

JAKUB NIEDBALSKI
University of Lodz

The Trajectory of Suffering—Parents of Children with Intellectual Disability on the Future

Abstract: The aim of the research was to characterize the situation of intellectually disabled individuals and their families, with special stress on parents' doubts and dilemmas which grow as their disabled children mature and enter adulthood. The subject of the study was to analyze the processual character of transformations related to bringing up children with intellectual disabilities that take place in generational families, in particular, those which are related to transformations on the level of parents' perceptions, role, and identity. These notions were reconstructed on the basis of the personal experiences of parents of disabled children. The theoretical basis of the research was the concept of a trajectory of suffering, and the applied methodology was the grounded theory methodology.

Keywords: parents, children, disability, trajectory, qualitative research.

Introduction

The family is the space where a child's development and upbringing take place. It is where an individual first develops and acquires the characteristics and attributes of a "socialized person." In particular, in the first stage of life, a child is completely dependent on their closest caregivers. A properly functioning family, its permanent blood ties, and strong, stable, emotional, and social bonds are a condition for the successful development and upbringing of every child (Dykcik 2005: 28). It can be considered that both their life as well as physical and mental development are strongly influenced by the quality of care and contact with their parents.

Thanks to socialization and upbringing, a child becomes independent, and the parents of a properly developing child can proudly look at a growing young adult. Parents should enjoy the sight of growing children and the changes that take place inside them. These changes lead to maturity, in particular, to parenthood, and although the majority believe that it is one of the most important components that fulfill the lives of individuals, it is also related to numerous hardships, responsibilities, and many challenges. All the more, any changes and development of a child should be seen as a reward for the efforts of parenthood.

It is different in the case of people with intellectual disability, in particular, those of a significantly lower level of intelligence, because it is difficult to achieve the same psycho-social development level that could provide any basis for life autonomy or independence in social relationships. This, in turn, means that the expectations and requirements of peo-

ple with intellectual dysfunctions must be different as well. The situation of families with intellectually disabled children is thus, by its very nature, specific, and at the same time, it requires separate treatment. Parents are not able to enjoy the independence of their intellectually disabled children, or the progress and transformations that lead to maturity. Despite the great effort required at every step, parents of children with intellectual disability (especially those with severe disability) do not usually have the opportunity to observe their development, as is the case in families with fully capable children.

Furthermore, long before the child reaches adulthood, the parents usually know that their offspring will never be fully independent and self-reliant. Living with such a vision, they continuously need to work on themselves, applying various techniques that counteract their negative perception of reality, and which allow them to preserve relative mental and emotional stability. Therefore, the aim of my research is to reconstruct the process of the trajectory of suffering of a parent of a disabled child. I attempt to place this process in the wider context of the psychosocial conditions associated with the difficult experiences of parenthood and a worrying vision for the future. At the same time, I look for factors and conditions that enable parents of children with disabilities to maintain relative peace and quiet, mental balance, and, above all, the ability to act as mothers and fathers, often combining these roles with other types of social or professional activity.

A Child with Disability in a Family

There is a long-standing tradition in Poland related to research into disability carried out by scholars with backgrounds in such sciences as pedagogics, psychology, or sociology. One area of attention is the situation of families with a child with disabilities. A diagnosis of abnormalities related to periodic developmental disorders, long-term illness, or permanent disability makes it possible that a family may experience serious disturbances in its adaptive and protective functions (Dykcik 2005: 30). Parents experience such a diagnosis deeply, and they are usually unprepared to face new and difficult tasks. Kościelska (1995: 43–65) details the whole range of emotions that accompany the relatives of such people. She suggests that these emotions mostly concern the mother (with a higher risk of giving birth to a disabled child), who experiences a series of anxieties and concerns that accompany her before motherhood, during her pregnancy, and primarily as soon as the child is born (ibidem: 43–55). While describing emotions related to identifying the defects and handicap of a child, Kościelska (1995: 46–50) presents the following range: the fear of hostility, concern about missed opportunities, the fear of their child confronting new life situations, as well as fear of the future. Another, equally difficult feeling that the parents of a child with disabilities are tormented with is the one 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.

The studies show that one of the effects of intellectual disability in a child may be the underestimated self-esteem of the parents. The sense of value that is experienced by parents raising intellectually impaired children is often lost, which in turn leads to social

exclusion. Many families experience marginalization within themselves (Kowalik 2001). Society avoids any contacts with disabled individuals and their families, as they are afraid of their differences, problems, and sometimes strange, incomprehensible behaviors. This, in turn, leads to so-called apparent integration. In other words, we are in favor of it unless it affects us personally, e.g., we support integration, but we do not want our child to be part of an integrated class (Stelter 2013: 35–36). According to Kościelska (1995: 53–54), with the birth of an “irregular” child, some parents experience the “irregularity” of themselves, which may sometimes take the form of self-destruction or even an identity crisis. Such a situation determines the hostile attitude not only towards themselves but also towards their surroundings. Dykcik (2005: 37) concludes that the disability of a child in a family is often grasped in negative categories, namely crisis or conflict, or destructive ones, in particular, in the case of a significant functional imbalance. According to Mikołajczyk-Lerman (2011), the everyday difficulties of a family with a disabled child are related to all spheres of married-family life and to all members of the family. A characteristic feature of the functioning of families who care for a disabled son or daughter is the deteriorating physical shape of the parents associated with the aging of the body. When we compare that fact with never-ending—or sometimes increasing—problems of disabled adults, we can see that family resources shrink in the face of even greater family-life challenges (Cytowska 2012). The research carried out by Pisula and Dąbrowska (2004) shows that expectations of mothers towards their child’s future differ regarding the age of the mothers and the children. Mothers of older children are usually aware of their offspring’s limitations and barriers that are hard to overcome, while mothers of small children believe in positive and big changes in their child’s functioning. On the other hand, the purpose of Żyta’s (2011) research was to describe the thoughts, feelings, and reckonings about various life aspects of family members of people with Down syndrome. One notion that was often raised during the interviews she conducted was planning the future of intellectually disabled individuals, and the vision of the adult life of those with Down syndrome developed by family members.

Also, numerous foreign studies suggest that thinking about the future of disabled children is something permanent in their parents’ lives, regardless of the period of life they are currently in (see Docherty, Reid 2009). The main topics of foreign research devoted to families of intellectually disabled adults can be determined therein. They include notions of parenthood and fulfilling the role of mothers/fathers towards adult children (Heller, Arnold 2010). The problems of adulthood and fatherhood of adults with various types of disabilities also appear (Hodapp 2007; Hodapp, Glidden, Kaiser 2005). There is also research into the challenges of parenthood roles in the context of long-standing care and support in generation families (Miltiades, Pruchno 2001). Researchers’ interest is also stimulated by the aging 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, Seltzer 2007).

