

Jakub Niedbalski*

University of Lodz

ORCID: 0000-0002-2803-7628

**IDENTITY AND THE SENSE OF SUBJECTIVITY
IN PARENTS OF CHILDREN
WITH INTELLECTUAL DISABILITIES
IN THE CONTEXT OF FAMILY LIFE DESTABILIZATION**

The lives of families who take care of people with disabilities are full of unexpected events, unwanted situations, and difficulties that accumulate at every step. Therefore, bearing in mind the purpose of this paper, I focused on determining those conditions which are a source of destabilization in the lives of families with intellectually disabled children. I attempt to reconstruct the sources of threats to the sense of subjectivity and the shaping of the identity of parents who have children with disabilities. The theoretical framework of the analysis is symbolic interactionism. The research material used in the presented article is composed of personal experiences of parents of disabled individuals, and unstructured interviews were performed with these people. Analysis of the research material was performed in accordance with the procedures of grounded theory methodology.

Keywords: family, disability, identity, subjectivity, life destabilization

INTRODUCTION

The birth of a disabled child causes far-reaching changes in the lives of the whole family. These changes affect all members, not only the parents but also the siblings and grandparents. The literature on the subject emphasizes that the presence of a disabled child is a source of acute stress for the entire family (Bebko et al. 1987; Wolf et al. 1989; Hananstein 1990; Beckman 1991; Pisula 1993). A disability in a child such as an incurable disease may be considered a critical life event (Farber 1968) because it exerts a direct influence on the functioning of the family. Everyday life with a disabled child requires many sacrifices. The parents encounter problems almost every day, and these have a negative impact on their relationships inside and outside of the family.

The presence of an intellectually disabled person in a family has a unique effect on family dynamics. In the case of a family with a child with intellectual disabilities, its functions are

* Corresponding author: Jakub Niedbalski, Uniwersytet Łódzki, Wydział Ekonomiczno-Socjologiczny, ul. Re-wolucji 1905 r. 41, 90-214 Łódź; e-mail: jakub.niebalski@uni.lodz.pl.

most often distorted, and playing more important roles requires a serious amount of work, involving a great deal of psychological stress. As a result of experiencing an increasing number of difficulties in family life, which often exceed the capabilities and mental resilience of family members, some people, especially the parents, encounter a role crisis and identity disintegration. In the case of families with a child with intellectual disabilities, the excessive effort involved in the child's upbringing and poor results often lead to burnout syndrome. Whether a disabled child's development adversely impacts its family and the behavior of the parents themselves is largely determined not only by their personality features and their emotional attitudes towards the child, but also with their views on the upbringing process (Stelter 2013: 90–91).

In a situation where a traumatic life event such as the presence of a disabled child is accompanied by everyday problems, we can expect what Sekułowicz (1998) calls the “sea waves effect,” namely the accumulation of problems. According to Reyman and Kucyper (1994: 31), the most frequent life troubles stated by mothers are insufficient sleep, the need to constantly focus on the child, being with the child at all times, no time for entertainment, the inability to rest, the necessity to use public transport, the arduousness of frequent visits to specialists, a lack of physical strength, a sense of a permanent “connection” with the child, a lack of understanding of the problems associated with being the mother of a child with disabilities, a lack of satisfaction with intimacy with the husband, loss of contact with former colleagues and friends and feelings of disappointment towards them, considerable financial burdens, disappointment at abandoning old plans and dreams, irritations resulting from the prolonged dependence of the child, a lack of time for themselves, constant feelings of fatigue, and fear of the future.

These and other problems cause parents of children with disabilities to function worse than parents of fully capable children (Harper 1984), and it depends on many factors. An important feature of parental stress is its permanent nature. Family relationships and the type of disability that occurs in the child are also of great importance. According to Bouma and Schweitzer (1990), the degree of the stress experienced by parents of children with various types of chronic disorders varies. The socio-economic and demographic situation of the family is also of importance. In the article I therefore mainly focus on determining the factors and their impact on stabilizing versus destabilizing the situations of families with disabled children, and on determining the conditions which modify the life situations of families (based on similarities and differences among various cases). Based on the assumptions of the assumptions of symbolic interactionism, which is the theoretical framework for this analysis, I look at them through the prism of a network of connections and interpersonal interdependencies in the personal, social, and institutional dimensions.

PARENTS OF CHILDREN WITH DISABILITIES IN THE LITERATURE ON THE SUBJECT

The literature on the subject stresses that when a child with a disability comes into the world, it determines the family life, allocating new duties, functions, and tasks to each family member, and it destroys the previous organizational order (Boczar 1982; Borzykowska

1997; Dykcik 2005; Minczakiewicz 2002; Twardowski 2008; Wojciechowski 1990). Such a diagnosis is especially bitter for the parents, who are usually unprepared to take on new and difficult tasks. Mrugalska (1995: 66) claims that “without fear of exaggeration, the experience of this period can be described in terms of a mental crisis. The more viciously the first information was given to parents, the fewer the necessary explanations it included, and the less it took into account the feelings of those who listened to this ‘judgment,’ the harder the experience”. The staff of the hospital where the birth takes place, along with the doctor that the mother consults during her pregnancy, play a significant role here. Zakrzewska-Manterys pays a great deal of attention in particular to that initial issue (1997: 202 and further). She writes that the birth of a child with intellectual disabilities is not a common situation, and it causes a stir among the hospital staff in the maternity ward as well.

