child who, as it turns out, they love more and more (Auliffe, Thomas, Falkmer, Cordier, 2019). The great challenge around the world today is not only to give birth to a child with Down syndrome, but also to show it to the world without shame. At the same time, it is a challenge for the modern world to raise children with ASD who appear in families more and more frequently.

Indeed, the diagnosis of a child with ASD poses unique challenges for parents. The whole family system often has to reformulate its own goals, dreams, attitudes and values (Chrostowska, 2018). For parents, this is a very serious crisis situation that causes an escape into loneliness or triggers suffering. It is undoubtedly a long-term burden for parents, siblings, but also for the whole family system (Barłóg, 2020). At the same time, having a child with Down syndrome or ASD can eventually trigger many positive attitudes and values within the whole family system. Many such families become integrated in positive attitudes

after some time and being with a child with a disability triggers a lot of positive feelings full of happiness and joy and special values.

### **1. ASD and Down Syndrome**

ASD is nowadays one of the most common disorders and according to the state of the art Autistic Spectrum Disorder is classified as a developmental disorder, as an exemplification of holistic developmental disorders (Currenti, 2010). It is a neurodevelopmental disorder considered to be one of the most severe developmental disorders. Autism is characterised by abnormalities in social development, in the formation of social relationships, in interaction, in cooperation with other people, in communication and in behaviour, particularly in restricted patterns of both activities and interests (Banasiak, 2020). In line with the World Health Organization, the term ASD (or *autistic spectrum disorders*) is established in the ICD-10. In the current classification of the American Psychiatric Association (DSM - 5), one diagnostic category was created from the so-called triad of autistic disorders. The term holistic developmental disorder was dropped and replaced with three categories: autistic disorder, Asperger syndrome and holistic developmental disorder not otherwise diagnosed in the autistic spectrum disorder, i.e. ASD (Barłóg, 2020).

High-functioning children are children with Asperger syndrome. The term is attributed to a psychiatric doctor named Hans Asperger, who described this type of disorder in children in 1944. Nowadays, Asperger syndrome is a disorder characterised by difficulties in understanding social behaviour with immature empathy and difficulties in controlling emotions (Attwood 2013).

Down syndrome, first described by physician Langdon Down in 1866, is the most common form of severe mental retardation, although not all people with Down syndrome are severely mentally retarded. The vast majority function at the level of moderate mental retardation. There are three karyotypes that cause Down syndrome: regular chromosome 21 trisomy, mosaicism, and translocation. Different types of translocations and, rarely, combinations of mosaic translocation can also be observed (Raaya Alon, 2019).

### **2. Motherhood and fatherhood of parents of children with ASD and Down syndrome**

One of the most important roles in a person's life is parenthood, the fulfilment of the role of mother or father, and the greatest joy for parents is the information about the birth of their child. The diagnosis of the birth of a child with a disability is an unspeakable shock for parents and is often associated with the suppression of this first information from

consciousness. The news that a child has been born with Down syndrome, but also the diagnosis that a child has ASD, is particularly traumatic. This diagnosis puts parents in a situation of crisis and distress, extremely difficult to accept. Parents must assume the role of difficult fatherhood and difficult motherhood (Aksamit, 2018). In this first, painful information, parents experience a sense of isolation, a sense of loneliness, a sense of hopelessness and despair (Gosztyła, Prokopiak, 2017). Research confirms that the escalation of many difficult, negative experiences occurs within the first year of diagnosis. It is only the positive experiences of parents connected with caring for their child that slowly give satisfaction from contact with their child and the belief that things can be better or the child will change positively (Jaranowska, 2016).

### **3. Attitudes and values of parents of children with ASD and Down syndrome**

The term attitude was introduced to literature by William Thomas and Florian Znaniecki at the beginning of the twentieth century to indicate the processes of individual consciousness that determine a person's attitudes towards another person, other people or the community. In contemporary literature, the issue of attitudes is analysed in relation to such components as: behavioural, affective, cognitive (Chrzanowska, 2015).

Attitudes are most often perceived on the basis of a certain behaviour, and in relation to people with disabilities it is an ongoing disposition to accept or negate the disability, which may be accompanied by certain stereotypes, prejudices or even stigma. The very etymology of disability terminology can be a label for the person to whom it is addressed (ibidem). At the same time, the specific resources of a family with a child with Down syndrome and a family with a child with ASD include the adopted value system. Many definitions, but also classifications of values, are found in the literature. As early as in antiquity, it was believed that the good occurs independently of human aspirations and desires. Without the most basic resource of values or the formation of humanity, it is impossible to function in a sense of responsibility, to function in axiological readiness and action. This is a humanistic and moral assessment at the same time (Szmyd, 2017).