Contemporary British and American studies carried out into families with disabled adults using the clinical research model raise the problem of adapting to the role of a parent-guardian. What is more, there is multiannual research carried out regarding the positive and negative impact of children’s disability on the physical and mental fitness of parents and siblings in connection with their lifelong roles of guardians. Contemporary research

also covers the issues of parents' aging, as guardians, and the aging of their adult children. Seltzer, Floyd, and Greenberg (2005) analyzed the relationship between the lifetime and long-term disability of children and the health status of their parents. They found that parents with an adult child that has been disabled for its whole life would face untypical caring challenges, which may cause stress and impact their health. In turn, Johnson (2000) notes that stress related to being a long-standing guardian for a disabled child is a risk factor that may increase the probability of there being physical and mental consequences for the parents. On the other hand, Richardson (2012), in her research into the level of stress, cooperation, and satisfaction of married couples with children with intellectual disabilities, found that the most difficult period for parents seems to be the period of childhood and adolescence. Those parents, as well as the parents of children with an intellectual standard, observed a decrease in the quality of the relationship during childhood and adolescence. However, there is an increase in the quality of mutual relations when the disabled child, despite their adulthood, still requires care, and the mother and father are often afraid of what will happen to the child after their death. Stelter (2013: 71), while interpreting Richardson's research, concludes that this increase is due to the fact that parents do not expect their child to be independent, so they are not disappointed that the child is still at home despite it being an adult. Additionally, over the years, parents develop satisfactory ways of working together as a couple to enjoy the relationship and each other, sharing responsibilities and coping with difficulties (Gorchoff et al. 2008).

Summing up, we can say that a family with an intellectually disabled child fulfills 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 influence. A family that brings up a child with 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 often poses a specific stress factor. However, the very presence of a child with limited mental capabilities within a family system does not make it dysfunctional at once; it is only the way in which families deal with the crisis of the child's disability in different situations and periods that determines its functionality or dysfunctionality (Stelter 2013: 33).

The Methodology of the Research

The methodological framework for the research is shaped by the principles of grounded theory by Glaser and Strauss (Glaser, Strauss 1967; Glaser 1978) and the biographical method (Denzin 1990). As suggested by Domecka and Mrozowicki (2008: 139), the combination of those two methodologies is possible thanks to the cohesion of assumptions that they are based on (i.e., assumptions of the processual character of social reality and the bilateral dependence between the actions and the shape of a social structure), and it is recommended when the procedures of both these approaches are treated as complementary. On the one hand, the biographical data present a whole picture, which is composed of the actor, as well as the action, the context of the action, and the connections between those elements. Reconstructing these elements is a necessary condition to understand the researched phe-

nomenon. On the other hand, the analytical procedures of grounded theory make it possible to go outside the individual life stories and explore general patterns and mechanisms that shape the social relations and the logics of actions (Domecka, Mrozowicki 2008: 139).

Selecting the above methods allows us to reflect on the processual character of reality (Glaser, Strauss 1967; Strauss, Corbin 1990) and to adopt a holistic view of the research subject. In the context of this research, it is also important that these methods provide a chance to gain an insight into the problems, seen through the subjects' eyes (Hirschfield et al. 2005: 252). It is significant, as the research assumptions were based on the desire to learn about the subtle nuances and to reach the subjective ways of perceiving the surrounding reality. As a consequence, an attempt is made to understand and interpret the individual meanings for categories of disability provided by the child's parents.

The research material adopted in this study is information obtained from parents who have experienced significant transformations in their lives related to the process of bringing up and taking care of their disabled children. Non-structured, free interviews were conducted. The use of this type of data acquisition tool meant that each of the interviews was individualized. This means that the course of each interview was moderated on an ongoing basis, and its content depended primarily on what issues were pointed out by the interviewee and how he/she emphasized the information that arose during the interview.

In total, at this stage of research, 35 reviews were carried out between 2017 and 2019 among parents of children with intellectual disability. The interviews were performed with 22 women and 13 men, between 36 and 78 years old. The interviews usually lasted from 1 to 3 hours. Before analysis, the interviews were transcribed verbatim, preserving the details of the interviewees' utterances as faithfully as possible.

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, the researcher, while collecting, encoding, and analyzing the materials, makes simultaneous decisions about where and what data to collect (Glaser 1978: 49–50; Strauss, 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 and 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 the moment when subsequent cases confirm previous analytical findings (Glaser 1978: 142).

The Parenthood of a Child with Intellectual Disability— a Trajectory Process of Suffering

Only a brief description of the trajectory model will be presented here, taking into account the specific situation of parents bringing up a child with limited mental abilities. For this purpose, we will refer to the course of the trajectory process proposed by Riemann and Schutze (1992, 1997), and we will illustrate it with reference to the observations made by Zakrzewska-Manterys (1995) in her book entitled *Down and Doubt Syndrome. A Study in the Sociology of Suffering*.

The trajectory process is usually extended in time, and it rarely begins suddenly or spontaneously. Information that a child is intellectually disabled may be one such case. The very moment that a disability “appears” in the parents’ (and, more broadly, the whole family’s) lives is highly differentiated and can refer to the pregnancy (which often happens nowadays in the era of prenatal examinations), but also to some perinatal circumstances or various complications that accompany neonatal and early childhood diseases. However, regardless of when this moment is situated in their life space, it is always unwanted and brings a whole array of extremely difficult experiences and negative emotions. Using the nomenclature adopted by Riemann and Schutze (1992, 1997), these events can be described as an “accumulation of trajectory potential,” i.e., the possession of certain biographically conditioned dispositions to be wounded. In the case of the parents of intellectually disabled children, their expectations of the child (especially an unborn one) and of their parenthood may account for this potential, and thus herald the future trajectory. The average parent wonders who their child will be in the future and what it will achieve, as opposed to whether their child will ever speak, walk, or be able to live independently. It does not occur to them that their child may be far from perfect. As they do not think about any dangers of the potential trajectory, they do not have any resources accumulated to counteract it; therefore, the potential of trajectory has the conditions to grow (Riemann and Schutze 1992: 104). Accumulating the trajectory potential takes time, and it does not stop at the moment of diagnosis, which is often rather a presumption than a fact. This means that parents function between some calming thoughts—“everything is fine”—and the overwhelming and difficult to control fear that something bad has happened. As Zakrzewska-Manterys writes (1995: 88),

this flickering of trajectory constituted a circumstance which, on the one hand, facilitated psychological coping with the situation, giving me the hope that maybe the ‘situation’ does not exist. However, on the other hand, the destructive power of the growing welter could not be ‘tamed’ by mechanisms of dealing with the situation, since the entire effort of consciousness was focused on dealing with the trajectory.