On the other hand, it is not an event that could significantly disturb the most important relationships taking place in the ward (*ibidem* 202). Staff members have standard and “institutionalized” ways of dealing with such circumstances. As Zakrzewska-Manterys suggests (Zakrzewska-Manterys 1997: 202), “professional trajectory operators” apply various strategies to get out of this situation at the lowest possible mental cost. At the same time, she points out that these procedures, although directed at the mother of a disabled child, are primarily intended to benefit the medical staff. “Mechanisms of dealing with the trajectory employed by the staff, doctors, in particular, include transmitting their knowledge and opinions to the mother and the attempts to impose their own definitions of the situation to the greatest possible extent” (Zakrzewska-Manterys 1997: 207). Such a situation somehow forces a mother to certain behaviours, causing her to experience an abundance of unnecessary anxiety. The fact that the mother is treated by the staff in a way that is in many cases indifferent, above all, exposes her to additional stress, makes hospitals particularly unfriendly places. In such a reality, with no proper support, it is hard to expect that parents of a child with intellectual disabilities would not experience severe anxiety or depression.

Therefore, the literature on the subject devotes a great deal of attention to researching the emotions that accompany the parents of a disabled child. The fear and the accompanying anxiety for the child’s development and future are felt particularly strongly. There is also a feeling of being lost and the uncertainty caused by insufficient information, as well as a the lack of schemes of conduct that parents might develop in the new situation (Wyczesany 1998: 156).

Małgorzata Kościelska (1995: 43–65) presents a whole range of affective states that accompany the relatives of people with intellectual disabilities. As she suggests, these emotions mostly concern the mother, who experiences a series of anxieties and concerns that accompany her both before motherhood, during her pregnancy, and primarily after the child is born (*ibidem* 43–55). Kościelska (1995: 46–50), while describing emotions related to identifying a child’s defects and handicap, presents the following range: fear of hostility, concern about missed opportunities, fear of their child confronting new life situations, and fear of the future. Another equally difficult feeling tormenting the parents of a child with disabilities is what Kościelska describes as “mourning,” which includes “the psychological state of the parents that occurs right after they lose their dream child and are confronted with the child that has been born” (*ibidem* 52). This group of feelings includes despair, sadness, apathy, depression, and discouragement. According to Mrugalska (1995: 53–54), when a disabled child is born, some parents experience what the author calls “irregularity of self,” which may sometimes take

the form of self-destruction or even an identity crisis. Such a situation determines a parent's hostile attitude not only towards themselves but also towards their surroundings. Kościelska (1995: 57) points to a very difficult phenomenon regarding the parents' love for a disabled child, at the same time stating that it is often a painful feeling because it is experienced alone and with a sense of opposition to social attitudes (ibidem 57–58). In turn, according to Cytowska (2012), a characteristic feature of the functioning of these families is the worsening physical condition of the parents related to the aging of their bodies. When we compare this with never-ending –and sometimes even increasing – problems of disabled adults, we can see that family resources shrink in the face of even greater family life challenges. Resources also dwindle as the family structure changes with the flow of time: independent siblings leave home, and the parents might divorce or one of them might die. Pisula and Dąbrowska (2004) carried out interesting research in this field that showed that parents' expectations of the future differ regarding the age of the mothers and the children – mothers of older children are usually aware of the limitations of their offspring and the barriers that are hard to overcome, while mothers of small children believe in positive and major changes in their child's functioning. Johnson (2000) and Solomon and Draine (1995) note that stress related to the long-term role of being a guardian to a disabled child is a risk factor that may increase the parents' vulnerability to physical and mental problems. The authors highlight that there is a difference in coping mechanisms between parents of children with developmental disorders and those with mental disorders, and they also differentiate how those two groups of parents deal with long-term stress. According to the researchers, adapting to stress is especially important for middle-aged parents with adult children with mental disorders, and this is the factor that differentiates them from parents of adult children with developmental disorders.

Researchers' interest is also aroused by the aging of parents of disabled adults (as well as the disabled people themselves), their challenges in everyday life, as well as the position, roles, and features of the siblings of the disabled adults (Orsmond and Seltzer 2007). Among the abundance of studies undertaken in this field, it worth mentioning those by Seltzer, Floyd, and Greenberg (2005), who analyzed the relationships among lifelong and persistent disability in children and the health of their parents. They state that parents with a child that has been disabled for its whole life will face untypical caring challenges that may cause stress and impact their physical and mental health. Like the other family members, parents – as guardians –have different ways of dealing with the long-term requirements demanded by their role as guardians of an adolescent or adult child with a disability.