### **4. Methodology of author's own research**

The aim of author's own research was to search for knowledge concerning parents' attitudes towards particularly difficult types of disability, i.e. towards children with Down syndrome and children with ASD. It was also a search for factors, circumstances which have a decisive influence on such attitudes and values. The main problem was contained in the question of what attitudes do the surveyed parents of children with Down syndrome and parents of children with ASD have towards disability. As specific problems, the research

questions were formulated to ask whether the surveyed parents present mostly positive attitudes and whether these attitudes are differentiated by such demographic variables as the gender of the surveyed parents, the gender of the child, the age of the parents, the age of the child, the education of the parents. The next question asked what values are presented by parents of children with Down syndrome and parents of children with ASD. The research used the method of diagnostic survey with the use of such techniques as Scale of Attitudes towards Disabled Persons, Questionnaire of Attitudes towards Disabled Persons and Axiological Questionnaire (Sękowski, 1991). The research was conducted in Podkarpackie Voivodeship in 2021. A total of 88 parents were interviewed, including 44 parents of children with Down syndrome and 44 parents of children with ASD.

## 5. Results

Demographic variables were analysed in the study. Thus, in the group of the examined parents of children with ASD, 75.0% were mothers, i.e. women, and 25.0% were fathers, i.e. men. In the group of parents of children with Down syndrome, 63.6% were women, i.e. mothers of children with Down syndrome, while 36.3% were men, i.e. fathers of children with Down syndrome. The study confirmed that in the case of the surveyed parents by age of the respondents, the least numerous were young parents, i.e. under 30 years of age. The majority of the surveyed parents with a child with ASD are educated - 63.5 % have a university degree. The results are different in the group of parents with a child with Down syndrome, where almost half of the parents surveyed have a secondary or vocational education (47.7 %) and 52.2 % have a university degree. The surveyed children with Down syndrome were aged 0 to 5 years, which is 45.5%, followed by those aged 6 to 15 years, i.e. 43.9% and far fewer aged 16 to 25 years, i.e. 18, 0%. In the group of children with ASD, those aged 0 to 5 years were 20.4%, followed by those aged 6 to 15 years (45.3%) and those aged 16 to 25 years (43.9%). In terms of gender, more than half of children with Down syndrome were girls (59.0%) and 40.9% of children with Down syndrome were boys. In the group of children with ASD, the vast majority were boys (61.3%) and girls constituted 38.6%.

As a result of the survey with the Attitudes towards Disabled Persons Scale, parents taking care of a child with disabilities on a daily basis presented their attitude towards such persons as definitely positive. Selected results from author's own research are presented below.

- The vast majority of surveyed parents of children with Down syndrome (77.2%) and with ASD (65.9%) say that people with disabilities can start their own families.
- All surveyed parents of children with Down syndrome (100.0%) and almost all with ASD (97.7%) accept a person with a disability as their friend.

- The vast majority of surveyed parents admit that they can work with a person with a disability (100.0%, 90.9%).
- The vast majority of parents of a child with Down syndrome (86.3%) and the same number of parents with a child with ASD admit that such people can have achievements, for example in sports.
- Most of the surveyed parents of children with Down syndrome (77.2%) and parents with a child with ASD (84.1%) admit that such people can also earn their living.
- The vast majority of parents with a child with Down syndrome (86.3%) and parents with a child with ASD believe that a person with a disability can provide assistance to a non-disabled person.
- Almost all surveyed parents claim that close contacts with people with disabilities should be sought (90.9% of parents with Down syndrome, and 100.0% of parents with a child with ASD).
- Most of the surveyed parents believe that children with disabilities should not be treated with great indulgence (59.1% of parents with a child with Down syndrome and 79.5% of parents with ASD).
- There are also parents who, despite many everyday difficulties resulting from caring for a child, admit that "there are no differences in the behavior of people with and without disabilities" (31.8% of parents of children with Down syndrome and 25.0% of parents with a child with ASD).
- Most of the surveyed parents claim, however, that such people are not more unhappy (86.3%) and less patient (27.2%) in the opinion of parents of children with Down syndrome, and 93.1% and 18.1% respectively in the opinion of parents children with ASD.
- A smaller percentage of the surveyed parents with a child with Down syndrome (27.2%) and ASD (20.4%) believe that people with disabilities are more childish and that they are often naive.
- Despite the fact that the surveyed parents have already accepted the fact of their own child's disability, in 13.5% of parents of children with Down syndrome and in 9.0% of parents of children with ASD, the sight of a person with a disability causes fear, anxiety, certain fears and even a sense of helplessness.
- Few of the respondents (13.6% of parents of children with Down syndrome and 15.9% of parents of children with ASD) admit that the sight of a person with a disability still makes them anxious, and that the behaviour of people with disabilities is often still annoying for them.
- Half of the parents surveyed (50.0%) believe that people with disabilities still have difficulties in social interaction with non-disabled people.