A consequence of these events is the breakdown of expectations towards the normal (and thus known) course of events. As Riemann and Schutze (1992, 1997) state, a person affected by a given problem cannot shape their everyday life through active patterns of action. This phase in the development of the trajectory process is described by the authors as “crossing the border between the intentional and the conditioned mental state.” The same applies to the parents of a disabled child, who are aware of the painful but irreversible truth that they can no longer live according to the schemes they know. Referring to her personal experiences, Zakrzewska-Manterys (1995: 93) describes those events as follows:

All determinants of my identity become blurred, and they were replaced by a certain internally determined state of mind forcing me to put myself into one category only: a mother of a handicapped child. Some dominating feelings start to appear, telling me that me and my child will ‘always,’ ‘to the end of our lives’ be doomed, that nothing else will ever be important again.

Over time, an individual is capable of achieving a balance in the sphere of everyday matters, although this condition is difficult to be defined as stable, and this is related to the fact that responses to trajectories are usually inappropriate. Thus, this phase was defined by Riemann and Schutze (1992) as the ‘unstable equilibrium of everyday life.’ It often leads

to the phenomenon of “accumulated disorder” as a result of concentrating on one mode of problems and avoiding others, which generates side effects and leads to the overlapping of different problem systems. As a result of the “accumulated disorder” and irrational actions, an individual breaks down. They become a stranger to themselves, and they are no longer able to act as before; they do not understand themselves (Stelter 2013: 121). In hindsight, it can be seen that all kinds of actions from this period are not characterized by logic; they are not connected with each other. As Zakrzewska-Manterys writes (1995: 97),

there is no time or ‘logic’ link between them; they are just a mosaic of different scenes. Visually speaking, my theater does not stage a play, but a cabaret where each actor performs a different sketch and their order is arbitrary. (...) The events ‘swirl,’ as if around the most important problem, namely the suffering, but they do not touch it directly.

Another phase of the trajectory process is the so-called “break-down of orientation towards oneself” (Riemann and Schutze 1992, 1997). An individual experiences disintegration of everyday actions. They stop coping even with simple things that they had dealt with in everyday life until then. There are doubts as to whether anything still goes on in the familiar mode. The world seems to be strange, and the individual stops trusting themselves. There are doubts regarding their possibilities, their own identity. As Zakrzewska-Manterys claims (1995: 99), the doubts also pertain to others—doctors, rehabilitators, welfare institutions, and the people closest to them. The situation becomes very complicated as, on the one hand, the person affected by the trajectory does not trust others, and on the other, they feel the need for support and understanding. At this stage of the trajectory of suffering, the parents of a child with restricted intellectual capabilities can focus all their effort so no one knows that their child is disabled. Alternatively, they can devote their time and effort to confirming/rejecting the diagnosis, or they can rehabilitate or care for that child (Stelter 2013: 121).

After the breakdown in self-orientation, an individual understands that what happened is something very important and will have a significant impact on their life. This is done through an attempt to explain the reasons for their own suffering and through the moral evaluation of the occurrence, namely the “rationalization of the trajectory” (Riemann and Schutze 1992, 1997). Redefining one’s own situation is also an analysis of the influence exerted by the process of suffering on the previous, present, and future mode of life. A new self-definition may trigger the desire to escape or contain its dynamics (Stelter 2013: 122). This is how Zakrzewska-Manterys comments on this situation (1995: 106–107):

This is when I started to realize that no one but me can be responsible for defining my biographical situation (...). I was becoming aware that the possibility of getting out of the trajectory will never appear as a result of ‘doing something’ with my child, but only as a result of doing something with the sense of my world. Anger and rebellion were the dominating feelings of that time. I rebelled against the world, which offered me various definitions of my son (...). I rebelled against my own helplessness and loss. However, I rebelled against something that could be called my symbiosis with the world.

Ultimately, with a new way to define his or her own life situation, an individual takes steps to either escape from or to gain control over the trajectory, thus undertaking practical work on the trajectory (Riemann and Schutze 1992, 1997). Escaping from the current life situation is not an escape from identity burdened with suffering. The only appropriate solution to this situation is an attempt to organize their world in such a way that will allow

the individual to live with the trajectory. For the parents of an intellectually disabled child, burnt trajectory potential may mean accepting a child as it is and accepting themselves as parents. This moment is best reflected in the words of Zakrzewska-Manterys (1995: 108), who says: “the birth of my child was the most enriching, the most valuable experience of my life.”

The trajectory does not always develop according to the above-mentioned stages. It may be a fuzzy process, where successive stages overlap. The chronology of the process—where deviations from the basic scenario may occur—will not be preserved. It is the process of following an individual path through suffering.

The Trajectory Process Continues...

After an extremely turbulent and dynamic time, when the parents go through the five stages of the trajectory of suffering already mentioned, the situation becomes relatively stable and work on the trajectory starts. However, it turns out that it is not a condition that can be described as a current state. On the contrary, it can be seen in terms of *unstable stability*, because in the life of a family with a child with disabilities, there is nothing completely stable and secure, and the dynamics of change often lead to inevitable perturbations. Despite that, to some extent, the parents succeed in taming the course of the trajectory of events in the sense that they are aware of it, they can comprehend it better, and they can redefine and work out appropriate strategies of action. However, such temporary “calming down” of a situation is interrupted when the child enters the next stage of development, namely adolescence, and later maturity and adulthood. This is also characterized by relative stabilization, but it is preceded with another “awakening” of the parents.

In other words, each breakthrough may not become a starting point of a biographical action plan, only a relatively short period when the trajectory is no longer a processual structure that dominates the lives of parents of a child with disability. This is true biographical irony because the trajectory process emerges from a highly active biographical process. Riemann and Schutze (1992: 98) point out that such a trajectory process, at least in the beginning, throws the individual into a state of shock, passivity, and even sometimes into a state of paralysis, especially when it comes to organizing everyday activities. It is often the case that in the middle of those breakthrough events, when the parents feel that they have just discovered some new potential to act, they are burdened with the upcoming changes which are related to the beginning of their child’s adolescence. It is clearly stressed in the following statement:

Yes, well, unfortunately, when we thought we were past the worst, and that it would be just better, it turned out that we were just entering the time of real disappointment, because even though we managed to do a lot and let’s say we were out of the woods with Maciek, there came the deadlock at the beginning of his adolescence, and gradually, instead of improvement, there was deterioration, returning to the previous state. So, my wife and I realized that we can’t do more, or even that it might get even worse, which really worried us because we thought about the future right away [i.18.02]¹

¹ I use indications of the cited fragments of my respondents’ statements throughout the whole article, where the letter “i” means an interview, the first figure indicates the year when the interview was carried out, and the last figure is the consecutive number of the interview.