Summing up, we can say that a family with an intellectually disabled child fulfils the same functions as a family with a healthy child. However, the difference is in the conditions in which particular tasks are implemented, and in the intensity of their influences (Stelter 2013: 33). A family that raises a child with a mental disability functions in conditions of permanent overload. The distortion of the correct development of the child impacts the functioning of each family member, and it is often a stress factor. However, the mere presence of a child with limited mental capabilities within a family system does not immediately make it dysfunctional (Stelter 2013: 33); it is how the family deals with the crisis of the child's disability in various situations and periods that determines its functionality or dysfunctionality. One of the dimensions may be the problem of adequately fulfilling parental roles –defining oneself as a parent while maintaining a sense of one's own subjectivity.

SOCIAL SUPPORT FOR PARENTS OF CHILDREN WITH DISABILITIES

Adequate support is believed to be a crucial issue determining the lives of persons with disabilities and their families. At the same time, the support provided to families of persons with disabilities is not only varied but also multi-faceted. Kawczyńska-Butrym (1998) divides support into informative, emotional, and material (including financial). Karwowska (2003), however, distinguishes the following types of support: preventive and educational, compensatory, psychological and pedagogical, rescue, informational, and spiritual. According to Sęk and Cieślak (2004), several of the most frequently implemented types of social support can be identified: formal and informal, professional and non-professional, self-help and voluntary. Social support can also be considered in the context of objectively existing and accessible social networks which, through the existence of ties, social contacts and affiliations, perform functions helpful to people in a difficult situation (Sęk and Cieślak 2004). In practice, there is actually no way to separate various kinds of social support, because it is provided in parallel.

At the same time, this support has undergone significant evolution in recent decades. The paradigm in the perception of people with disabilities and the system of assistance offered to them has changed from an institutional model where the patient was at the centre, through a rehabilitation model aimed at the client-consumer, to a civic model where a person with a disability is treated as a citizen-member of the community (Żyta and Ćwirynkało 2015: 377). Perspectives on the topic of supporting families of persons with disabilities are also evolving, and they consider the transformation in the scope of handing over the care competences from the state to the local communities, the involvement of non-governmental organizations, as well as clearer emphasis on the role of volunteers and relatives of persons with disabilities.

Changes in the approach to the support for families raising children with disabilities are related to both an increase in awareness of the rights vested in the members of these families, and to the general tendency to consider subjectivity and self-determination of all people while providing them with the necessary social support. The modern approach is based on the premise that parents need not only to be instructed on what to do and what to avoid in order to ensure proper education, upbringing and rehabilitation of a child with disabilities, but also to support them in fulfilling their parental roles (Żyta and Ćwirynkało 2015).

Despite such wide-ranging changes that have translated into the lives of families of children with disabilities, there are still a number of shortcomings and deficiencies in the support system for these families. Citing Żyta and Ćwirynkało (2015: 283) we can list here: a lack of appropriate forms of institutional, individualised assistance in the field of counselling and family therapy; incompatibility between the forms of assistance with the needs of the child and the family at different stages of life (with the growing up of children new challenges appear in the upbringing, educational, medical and legal spheres) and their low openness in terms of programmatic and functional cooperation; overburdening of families of people with disabilities (taking place while appreciating their role in the care and rehabilitation of disabled family members) and their dependence on local communities, charities or state funds; problems in contacts between professionals and parents (lack of communication, ineffective communication, professionals criticising and blaming parents); limited or incorrect understanding of standardisation by social services, professionals and parents alike; lack of alternative

forms of housing for adults with intellectual disabilities (small number of sheltered flats, living with family or in a social welfare home more often than living independently); social workers being unprepared to work with families of children with intellectual disabilities; lack of financial resources for the creation of emergency intervention centres or specialist counselling centres and the employment of qualified professionals; and imperfect systems of informing parents on methods of treatment, therapy and rehabilitation of a given disability and on available forms of family support.

According to Speck (2005) the crucial issue for the reorganization of the support system and its adjustment to the needs of families with disabled children is to actually execute this principle: as much support as necessary, as much self-help as possible. Therefore, it is stressed that parents should retain their primary and basic responsibility for their child's becoming and success while being accompanied by professional support, but they are not to be turned into support specialists: they must remain the parents. At the same time, professionals supporting a family should distance themselves from the view that only the actions of professionals are appropriate for the child. According to Żyta and Ćwirynkało (2015), a modern support system should make it easier for them to perform these diverse roles. It is also important to have access to professionals who are open to dialogue and ready to listen to their arguments, who do not dominate them and who do not overstate their professional authority. A visible direction in the approach of supporting the families is promotion of mutual support by parents.

THE THEORETICAL INSPIRATIONS AND METHODOLOGICAL BASIS FOR THE RESEARCH

In this study I refer to the theory of symbolic interactionism, which is rooted in the interpretative paradigm. The nature of social reality is of a processual dimension here, changeable and dynamic (Blumer 2007; Prus 1999). Particular individuals do not recreate a certain scheme; they are creative entities. Hence, symbolic interactionists are inclined to perceive people as active social actors who continuously reconstruct the picture of themselves, of the surrounding reality, and of the place in life space imagined in that way, and during interactions with the other members of a given community (Turner 2004: 418–421; Szacki 2002: 545 and further). Following Piotrowski (1998: 54), I adopt an interactional model of identity, where it is understood as “an object, result, and resource of interactions,” combined with mechanisms of identifying and interpreting oneself and others in mutual relationships as social actors. As Rosner writes (2006: 123), “what is constructed shall be reconstructed and reinterpreted” – the change in social experience causes the pressure of reconceptualizing oneself.