- More than half (68.1%) of parents of children with Down syndrome believe that such a person can be more easily offended, while parents of children with ASD (56.8%) disagree with this statement.
- The vast majority of parents surveyed (90.9% with a child with Down syndrome and 79.5% with a child with ASD) are of the opinion that children with disabilities should not be educated only in schools and special childcare centres.

In conclusion it should be stated that both in relation to positive characteristics, as well as in relation to negative characteristics, the vast majority of parents surveyed present similar attitudes and opinions, formulating similar answers. Their attitudes towards people with disabilities, enriched by their experience of working with a child with disabilities, change in a positive and accepting direction, especially in the group of parents with a child with ASD.

Next, selected results from a study of parents of children with Down syndrome and parents of children with ASD, using the Attitudes to Disability Questionnaire, will be presented. Due to the limitations of this article only selected outcomes are presented. The results obtained using another tool confirmed again that both positive and negative statements are similar in the group of parents with a child with Down syndrome and a child with ASD.

- More than half of the surveyed parents of children with Down syndrome (52.7%), and half of the parents with a child with ASD say that they would accept a person with a disability as their best friend (50.0%).
- All respondents or 100.0% of parents of children with Down syndrome, and 93.1% of parents of children with ASD would accept a person with a disability as their neighbour. Similarly, all respondents (100.0%) accept a person with a disability in their company, and as a companion, as a playmate of siblings, as a visitor to their home and as a classmate of their child (100.0%).
- Approximately half of the parents surveyed say they would accept such a person as their life partner (54.5% of parents of children with Down syndrome and 50.0% of parents of children with ASD).
- The vast majority of parents surveyed (81.8% of parents of children with Down syndrome and 77.2% of parents of children with ASD) say they would show up with a person with a disability in a public place.
- All parents surveyed would invite such a person to their home (100.0%).
- Similarly, 100.0 % of parents with a child with Down syndrome, and 90.9 % of parents with ASD say that people with disabilities have the opportunity to express themselves creatively in various areas of arts and creativity.

- The vast majority of surveyed parents of children with Down syndrome (88.6% ), and (90.9% ) parents of children with ASD believe that people with disabilities can achieve benefits from education.
- Only 9.09% of parents with a child with Down syndrome and 4.5% of parents with ASD believe that people with disabilities cannot participate in similar forms of entertainment as non-disabled people.
- All surveyed parents of children with Down syndrome (100.0%) and 88.6% of parents with ASD confirm that people with disabilities are capable of experiencing feelings.
- About half of the surveyed parents of children with Down syndrome (50.0%) and parents with ASD (54.5%) believe that people with disabilities can compensate for their deficits.
- All respondents (100.0%) of parents with Down syndrome and ASD claim that people with disabilities should not stay in a closed childcare institution, and only one of the surveyed parents cannot agree with this view.
- Also few of the surveyed parents of children with Down syndrome (9.0% ) and with ASD admit that people with disabilities are aggressive (18.1%).
- The vast majority of parents surveyed disagree with the statement that people with disabilities come from neglectful backgrounds (81.8% of parents of children with Down syndrome, and 90.9% of parents with ASD).
- Very few of the parents surveyed believe that contact with people with disabilities is burdensome (22.7%) and that people with disabilities are unhappy (4.5% of parents with Down syndrome and 9.05% of parents with ASD).
- Almost all parents of children with Down syndrome and parents with a child with ASD (95.4%) disagree with the statement that the physical appearance of people with disabilities offends them. Also 77.2% of the first group and 75.0% of the second group of parents surveyed do not confirm that people with disabilities are fearful.
- Few of the parents surveyed feel pity at the sight of people with disabilities (22.7%) and over half of them (54.5% ) disagree with this view. Similarly, a small number of 13.6% of parents with a child with Down syndrome and 9.0% of parents with a child with ASD believe that seeing people with disabilities makes them feel fearful and anxious and that the behaviour of people with disabilities is often annoying.
- Half of the parents surveyed believe that people with disabilities find it difficult to socialise (50.0%). More than half (68.1%) of the surveyed parents of a child with Down syndrome agree that such a person is easier to offend. In contrast, 79.5% of parents of children with ASD disagree with this statement.

- Nearly all surveyed parents (90.9% of children with Down syndrome and 79.5% with ASD) are of the opinion that children with disabilities should not be educated only in schools, special childcare and educational centres.