This fragment explicitly demonstrates that during a spontaneous narration, and the recollection process characteristic of this narration, the person is usually dragged into the stream of experiences for the second time, characterized by the chaos of expectations, orientations, and relations to the world and identity.

The “awakening” often takes place gradually along with situations that appear (more and more often), e.g., when the parents start to lack strength or when a child reaches a certain size, so it is hard to move the child freely and without much effort, etc. This is how the parents’ lives (and other family members’ lives) change after coming to terms with a disability, when it is again brought down to *reconstructing the way of organizing* various aspects of life. It means, in practice, that parents cannot manage their resources, for example, time, the way they used to, but they also need to plan for a variety of circumstances that pertain to their child.

For us, that meant turning our world upside down. That’s the truth. When Tomek was born, everything changed. I needed to take care of the child, and I stayed at home. While Tomek was small and I had more strength, I coped on my own. But when he grew up, when he became bigger than me, it was no longer possible for me to take care of him on my own. So, my husband needed to help me more, and this was another moment that we needed to rearrange some things, change something in our life [i.18.10]

When a child enters adolescence, there is not only the need to reconstruct how life is organized, but there are also some new problems that the parents had not encountered before. Therefore, there is a need to update previous and developed formulas of coping with the everyday life of being a parent of a child with disability. In this context, a significant problem of parenthood is the parents’ dilemmas regarding their willingness to provide their child with conditions for independence. It is often accompanied by questions related to the child’s sexuality. According to Giryński, adolescence is a particularly important stage in the development of a mentally disabled person, when their needs in this area of their life begin to grow, regardless of the their psychophysical condition. Based on his research, Giryński (2005: 61) claims that parents and teachers are not always willing to support the psycho-sexual development of intellectually disabled children. This is reflected below in the fragment of a statement made by one of my interviewees:

He does those things, he does, unfortunately. He, himself. I don’t know what he really does, but he feels and enjoys it. You don’t need a fit mind to feel pleasure. But I’m not going to explain this to him, I won’t tell him what it means. Because how I am supposed to do that? It is as if I was talking to a child about these things [i.17.04].

At the same time, as suggested by the statement above, disability means permanent unpredictability. Many parents point out that there is no guidebook that can show what to expect in a given moment of development. Often, disability is associated with a kind of puzzle and uncertainty as to where the disability ends and where the child’s character traits begin. However, a particularly perceptible consequence of the disability of their child is the necessity to give up numerous things (Sałkowska 2015: 117). However, many parents do not identify this abstaining with sacrifice; staying at home and taking care of the child—especially for mothers—is usually treated as a conscious decision, not coercion (although this is how it is often perceived by those closest to them). Furthermore, the disability may mean giving something up, but at the same time, it can be a challenge for parents (*ibidem* 2015: 118).

No, it's not like it was a problem for me that I had to quit my job. There was simply no other way, but it was not like I broke down instantly; but every day, every hour that you need to plan—that was the challenge [i.19.07]

The issue of the future of a disabled child is both problematic and painful for parents. There are doubts, and there is also an important question they must ask themselves: what will happen to my child after my death? The more the child depends on carers, the more difficult the question becomes. The awareness of putting a child in a place that fails to guarantee development and support is often painful for the parents. Konicieczna (2012) attempted to answer the question of how parents of people with intellectual disability respond to the issue of providing their child with a decent existence in the event of their own illness and/or death. It turned out that only a small group had thought this issue through and was capable of verbalizing their decisions. Almost half had left the decisions to other people, to institutions, or to God. Their statements show that they did not see a good solution to this problem. They were bitter because of the low quality of services offered by social welfare homes, and they experienced an abject lack of support from the institutions as well as their family and friends. Some directly expressed the belief that it would be better if their disabled child died together with the parent or shortly afterward (Konicieczna 2012: 279).

I can't imagine what might happen to Magda when she's left alone. I say alone because I don't want to get my other kids involved in this. They have the right to their own lives. They must remember about their sister, but I can't expect them to give up their own lives for her. It's enough that I had to do it. But on the other hand, I can't imagine Magda going to an institution. Nobody will provide her with the help she receives from us at home. I prefer not to think about it because it simply terrifies me [i.17.04].

For parents, this means crossing another border or reaching a turning point, when they realize not only that their child is different, but also that there is a new version of this “otherness,” which means their son or daughter will be unable to achieve subsequent stages of both psychophysical and social development. This leads to a breakdown in expectations for a normal (known) course of events that they were used to, and if it is not due to their previous personal experience (e.g., because they already have healthy children), it is due to their biography where they transferred from childhood to adolescence, and maturity to full adulthood. A parent realizes that they can no longer live according to the schemes they are familiar with, and the narration often brings such phrases as “always” or “for the rest of my life,” which means that they start to realize the inevitability and unchangeability of the situation they and their child are in.

Reasons for Increasing Trajectory Potential

The majority of actions involved in taking care of an intellectually disabled child are related to nursing and working on a body. Feeding, hygiene, washing, administering medications—all of those actions are in the foreground, and they are the daily struggles of caregivers. The endless repetition of procedures accompanied by the accumulation of new responsibilities and interaction problems (there are often some tensions between the parents in the background) mean that, for the family members, adolescence becomes not only a time of other disappointments but also feelings of hopelessness and anguish. This is especially true as

it is gets harder and harder for the parents to carry out particular actions with their son or a daughter as the child gets older and there are physiological changes.

At the same time, the changes in appearance and behavior of an adolescent child with a disability are not only a source of suffering for the parents, but they also threaten how they maintain relationships with those around them. Bodily changes often lead to a reconstruction of the way an adolescent child with a disability is perceived by others, and such children may directly cause reluctance or even disgust. The body, as a carrier of biographical identity, changes significantly and sometimes very visibly during adolescence. What an individual has been so far is irreversibly changed, leading to the need to reconstruct other people's vision of the individual.

A small child with a disability, even though different and often with a clearly visible dysfunction, is better received by the social environment than adults and adolescents. It also often happens that during childhood, especially in infancy, a disabled child is not very different from his or her fully capable peers. This makes it easier for the social environment to accept such children, and they trigger less intense responses to their disability, which directly influences the relationships between the parents and the "outside world" (external to the family). A new condition arising from a disabled child entering adolescence may mean that others are unwilling to deal with the disabled child, creating a greater distance between themselves and the child and, as a result, the parents. This refers not only to strangers but even the closest relatives who avoid serious conversations with the parents, are uncomfortable, and become not only emotionally but also psychologically distant. One should look for reasons for this condition in the socio-cultural perception of a body which is considered to be normative. Changes in the appearance of an adolescent child with a disability are a clear contradiction of this normativity, which makes them a barrier that is difficult to overcome for many, both in their perception of disability but also through direct contact with someone who has some visible and not concealed dysfunctions.