In psychosocial terms, this is the feeling that you are someone and that you may become someone in the future. The human sense of identity is mainly related to our own existence, the feeling of distinctiveness from our surroundings, internal cohesion, and our own value, autonomy, and independence (Piotrowski 1998). Identity understood in such a way is a notion that connects to the subjectivity of an individual, who – according to Pietrasieński (1987: 249–271) – may be taken as “the ability to realize the fact of being subjected to transformations and influencing those transformations thanks to one's own more or less autonomous

actions.” As Sztompka indicates (2005), the term subjectivity emphasizes the active impact of the actions of individuals and communities on the shape and functioning of the social structure. They assume that there are some mutual correlations between the actions and the mentioned structures and phenomena on the micro- and macro-social scales.

The subjective activity of an individual is one of humanity’s attributes. This activity is governed by the objectives chosen or generated by the subject itself. Thanks to this subjective activity, human fate is no longer determined only and unambiguously by external circumstances, and the person ceases to be a passive object of manipulations (Karmolińska-Jagodzik 2014: 119). This means that subjectivity is combined with action. A subject is someone who undertakes an action regardless of its direction or strength towards the person to whom this activity has been initiated. Therefore, interpersonal contact may be a form of subjectivity that is bi-directional, meaning two-way subjectivity (Karmolińska-Jagodzik 2014: 121).

The research material adopted in this study is information obtained during non-structured free interviews with parents who had experienced significant transformations in their lives-related to the process of bringing up and taking care of disabled children. In total, at this stage of research, 30 reviews have been carried out between 2017 and 2019 with parents of children with intellectual disabilities.

The premises that supported the selection of the above-mentioned technique arose from the accepted ontological (human experiences, interpretations, knowledge, evaluations, interactions perceived as significant interdependencies of the social reality) and epistemological assumptions (the legal manner of data generation based on those ontological assumptions comprises interaction, conversations with people, listening to stories and gaining access to the knowledge, evaluations, and impressions of individuals). The data are complete and in-depth, which complies with Rubin and Rubin (1997: 205) as they state: “qualitative research is applied in case of notions that require deeper comprehension, which is served best by detailed examples and expanded narrations.” The motive behind selecting this technique was the need to identify the “factual” ways of life, the actions of individuals, and the processes of creating meaning, therefore the desire to bring science closer to “life” and “recognition of social reality from the perspective of the subjects that create it” (Wyka 1993: 34).

The analysis and interpretation of the research material were conducted in compliance with principles of grounded theory (GT) methodology (Gorzko 2008; Charmaz 2006; Konecki 2000; Strauss and Corbin 1990; Glaser 1978; Glaser, Strauss 1967). Hence, the selection of subsequent cases for the research was of a theoretical character (*theoretical sampling*) based on the constant comparative method. Thanks to theoretical sampling, while collecting, encoding, and analysing the materials a researcher makes simultaneous decisions about what data to collect and where (Glaser 1978: 49–50, Strauss and Corbin 1990: 177). While applying the constant comparative method in my search for other data, I attempted to choose cases that are both highly diverse yet similar to each other, to grasp the maximum number of conditions that differentiate the presence of categories and their mutual correlations (Glaser 1978: 45–53, Charmaz 2009: 74). The selection of cases lasted until theoretical saturation was achieved: i.e., until subsequent cases confirm previous analytical findings (Glaser 1978: 142).

The usefulness of GT methodology in this research resulted, to a large extent, from the specificity of the explored environment. Using the methodology a researcher can lean on their

own experiences, and the direct contact with the subjects allows for the freedom to discover social phenomena that would be impossible to find with other methods, quantitative methods in particular. At the same time, the GT procedures offer specific strategies which can provide the researcher with ways to permanently verify and autocorrect the analysis of the empirical materials. Therefore, we obtain a whole array of tools that give the researcher significant flexibility, with the simultaneous possibility to continuously verify the analytical process. GT methodology makes it possible to attain the perspective of the social actors and grasp the processual dimension of the researched phenomena (Glaser 1978: 11). Additionally, the flexible approach to the data sources provides the researcher with the opportunity to lean on every kind of information, which proves to be especially important when the problems refer to phenomena that are difficult regarding both the collection and the analysis of the empirical data, especially when it comes to spheres of social life and notions such as disability. Data analysis was supported by Computer Assisted/Aided Qualitative Data Analysis Software (CAQDAS). The analytical and conceptual work was carried out using the NVivo application (Niedbalski 2014; Niedbalski and Ślęzak 2012: 141).

RESEARCH RESULTS

Nowadays, in times of exceptional dynamic changes in society, an individual has much more influence on creating one's own self and identity than it was possible only a few decades ago. This is related to opportunities to make multiple choices related to, among others, belonging to a given group or community. Thus, there is a possibility to experiment with the identification of self. This, in turn, enables the adoption of various identities multiple times, although these dynamics and this flexibility are not possible for everyone or in every case. An example here may be the parents of intellectually disabled children, who are significantly limited in this respect. Most of them are fated to being **assigned the identity** of a parent of a child with intellectual disabilities. This is because the importance ascribed to the child's disability by its parents is largely related to the importance ascribed to the disability by the surroundings (cf. Gustavsson and Zakrzewska-Manterys 1997; Kościelska 1995).