In general, it should be noted that both in relation to the so-called positive and negative features, the respondents from the group of parents of children with Down syndrome and from the group of parents of children with ASD gave similar answers, which may indicate the presentation of similar attitudes of the surveyed parents towards people with disabilities. The situation of parents with a child with Down syndrome, with a visible disability of their child, undoubtedly causes this group of parents to perceive more negative features, i.e. problems resulting from their social relationships, a sense of loneliness, helplessness, but often also from the perceived social distance.

Interpretation of selected results from author's own research using the Axiological Questionnaire.

The research has confirmed that parents of children with disabilities such as Down syndrome and ASD present a whole range of values which help them to love their child with disability more and to find the sense of meaning in their own life, to overcome borderline situations like crises and breakdowns resulting from difficult situations caused by the child's behaviour, especially with ASD, but also by the isolation of the environment, especially with regard to parents of a child with Down syndrome.

- For the vast majority of parents surveyed, it is religion that plays a unique and huge role in their lives, helping them to get through successive breakdowns and crises. This is true for 91.9% of parents of children with Down syndrome and 77.2% of parents with ASD.
- Only a few of the respondents, i.e. 9.1 % of parents of children with Down syndrome and 11.3 % of parents with a child with ASD, are not interested in religious matters, while the majority of the respondents (86.3 % of parents of children with Down syndrome and 68.1 % of parents with ASD) consider themselves to be religious. However, more than half of the respondents (63.3 % of parents of children with Down syndrome and 70.4 % of parents of children with ASD) declare that they pray very often. Only a few of the parents surveyed admit not going to church (4.4% of parents of children with Down syndrome and 18.1% of parents of children with ASD).
- The research confirmed that parents of children with disabilities (100.0% of parents of children with Down syndrome and 95.4% of parents of children with ASD ) claim that the family has a valuable and irreplaceable function in society.
- The vast majority of respondents i.e. 70.4% of parents of children with Down syndrome and 68.1% of parents of children with ASD believe that their mission is to act selflessly for others. They are very keen to help others, the weaker ones, and to participate in many organizations and aid campaigns.

- Only a few of the parents surveyed agree that people should not be constrained by any moral rules. This is stated by 4.5% of parents with a child with Down syndrome and 18.1% of parents with ASD.

### **Discussion of results and conclusion**

The research confirms the great moral value that children with disabilities, even those as difficult for parents as Down syndrome or ASD, can have on the family system as a whole and on parents in particular. A child with Down syndrome or ASD affects not only the person affected, but also other people in their lives who are involved. It affects many aspects of the family and especially the parents' lives and can determine the child's abilities and limitations, but also the functioning of the whole family system (Pawlikowska, Maciejewska, 2018). Parents' attitudes are being modified towards acceptance of "otherness" and in particular towards appreciation of their child's efforts to function similarly in the world of healthy non-disabled people. For both parents of children with Down syndrome and parents of children with ASD, education is not a determining factor of attitudes towards people with disabilities, as the vast majority of parents surveyed are educated people, concerned about the welfare of their own children with disabilities. Regardless of the disability of the surveyed children, the presented attitudes of parents of children with Down syndrome and ASD are largely positive. Parents, despite the difficulties, believe in the possibility of integration and inclusion, normalization of the lives of people with disabilities, and even demand this normalization, meeting the special needs of their children, and the right to education like for others. The appearance of any developmental abnormalities in a child is always a stressful situation for parents expecting help and support (Wrona, Wrona, 2016).

The research also shows that parents involved in helping others, characterised by a high level of moral and religious values, tend to present positive attitudes towards the weak, the vulnerable, those in need of help and support, towards people with disabilities and their families. It is also an attitude of taking responsibility for one's own actions and for the welfare of a child with Down syndrome or ASD. Self-awareness, motivation, control of emotions, the ability to set goals, to make decisions, solve problems, evaluate difficult situations independently, and the ability to self-motivate are important here (Mitchel, 2016). It is also involvement into activities, inclusion strategies, introducing the child with a disability into the process of inclusive education, i.e. teaching children with special educational needs in a typical mainstream school environment. All of this results in parents taking determined action to improve the situation of their child with Down syndrome or ASD. Searching for the best strategy for the child (Niedbalski, 2019), the best doctor for the child, the best therapy or rehabilitation, worrying about the child's future, are the main actions of parents (Drabata, 2019). The attitudes and values presented by parents of children

with Down syndrome and ASD are still not always supported in Poland by the professional system of help and support for such families (Chrostowska, 2018). However, for such families as families with a child with Down syndrome and families with a child with ASD, love is stronger than pain and motherhood and fatherhood is a unique vocation and value for them (Sozańska, 2016).

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