Unfortunately, as Staś grew, he no longer fitted in a regular baby stroller, so we needed to take him in a different, special stroller. And then it was no longer possible to hide that he is not a normal child because the stroller itself aroused some interest. But it was even worse when Staś's appearance changed, and he turned from a child that looked almost normal into a teenager and then an adult who clearly looked like an ill person [i.18.02]

Another cause of the increasing trajectory potential is the issue related to the growing gap between the expectations of parents and those around them, and the restricted psychophysical abilities of the disabled individual. Adolescent children taking over the roles and responsibilities of aging parents deepens the dissonance between the parents of healthy children and the parents of children with disabilities. There is a social expectation, and there are social "standards," but they cannot be met by disabled children.

Well, I know that Bartek will be an adult, but he will never have kids, and my husband and I will be older, but we will never be able to count on support from our son—this just won't happen. He will never achieve the level of development to be self-reliant, independent or responsible not only for himself, but also for others [i.18.09]

Parents desire self-sufficiency for their child; they hope that their son or daughter will do well at school and will have a successful career in the future. A child with special needs is not only a threat to those dreams, but these two aspects often rule out each other. It

is worth noting in this context that adulthood is not only a metric fact but also a process related to achieving subsequent stages of maturity. It is composed of biological maturity (the end of growth processes and the arrival of the ability to procreate), social maturity (e.g., the ability to live independently), and emotional-moral maturity. Maturity can also be seen in accepting oneself and one's own limitations. This is also a period of undertaking family, social, and professional roles. Unfortunately, also in this aspect of life, the parents of an intellectually disabled child must usually come to terms with the fact that their son or daughter will never become a mother or father, they will never start a family or have a fully independent life.

I'd really want that, really, but I know that it's completely unreal. I know not only that I will always be a mother of a child that will never grow up, but also that my child will never be a parent. And because this is my only child, I will never taste what it's like to be a grandmother, because I'll never see my grandchildren [i.18.06]

At the same time, the frustration and disappointment of parents of a child with disability are intensified because of social requirements and expectations both towards the parents themselves and their offspring (especially an adolescent child). Parents see their child through the prism of social opinion, according to which one of the most significant values in life is having your own child. You must love it, take care of it, and do everything to provide your child with the best development possible. When a child is intellectually disabled, the parent realizes the negative evaluations ascribed by the social environment to those children. This leads to an ambivalent attitude towards a child that, on the one hand, must be loved, but on the other, is rejected because it is handicapped. This is the case with many parents—the crisis of values is gradually replaced by a new kind of a crisis, called a real crisis, which involves providing a child with proper care and rehabilitation. Overcoming the crisis is based on dealing with the problem of handicap, which the parents will need to deal with until their death (Kowalik 1989).

For me, now, it's most important that Magda has the best possible living conditions. I know I won't change how she is, and I can't do anything else to heal her. I can just give her a sense of comfort, peace, and the best life possible despite various unfavorable conditions and many barriers or limitations we need to face together [i.17.05]

The changes related to a child entering adulthood are replaced by the parents' concern about the quality of life, in particular, the process of aging and the vision of their death. According to Sałkowska (2015: 91) “parents at the beginning of their parenthood, when their child is still small, fear that it will experience a significantly reduced quality of life, because this is how they would feel in the place of the child, not being able to benefit from all intellectual opportunities or entertainment.” These concerns grow over time as the child matures and becomes an adult (in a physical sense). The parents gradually start to feel not only the problems related to their aging but also those which result from the physical changes in their son or daughter which accompany the adolescence. The changes are largely related to their child's increased weight but also to their development stopping or even regressing.

Tomek is like my beloved cat. This is how I refer to him caressingly, because he fawns all over me, but sometimes he can also show a claw (laughter—note by JN). A big cat, as you can see, because he's already an adult man. He's an adult and I'm becoming old. This is where I see the problem for the future, he will be bigger with time and I, well, nobody will give my additional strength, and time is unfortunately passing [i.18.03]

The parents' concern is not only about caring for the child but also meeting his or her physical and emotional needs. They demonstrate their full and unconditional acceptance of the ill child with every gesture and action. In expressing such full acceptance, non-verbal communication channels, such as gestures or using the eyes, etc., prove to be the strongest forms of communication. Touch, as an act of communication, becomes the basis for a strong bond with the child; it is an expression of physical presence and, at the same time, the full acceptance of the child (cf. [Kacperczyk 2006: 248](#)). In Heslin's taxonomy (1974), touching someone in this way is merely functional and professional, which means that touching someone is purely instrumental, intended to accomplish a given task. In the accompanying actions, the person who is touched is treated more like an object than a human being. Thus, the parents' concern is that their child will be treated as an object; it will be deprived of the dignity and subjectivity that the parents have struggled to achieve and express through their own actions.

Who better than me will be able to understand Maciek? I've been with him for years, and I know his every gesture, every move, every grimace on his face. We have this language of ours here, a way of communicating. And you need to have the patience of a saint with him. This is why I don't know if anyone else would be able not only to devote as much time as he needs but even to try to understand him [i.18.05]

Intellectually disabled children are often helpless, dependent on others; a child that does not understand the surrounding world is unable to solve simple everyday problems. Such children often have problems with communication, cannot express their needs and feelings, and they are lost, even among relatives. This means that the parents may *feel mentally mutilated* when dealing with their child due to the child's restricted possibilities of self-realization. They are incapable of dealing with everyday problems; they are incapable of defining their feelings and needs; they are lost among people who do not understand their suffering. One of the dominant experiences related to being a parent of a disabled child is the sense of difference. Depending on the type of disability and its visibility (referring to Goffman's stigma category), as well as to the attitude of the social surroundings, the parents see the special way the society treats them, although the term "special" does not always have a positive dimension, as suggested by Stelter (2013: 76). The intellectual disability of a child means that parent may have the sense of a pejorative difference, and they may feel worse than the parents of healthy children (see [Popielecki and Zeman 2000](#)).