I don't think it would be anything new if I said that when somebody's looking at me and knows me, it means that they at least know my situation, they immediately think, "oh, he's the one with that disabled child." Unfortunately, there are almost no situations where others look at me differently [...]. It is sometimes helpful, but in most cases, it just annoys me and my loved ones [...]. It makes me feel like a "slave" to the role of a father of a disabled child [i.5.17]¹.

Among the respondents, one of the dominant experiences related to being a parent of a disabled child is the **sense of difference**. The parents quickly notice that they are treated in a special way, unfortunately often pejorative. The parents' accounts painted a picture of an

¹ I use indications of the cited fragments of my respondents' statements throughout the whole article, where the letter "i" means interview, the first figure indicates the consecutive number of the interview, and the last figure is the year when the interview was carried out. For example, i.5.17 means that it was the 5th interview carried out in 2017.

environment that emphasizes their “otherness,” which has a negative influence on the possibility of working out an identity based on the belief of their own value and an awareness of their competences. Therefore, parents of children with limited intellectual abilities relentlessly battle for their identification and identity from the moment their offspring are born. It is often the case – in particular in small, local communities – that the mother and father of a disabled child are not seen as “regular” parents, but they are stigmatized with terms such as “the mother of a cripple,” “a bad father,” or “miserable parents.” These kinds of labels destroy the image of the mother/father, meaning that they often feel a very strong sense of disappointment regarding their parenthood (cf. Stelter 2013).

It has happened to me more than once that someone looked at me in an unpleasant way or said something unwelcome [...]. Anyway, I can say that I encounter such situations, and it just happens to be painful. Unfortunately, they make me feel like I am worse because I have an irregular child, and I feel worse then. Seemingly, I have got used to it, and I try not to pay too much attention to it, but the emotions tend to be stronger than common sense. In any case, I am not the one who lacks this common sense; rather, it's the others that do [...] [i.9.17].

When the immediate environment of the parents of a disabled child sees them as “inferior,” they start to feel an aversion to themselves, to depreciate their value in various spheres of life, which consequently makes them susceptible to negative emotions and even depressive states (cf. Popielecki and Zeman 2000; Rola 2004). It is worth stressing in this context that a parent of a disabled child suffers not only because of the child's psycho-physical handicap, but they also perceive and define themselves in categories of a given dysfunction (cf. Kowal 2012: 170). This is related not only to them losing a “sense of normality,” or the inability to identify it, but also having socially acquired patterns of this “normality” and being aware that they are not fulfilled.

For me and my wife, it was probably the worst when the others let us know all the time that we were falling behind. It was not even about them doing it on purpose, but in different situations, often completely normal, it turned out that we and our little Janusz² couldn't do something, or to put it figuratively, we “didn't fit” the standards. [...] And it unfortunately often excluded us from various things [i.7.17]

A child's disability often causes a **sense of inferiority** among the parents, and this has a direct impact on the interpersonal relations with those around them. At the same time, the character of the disability stigma differs depending on the extent to which the child's dysfunction is visible (or at least concealed). In this context, we can adopt a differentiation made by Erving Goffman (2005 [1963]), of *discredited* and *discreditable* people. The former have clearly visible signs of stigma, and the latter represent a category of people whose stigma can be identified only after getting to know them better (cf. Ziółkowski 1981: 118). In the case of parents of disabled children, the difference is that one group has some “control” over the dysfunction of their children, allowing them to hide the dysfunctions. As a result, they function in the belief that it is not immediately visible, so they attempt to adapt to the requirements of

² All names in the text have been changed.

the society by masking the disability and avoiding any “problematic” places and situations that might expose them (cf. Goffman 2005).

Every time I’m somewhere, I try to stay out of sight. But it’s getting worse as time goes on because the older Jaś is, the more difficult it is for us to move him. He is just getting heavier and heavier, and as we get older, we’re running out of strength. And although we are lucky because his illness does not give such clear signs as it is not visible physically, he still has some problems with moving independently, and you know, as he grows, he just arouses the interest of others that he is in a pushchair [i.3.17].

While the discreditable are not capable of effectively hiding the dysfunction and disability of their children due to its visible nature, it deprives them of the possibility to manipulate impressions (Niedbalski 2015). As a result, they believe that their child’s dysfunction is not only visible right away, but it also fails to provide them with a chance to adjust to societal requirements by covering it up, which means that the only effective means of limiting “difficult” situations is to avoid any circumstances and places that might expose them (cf. Goffman 2005).

Everything was terrifying for me [...] I didn’t want to see anyone or show myself to anyone at all. I thought I was, hm, how can I put it, “maladjusted,” that I would feel out of place among people, especially since I wasn’t comfortable that I would be seen as someone else, different [w.4.17].

However, regardless of whether we are considering a family with a visibly or non-visibly dysfunctional child, as Kowal stresses (2012: 170), a disabled individual, through their “otherness,” **loses the embodied schemes of morality** which are rooted in social awareness. This is how a child’s disability is permanently present, not only in the individual but also in their loved ones, making itself known not only in a strictly physical sense, but also as being aware of the “otherness.” Disability violates socio-cultural standards on “normality.” Therefore, a child’s disability remains a source of stigma for the researched individuals, especially in those social relationships where it becomes a reason for discrimination. According to Stelter (2010: 136–137), this means that in the case of the parents of a disabled child, especially an intellectually disabled child, we can talk about different parenthood – a parenthood that is characterized by the undermining of existing values and the resulting objectives, and that is based on concerns about the future of the child and being exposed to the social exclusion of this child.

Unfortunately, I have to admit with regret, I’ve already experienced various forms of unpleasantness many times because of my child’s disability. And I’m not even talking about such mundane things as staring on the street or on a bus, or the strange comments of passers-by, but even in such places like clinics or health care centers, where you should expect greater understanding, I also had such situations that you know, what can I say [...] I wish people saw me and my child as human beings, and not through the prism of disability [i.2.18].

The parents are often exposed to critical, unfair opinions of their child and ways of dealing with these opinions, and this makes them avoid encounters with other people because they are afraid of unflattering comments, criticism, or false compassion. These additional problems can happen to the parents on public transport, in stores, at the doctor’s, and in places where the child’s appearance or “weird” behaviour arouses morbid curiosity, reluctance, a lack of

understanding, or condemnation of allegedly improper upbringing (Reyman 1994; Grodzka 1995; Chodkowska 1995). As stressed by Perechowska (2008: 146), in social opinion, intellectual impairment is an evil that people are afraid of. This only increases the parents' feelings of anxiety about the hostility of the environment. The source of such intense anxiety is usually not so much the signs of this social hostility as the generalized bad experience, brought, for example, from the hospital, or lying in the perception of the child and themselves in relationships with other people (Perechowska 2008: 146–147). Hence, parents who bring up disabled children must often struggle with the unfavourable, dehumanizing, and objectifying face of the support system. At the same time, they are caught in what we can call a **stigmatization loop**, because they experience the nightmare of double stigmatization: social stigma and institutional stigma. On the one hand, the parents need to consider the negative experiences they have had dealing with employees of various institutions. On the other, they are also labelled as beneficiaries of aid, which often takes a pejorative and stigmatizing character.

For me, it's derogatory to ask for help. It should be simple there, [...], without a need to file thousands of documents and to prove everywhere that you need it. I'll tell you something, I sometimes feel like a beggar or a thief, because on the one hand, I need to ask to get something that is necessary for my child; and on the other, due to this hate campaign against families of the disabled, now I feel like I'm stealing from our beloved aid system and our country [...] [i.1.19].

Stigma can also have consequences in the form of **social ostracism** because a family with a disabled child tends to be seen as unwanted by its environment, and this may be accompanied by negative attitudes or even signs of hostility in some cases. Thus, we can talk about the phenomenon of social isolation of children with mental impairment in the two aspects of external and internal isolation. External isolation occurs where the parents feel pushed away by the environment. Internal isolation happens when a family separates itself from the influence exerted by the social environment (Borzykowska 1997: 52). One of the main reasons for the separation of families may be the negative responses of the surroundings to them having a child with mental impairment, but there is also the desire to avoid resentment. Social isolation may also arise from society's lack of contact and experience with intellectually disabled individuals (Ostrowska 1997: 83). Society's knowledge of these people's life problems is superficial and shaped by stereotypical opinions. It is worth mentioning that signs of isolation may, in some situations, lead the parents to make radical decisions such as moving home, which is well-illustrated by this statement of one of my interviewees:

In a city, especially a big one, the situation of disabled people is different. You not only have everything there, and you don't need to go somewhere else that is tens of kilometres away, but the people are also different because they mind their business more. Or at least, that's my experience because, I'll tell you, we moved from a small village a few years ago because we had no life there. There was just this facility [an aid centre – note by JN], and everyone knew everything about everyone else; there was gossip, and they wouldn't let you live your life [i.2.19].

The disability, as a **source of shame**, makes the parents try to hide their child's impairment, which additionally strengthens their belief about the need to cover a given disability (Niedbalski 2015). The emotions experienced in this way were linked to a lack of cohesion

between the manifested “I” of the parents and the response of others to the presented picture of their child. As a result, according to Jakubowska (2009: 164), verification of ego becomes the most important field when considering emotions. Emotions are an element of social control here, mediated by the flow of feelings that accompany an individual. Particular stress is placed on emotions such as fear of sanctions or being tagged as weird (because the parents of a child with a disability – which is “different” from healthy children – are also seen as strangers; they are “different” from parents with healthy children) (Turner and Stets 2009: 124). As highlighted by Thomas Scheff, individuals are in a state of continuous self-awareness, especially in relation to feelings such as *pride* and *shame* (Scheff 1990: 81–82). Therefore, people monitor the ego on an ongoing basis, which makes them evaluate themselves even when they are alone, and consequently, this leads to them experiencing feelings such as pride or shame.