I'll put it this way: I don't mind it anymore like I did before, but I'd be lying if I told you that I don't care. I know that people are looking, I can see it. I see them pointing their fingers at me. Maybe not directly, but I feel it, and I know that sometimes someone can think "that's sad to see" or "how unsightly it is," and then I feel the worst because I feel like I am worse as a parent [i.17.09]

This feeling of otherness may accompany the parents for the rest of their lives. Its framework is initially determined by the birth of a "dysfunctional" child. Gradually, they are labeled "a parent of a disabled child," which is usually based on social stereotypes, sometimes prejudices, and a lack of understanding of their situation. This happens because the "otherness" is often synonymous with strangeness, and experiencing one's own otherness and the otherness of other people is one of the most difficult emotional and social experiences. A visible disability features stress as its foreground character in social perceptions; it changes expectations, responses, and ways of communicating, and even the readiness to

enter into individual relationships. Just as being a woman in a biological sense does not determine a woman's role, being an individual with biological defects does not determine our strangeness categorically. It is only the emergence of the so-called negative feedback in our biography, where biological, psychological, and social factors overlap, strengthen, and intersect, which can trigger the pathologization of development (Stelter 2013: 8).

Strategies of Dealing with Trajectory

In order to deal with the previously discussed problems related to entering into the trajectory of suffering, the parents must develop certain strategies that could provide a measure of success when dealing with those key difficulties. Many of these strategies require the assistance and support of others (family members, friends, acquaintances) who could act as rescuing agents, protective agents, assisting agents, or control agents (Strauss et al. 1984: 17; cf. Kacperczyk 2006: 240). Although it is impossible to go into detail regarding the above-mentioned roles due to the limited volume of the paper, we should note that the basic strategies of dealing with key problems require organized actions, the presence of a certain organizational structure in the form of a family member, neighbor, or another arrangement which could help manage the obligations and requirements imposed by the situation of disability.

It would be hard alone, or even only with my husband. As a matter of fact, you're left alone in your need, but yet the help, if there was no help, either financial or direct in the form of activities, rehabilitation or simply care, even for a moment, is worth its weight in gold [i.17.04]

In the majority of everyday situations, the parents are left alone, and hence they need to deal with things on their own. In particular, there is no one and nothing that can substitute the mother or father in the most important activities, both the instrumental activities, referring to the fulfillment of physiological needs, and the more psycho-emotional ones. Therefore, it is extremely important for the parents to deal with the difficulties they encounter every day, when they have to deal not only with the household chores but also in a broader sense, with the society's lack of knowledge or understanding and sometimes even hostility.

All this has a direct impact on the behaviors and actions that take place between the parents and other people from their immediate environment. What Strauss and Glaser (1965) described as work on the context of consciousness, and what turns out to be one of the most important areas of building a relationship between parents permanently involved in the upbringing of a child with intellectual disabilities, is gaining in significance. From the perspective of the parents' lives, this means that they try to avoid "difficult" topics, both between each other and when dealing with the world. These topics might be related to the growing dissonance between the development of their child and their expectations which result from their knowledge about the normal mode of adolescence. The parents can, therefore, use a repertoire of behaviors and actions intended to avoid or significantly limit conversations on topics that are well known to them and which would carry to much emotional strain. The context of suspicion is used less frequently between parents themselves, but

more frequently (if external circumstances and the condition of their child allow it) when dealing with the society, which means that parents try to hide or at least neutralize as much as possible any manifestations of their child's "otherness." For example, this may mean that parents try to avoid public places or choose times of the day for walks when they would potentially meet fewest people. This is perfectly illustrated by a fragment of a statement made by one of my interviewees:

Unfortunately, but our society is not yet mature enough to accept disabled individuals. I'm not saying that this is the case with everyone, but it is true that, in a lot of situations, people don't know how to behave when they see a person with severe disability. This is why I prefer not to be exposed to such behaviors or even to this intrusive staring at me and my child [i.17.05]

A parent's reaction to what happens to a child is often a violent outburst caused by powerlessness and awareness that the situation will not change. However, the parents will have had many more experiences (during the first years of the child's life) and will have already worked through what happened to them in relation to the birth of their disabled son or daughter. They also understand that what happened to them is permanent and irreversible, and that both their lives and the life of their disabled child will be permanently "burdened" with the load of "otherness" and imperfection. Therefore, the outburst more often provides an outlet for attempts to rationalize the trajectory, which means a search for alternative solutions and sources of joy and life satisfaction. New attempts are made to explain the reasons for their own suffering and to morally assess what is happening. Redefining their own situation is also an analysis of the influence exerted by the process of suffering on the previous, present, and future mode of life—both theirs and their child's.

It is as it is. I can't do anything about it. I can only do what's important for me and my child and what makes me see the sense and even some kind of joy in it, because every gesture, every grimace, or movement of the head, is a lot for me, and it makes me happy when I see the satisfaction in the eyes of my child. I don't know who I'd be without my child, what my life would look like, but I can't imagine this life without him without what we have experienced together. All of this is a part of me, and without him I wouldn't be the person I am now [i.17.02]

The parents try to explain to themselves that they cannot do anything about their child's disability, despite the passage of time, and that they can still provide the child with the best living conditions possible. At the same time, they are unable to prevent numerous adverse changes that take place when their son or daughter reaches a certain age. However, they must consider the fact that, over the years, there are no visible effects in the form of their child gradually becoming independent. The parents start to focus more on the present time, gradually shifting their activity from rehabilitation, which was previously intended to achieve the highest possible level of development, to supporting the child with the intention of maintaining the achieved level and supporting the child's independence. However, when it turns out that despite everything the parents have done their child's condition in adolescence and adulthood is marked with regression, the parents focus on providing the greatest quality of life possible, putting the main emphasis on care and nursing procedures.

As I have already mentioned, I'm not counting on a miracle, because it won't happen. But I also have nothing to reproach myself for, because I did everything I could to make my child as independent as possible. It might be too big a word because Dominika needs constant care, but she doesn't lie down all the time, she can move in her own way, so this is my success. And now I want to keep it at all costs and not make it worse. I want her to have the best care, rehabilitation, simply a dignified life [i.18.09]

Within their rationalization strategies, parents also adopt a procedure that involves searching for “more serious” problems that other families need to struggle with, both those with disabled children (e.g., with a more “problematic” dysfunction) as well as those that struggle with deviant behaviors. In this way, a mother and a father can take comfort from the fact that their child will not become a drug addict or a criminal. For them, a socially dysfunctional family requires more compassion than a family with a disabled child.

Particular attention should be paid to the various standardization strategies that are manifested in the pursuit of “normal” family life, “normal” social roles, “normal” motherhood, or being the mother or father of a “normal” child. The participants of the research stressed that their lives are not so different from the lives of those who do not have a disabled child—they have similar duties and difficulties combining professional and family life. What is also important in this context is the thread of using social welfare and other support institutions. There are some ambivalent attitudes here. Some parents find it a pragmatic way to justify the functioning of the family and make it function relatively normally. At the same time, there are opposing voices that say that using social assistance may be perceived as the parents making excessive demands, which they try to avoid as much as possible. Furthermore, in their opinion, using the social welfare system may be interpreted as admitting to a weakness or the inability to cope (Sałkowska 2015: 119).

I know that those who don't have their own children, disabled children, and who don't know much about disability, in general, think that we are the type who would just keep taking money, rely on others, and give nothing back to society. It's sad, but that's what it's like, unfortunately. But I didn't choose this fate for myself and for my child. But I don't want to be perceived as a beggar, a man who “failed” in life, which is why, as long as I can afford it and have this financial independence, nobody will convince me to use any aid, especially state aid [i.18.02]

Another strategy for dealing with the trajectory is to *walk out of the disability*, which is largely based on blurring the signs of intellectual disability. As Woynarowska suggests (2010: 199–203), “a child with Down syndrome should be ‘normalized’ as much as possible.” Therefore, all therapeutic and rehabilitation procedures are intended to eliminate the deviation from accepted standards. It seems that these procedures may somehow resemble subjecting a child or an adult to training, “taming” them, so the intention is that they learn how to behave in a given situation, what to do to look like a normal person (Sałkowska 2015: 110).

My husband and I have always tried to make Marcyś as normal as possible. We wanted him to live a relatively normal life, as far as his condition allowed. And when he was an adult, we tried to get him out of the house, namely, to make him start going to work, actually to workshops, but we always used the phrase “work” [i.18.03]

The need to “walk out” is also understood by some parents as one of the social expectations of them, or even a kind of coercion (Sałkowska 2015: 111). This makes them feel not only obliged to undertake actions that will “normalize” their child, but they also perceive all signs of this abnormality as doubly depreciating, especially when the attempts to rehabilitate the child fail to have any effect. They feel incompetent, both in relation to their child, for whom they are incapable of providing a higher level of development (reflected, among others, in a greater level of independence) and in the face of disability as a socially constructed stigma.

On the other hand, there are also parents who, in the case of a disability that is impossible to “cover up,” or when the “normalization” process has little effect, decide not to pay attention, e.g., to other people’s behaviors or their staring. The parents often stressed that they have learned not to pay attention to comments and looks, explaining them in different ways or simply getting used to them. In some situations, it even happens that parents decide to completely evade the stigma. They choose not to respond because they believe it would be a waste of their strengths and health (*ibidem* 2015: 142).

It will always be the case that somebody’s gonna look at us a little differently. But it’s normal, I mean, otherness always triggers curiosity. But some not only get used to it, but they can also show great understanding, while others will just keep staring and making up different things [i.18.03]

When dealing with those closest to them, the parents feel the already mentioned staring, especially at the beginning. It can sometimes be very difficult, and it causes them frustration or irritation. However, over time, this staring becomes “unnoticeable” to the parents, in the sense that they get used to the situations where people pay attention to their child because it looks different. At the same time, many parents see this staring not so much as the bad intentions of others but rather their curiosity and lack of knowledge about the disability itself.

It is worth noting that the fear of normal people staring, and their potentially negative reactions, may also be accompanied by a sense of shame. According to Scheff (2003), the sense of shame encompasses a whole group of emotions, which can be a threat to social bonds. In particular, shame is related to the feeling of guilt, humiliation, or embarrassment and appears when an individual senses some difficulties in a given social relationship. The feeling grows when an individual is concerned that they do not meet expectations or do not meet the applicable standards, and the parents of disabled children are often involved in such experiences (see *Sałkowska* 2015: 141).

I seem to know how it works, but there’s still this element of uncertainty, the feeling that you could do more, and maybe you just don’t do something because you can’t, you’re not able to. In any case, this is a feeling that you like the child, disabled in his or her own way, not physically or mentally, but socially. There is a feeling as if both you and the child are defective products, faulty in a way. I say this on purpose because what I want to express is that you have the sense of shame because of all of that [i.17.08]

When dealing with the society, the parents also adopt a strategy of *challenging*—mostly through their openness in speaking about their children’s disability. It also has the advantage that parents who display this type of behavior usually do not hide their child’s disability but immediately inform the world that their son or daughter is (or will be) disabled, often in advance. Therefore, they do not need to inform everyone ad hoc, and the relatives know in advance how to behave towards them and their child. Hence, the parents’ openness is a starting point for the openness of other people, in particular, those who are in direct contact with mental handicap for the first time.

We’ve tried to follow this policy from the very beginning, if I can say so, that we won’t hide anything or sweep it under the carpet. We didn’t want to hide ourselves or our child from the world. Anyway, it’s better to have it out and express yourself directly than to use some unnecessary camouflage. We have always focused on directness in relations, regardless of whether someone liked it or not. In the end, we don’t need to meet or contact them [i.18.11]

However, it happens that the people may consider such openness as a behavior that is contradictory to the expected stereotypes of a mother or father of a disabled child. According to Sałkowska (2015: 144), this openness and acceptance of the response prove the transformations that take place in the perceptions of disability in general. It stops being just a family problem and a medical issue, and it becomes a social program (so there is a transition from a medical model to a social model).

Parents often seek the challenge by confronting the stereotypes normal people have with reality, thus showing that these beliefs are in no way reflected in everyday life. They usually point out that being the parent of a disabled child is not a reason for someone to show compassion or pity. The parents often stress that they do not need people's mercy. If they need anything, it is help organizing everyday life, in going back to professional work, or financial support, because they often cannot go back to work. However, they do not expect any special treatment.

The truth is that I—and parents like me—don't need compassion or mercy. It just makes me angrier and makes me feel worse rather than better. I always say, "if you want to help me, then instead of sighing, just do something to make me feel better so I can actually help my child" [i.17.03]

Dealing with the society also reveals behaviors contrary to stereotypes, which can be seen in the surprise of the interaction partners, for example, when it turns out that a disabled individual can read and write. Members of "normal" society are often convinced that a person with mental dysfunctions is not able to carry out such activities. This results from, among other things, "lowering the bar" for intellectually disabled individuals (*ibidem* 2015: 148).

As a parent of a disabled child, I know that he is disqualified at the very beginning and classified as a child that "can't do anything," is unable to do anything—simply as being "worse." But what a surprise when, despite the visible disability, he is able to do quite well with clothes, food, and even such activities as simple counting or reading, something that is apparently reserved only for people with full capabilities [i.18.04]

This triggers various responses from parents, but they often try to use that surprise or amazement of the normal people by teaching them a lesson or, more often, by simply trying to educate them and make them aware. This is how they try to convince others that their stereotypes, often rooted in their childhood and handed down to their own children, are harmful to both sides (Sałkowska 2015: 149).