What can I say [...]. I was ashamed that my child was disabled. I mean, I thought about it that when others found out, I would be seen as a father of “that retard”. I know it’s sad, but I just felt worse than those parents who had healthy children. I simply felt miserable that I would be seen as the one who raises an unusual child, because that is how I perceived it. And I wasn’t wrong, because when it came out, it was like that; I mean, they made me feel it at work and in my family [i.9.17].

Therefore, a disabled child’s dysfunction may affect the entire self-definition of the parents regarding various social roles and contexts, such as the family, work, or simply relationships with other people. According to Becker (2009), a negative feature attributed to a person is generalized, and in the course of further negative markings, an individual tends to identify themselves with the assigned role. Therefore, frequent work on the body is related to the social “coercion”³ that determined the efforts the parents made towards getting their child’s appearance and behaviour as close as possible to a pattern of “normality” that is applicable in a given community (cf. Niedbalski 2015). These efforts are often rehabilitation and revalidation actions, which are intended to bring the child up to a level of psycho-physical development that it is possible for him or her to achieve. This is particularly visible in the period of early childhood, when the parents have already recovered from the shock of their child’s disability but at the same time have not come to accept the inevitable and undeniable condition of their offspring. Many parents stressed that this was a period of intensified work, but also progress manifested by achievements in terms of development, especially the child’s growing physical and motor skills. At the same time, numerous interviewees stressed that when adolescence begins, the condition starts to slowly deteriorate in terms of previous rehabilitation achievements. As a result, the parents were not only disappointed with the “elusiveness” of the previous “achievements,” but they were also accompanied by a feeling of resignation, sometimes apathy and withdrawal, and in extreme cases, depression (often of a recurring nature).

I did everything I could. I just said to myself that I would put Tomek on his feet, and I did. It was a very difficult period, physically, for me and for Tomek, of course, because he had rehabilitation three times a week in a health care centre, and I exercised intensively with him at home on the other days [i.1.18].

³ In vivo code.

The parents' struggles, their efforts and the labour that is intended to improve the condition of their offspring, and then the fact that the child manages to overcome its limitations, achieves an appropriate level of fitness, or takes part, as far as it can, in family and social life, mean that the mother and father's identity becomes closer to the identity of parents of a "normal child." This is why they ignore many of their own needs, often acting at the expense of the other family members; they do everything to make their child similar to other healthy children. For this reason, and also because of the need to provide permanent and round-the-clock care for disabled children, parents (mostly mothers) resign from their jobs. This exclusion from the possibility of starting or continuing to work has several important implications. First, there is the strictly material dimension: an actual decrease in family income since only one parent (usually the father/husband) continues with paid work. Second, exclusion from work actually means poorer interpersonal relationships, which become not only extremely limited but also quite "specified," and is largely due to dealing with other people who are also bringing up or taking care of disabled people. This **homogeneity of interpersonal relationships** means that the parents are almost always in a closed environment with people who focus on disability issues. It is also worth mentioning that the workplace is one area of everyday life that lets people get to know, interact with, and be with people from outside the family. Third, the need to resign from work means that a parent has no opportunity for self-fulfilment. For example, in their profession, they are trained or improve their qualifications and follow a path of professional development. The lack of these opportunities, in turn, may have negative consequences in how they assess themselves and may intensify the *feelings of alienation and isolation*.

There was no other option, not only because Janek cannot be left alone. Not when he was a child and not now [...]. It was very hard for me that I had to say goodbye to my job. Not that I would hesitate for a moment about what to do, because Janek has been the most important thing for me, but there was some regret, and it got deeper and deeper when people started moving away from me. It was because the contact with the people from work was lost, and I felt that I was outside of everything that not so long ago had constituted the content of my life [i.04.19].

An intellectually disabled child determines the family life, assigning particular duties, functions, and tasks to each family member (cf. Twardowski 1999; Pisula 1998). In the case of a family with a disabled child, its functions are most often distorted, and playing more important roles requires a serious amount of work, which involves a great deal of psychological stress (Bakier and Stelter 2010: 135). We can thus talk about the **disorganization of family life**. In extreme cases, the care and upbringing of a child with limited intellectual capability may go beyond the adaptability of parents. It entails a lot of unpredictable moments. The child with intellectually impaired results in parental and marital roles possibly becoming limited or distorted, and the homeostasis of the family system is disturbed or even broken because of conflicts.

CONCLUSIONS

Parents of children with disabilities live in constant tension, and their everyday lives are marked by a series of unpredictable and permanent changes, for which it is hard to find

available patterns or scenarios, as parents of fully capable children can do. However, this does not mean that the parents of disabled children are at the mercy of what fate will bring them, nor that they are guided only by fatalism in life. Many parents try to organize their everyday life and maintain the greatest possible influence on their lives and the lives of their loved ones. However, even if they manage to achieve a feeling of relative stability, it is still entangled with the uncertainty of considering the health or future of their child every day. Therefore, it is a “shaky” stability, and the stability and instability categories are intertwined, thus creating a minefield which families with children with disabilities must navigate.

In such conditions, in this “shaky” and uncertain everyday life, the help and support of the immediate environment, especially family (grandparents) and friends, become particularly important. It not only allows the parents to cope more easily with the hardships of everyday life, but also to deal better with all kinds of failures, problems, and dilemmas. Unfortunately, many parents complain about feelings of solitude caused by a lack of spiritual support, lack of optimistic but real consolation, isolation, and a lack of help and understanding from those closest to them (Mrugalska 1995: 68). For this reason, it is extremely important to be able to rely on help offered from outside as well as their own persistence and patience in overcoming various types of difficulties related to the improvement and upbringing of a child with special educational needs (Dykcik 2005: 43). The normal model of life for children with intellectual disabilities is living and learning at home among family (Wyczesany 1998: 146). Hence, parents should be able to choose the forms of assistance offered to them, such as individual meetings with specialists, joint meetings with the parents and child, specialist visits at home, and meetings of parents in small groups (Wyczesany 1998: 119).

It is worth mentioning that the effects of a child’s disability are different depending on whether they relate to the father or the mother. Contrary to those mothers who often find a kind of relief in their everyday care-giving and raising duties which make them feel that they are doing something important for their child, that they are indispensable, the fathers are usually less able to work out a counterbalance to their negative experiences. This is because it is mostly mothers who take care of their children, while fathers take up paid work in order to ensure the existence of the family. Such a situation makes it difficult for the fathers of disabled children to cope with the tension they experience. Hence, in the case of the father it is often observed falsifying the image of the present by not accepting the real facts, which is intended to remove the negative thoughts and feelings that would be related to that. In other words, reality is perceived through a prism of avoiding awareness of its unpleasant aspects. However, this is related to the risk that in reality the fathers of disabled children do not solve their emotional problems at all (Niedbalski 2019).

The parents need aid institutions to help them take care of their disabled children and help them work on their development, and to create a possibility for each family member to lead their own life. As families are most often not self-sufficient regarding care, therapy, rehabilitation, or the processes of empowering children with various types of diseases or categories of disability, they need a whole range of services, and the parents should be provided with information about what they can utilize and where they can turn to (Mrugalska 1995: 78). As Dykcik emphasizes (2005: 30), in fulfilling various needs and expectations, the family are supported by various specialized health, education, multilateral therapeutic and

social support institutions, and it is worth stressing that when it comes to these institutions, it is the staff that creates a friendly and trustworthy environment, which the families with children so much expect. Those specialists must remember that every family is different, so how they communicate information about the child should be individual (Gałkowski 1995). Therapists who want to do their job well should provide the least stressful experiences for parents. It is thus important they be aware of their own personality features, and they have insight into their own system of values. Seeking help from others is particularly stressful for parents, so therapists should not hide the truth from them. They prefer an honest and open attitude to communicating information in an unintelligible, authoritative, and imposing manner. It is quite common that unsatisfactory assistance forces parents to travel from one centre to another in search of better therapists and more effective therapies for their child. These efforts often fail to provide satisfactory results, and they only deepen the parents' stress. This leads to helplessness, discouragement, and chaos, which does not serve the child or its family.

The combination of differences (and, at the same time, similarities) and generated needs is very specific, which means that even at the level of the disease itself (the type of disability) it is difficult to indicate a universal and always proven scheme of parental actions, and thus a set of activities necessary to meet the child's needs. It is more frequent that the disability is seen as a personalized notion, one depending on individual factors, and as such, the child's needs must be determined and verified, along with the level and type of support necessary for the family and the child to function. This, in turn, greatly complicates and hinders the possibility of actual aid and support offered by the institutions and organizations established for this purpose. The result is that the families acutely feel the gravity of situations in which there is a lack of compatibility between the support system and their needs in bringing up a child with disabilities.

Summing up, families with a disabled child require a systemic national policy to consider multidimensional support, including targeted financial aid, which would ensure equal opportunities for the normal social functioning and correct development and care of a disabled child.

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ZAGROŻENIA DLA TOŻSAMOŚCI I POCZUCIA PODMIOTOWOŚCI RODZICÓW DZIECI Z NIEPEŁNOSPRAWNOŚCIĄ INTELEKTUALNĄ W KONTEKŚCIE DESTABILIZACJI ŻYCIA RODZINNEGO

Życie rodzin opiekujących się osobami z niepełnosprawnością pełne jest nieoczekiwanych wydarzeń, niechcianych sytuacji oraz piętrzących się na każdym kroku trudności. Z tego względu na potrzeby niniejszego artykułu skoncentrowałem się na wskazaniu tych warunków, które są źródłem destabilizacji sytuacji rodzin z dziećmi z niepełnosprawnością. W ten sposób staram się zrekonstruować źródła zagrożeń dla poczucia podmiotowości oraz kształtowania się tożsamości rodziców dzieci z niepełnosprawnością. Ramą teoretyczną przeprowadzonych analiz uczyniłem symboliczny interakcjonizm. Materiał badawczy wykorzystany w prezentowanym opracowaniu stanowią osobiste doświadczenia rodziców osób niepełnosprawnych. Z przedstawicielami tej kategorii badanych przeprowadzone zostały wywiady swobodne mało ukierunkowane. Analiza materiału badawczego została oparta na zasadach metodologii teorii ugruntowanej.

Słowa kluczowe: rodzina, niepełnosprawność, tożsamość, podmiotowość, życiowa destabilizacja

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