Conclusions

The natural life cycle of a family with an able-bodied child goes through subsequent stages: from a very strong, even symbiotic relationship between the child and its parents, through the child's gradual move from limited to full independence, and then leaving the family home. Than the aspects that distinguish the relationship between a parent and a child from other social relationships are the asymmetry of relations that disappear as the child develops, the strong, intimate, and emotional bonds, and how the child's life and development depend on the quality of this relationship.

The child's intellectual disability does not so much disturb the natural life cycle of the family as it hampers it, and the family often remains at the level where there is an asymmetrical relationship between the child and its parents, especially the mother. This strong and permanent bond between the parents and a child with intellectual disability had a fundamental impact on the functioning of the whole family. It may lead to some serious disturbances in how the family members get on with each other. There is often a threat to the feeling of community and the sense of belonging to a family. It distorts the emotional balance and the emotional bond between the parents, between the parents and the children, or between the siblings (Stelter 2013: 68).

The disability itself is not the only problem encountered by the affected family system. Physical symptoms that mark a person with dysfunctions push them to the margins of society. In turn, they push the parents away from professional work, excluding them from their previous roles (social and professional), and leaving them outside the sphere of active, everyday interpersonal relationships. The related difficulties are part of a broader syndrome that destroys the "natural" interaction order (Kacperczyk 2006: 240). This happens because the parents, who are heavily involved in the disabled child's life, encounter specific difficulties rooted in the developmental processes of their son or daughter. Seeing a child with limited ability maturing and entering adulthood is often a difficult experience for the parents, all the more that they rarely receive proper support, either social or legal, when contributing to the disabled child's development towards autonomy and social usefulness. Additionally, the great majority of parents are left to fend for themselves with the emotional and social problems that result from their intellectually disabled child's psychosexual development (Stelter 2013: 76–77).

A significant hindrance, or even a factor that blocks the development of a child with limited intellectual abilities, is other people taking control of the child's development. After analyzing parents' behaviors which effectively block a child with mental disability from becoming independent, Twardowski (2008) lists the following factors: a lack of conditions for independent decision-making, weakening of the motivation to take independent actions, relieving the child of its responsibilities, and maintaining strict control over the child's actions. Due to such behaviors of the parents, a disabled child does not acquire the feeling of competence, which has an adverse impact on its cognitive development and the shaping of his or her sense of identity.

The researched individuals pointed to the dominance of the ideology of youth, fitness, health, and rationality. Zakrzewska-Manterys (2010: 90) notes that as we place greater emphasis on rationality, and the fact that almost all of our experiences are subject to reflection, there is an increasing distance between "normal" people and disabled individuals. However, at the same time, the discourse of emancipation leads us to strive for the fullest possible inclusion of intellectually disabled individuals in social and professional life. The paradox is that as the integration or inclusion process progresses, we need to shorten the social and cultural distance, so disabled individuals must acquire the competences of rational and reflexive citizens. The need to preserve normality, or to give such an impression, is a denial of the right to abnormality (Sałkowska 2015: 87).

The model of the course of a trajectory that developed as part of the empirical research can be divided into several characteristic stages that show the gradual development of pro-

cesses and mechanisms of growing suffering, the feelings of disintegration and chaos, as well as powerlessness and entanglement. The typical dynamics of the course of a trajectory are characterized by the following stages: the accumulation of trajectory potential, exceeding the border of the trajectory potential, the development of unstable balance, the state of destabilization, a breakdown of life organization and orientation, and biographical work on the trajectory.

Practical ways of dealing with the trajectory essentially involve attempts to “get rid of” the trajectory and free oneself from the dramatic chain of events and the accompanying reactions, or the attempt to regain control over one’s own life. If an individual really wants to and is able to make the effort to think through certain issues independently, working on the trajectory in the context of one’s own biographical experience can be significant and helpful in the process of rebuilding and reorganizing one’s life (Rzeźnicka-Krupa 2009: 206).

References

- Charmaz, K. 2009. *Teoria ugruntowana. Praktyczny przewodnik po analizie jakościowej*. Warszawa: Wydawnictwo Naukowe PWN.
- Cooley, Ch. H. 1909. *Social Organization: A Study of the Larger Mind*. New York: Charles Scribner’s Sons.
- Cytowska, B. 2012. *Trudne drogi adaptacji. Wątki emancypacyjne w analizie sytuacji dorosłych osób z niepełnosprawnością intelektualną w współczesnym społeczeństwie polskim*. Kraków: Wydawnictwo „Impuls.”
- Denzin, N. 1990. Reinterpretacja metody biograficznej w socjologii: znaczenie a metoda w analizie biograficznej, in: J. Włodarek, M. Ziółkowski (ed.), *Metoda biograficzna w socjologii*. Warszawa–Poznań: PWN, pp. 55–69.
- Docherty, J., and Reid, K. 2009. “What’s the next stage?” Mothers of young adults with Down syndrome explore the path to independence: a qualitative investigation, *Journal of Applied Research in Intellectual Disabilities* 22(5): 458–467 (<https://doi.org/10.1111/j.1468-3148.2009.00492.x>).
- Domecka, M., and Mrozowicki, A. 2008. Robotnicy i ludzie biznesu. Wzory karier zawodowych a zmiana społeczna w Polsce, *Przegląd Socjologii Jakościowej IV*(1): 136–155.
- Dykciak, W. 2005. *Pedagogika Specjalna*. Poznań: Wydawnictwo UAM.
- Giryński, A. 2005. Asertywność osób niepełnosprawnych intelektualnie — próba diagnozy, in: J. Głodkowska and A. Giryński (eds.), *Rehabilitacja społeczna i zawodowa osób z niepełnosprawnością intelektualną — od bierności do aktywności*. Warszawa: Wydawnictwo Naukowe AKAPIT.
- Glaser, B. G. 1978. *Theoretical Sensitivity. Advances in the Methodology of Grounded Theory*. Mill Valley, CA: The Sociology Press.
- Glaser, B. G., and Strauss, A. L. 1967. *The Discovery of Grounded Theory. Strategies for Qualitative Research*. Chicago: Aldine.
- Gorchoff, S. M., Oliver, J. P., and Helson, R. 2008. Contextualizing Change in Marital Satisfaction During Middle Age: an 18-year Longitudinal Study, *Psychological Science* 19 (11): 1194–1200 (<https://doi.org/10.1111/j.1467-9280.2008.02222.x>).
- Heller, T., and Arnold, C. K. 2010. Siblings of Adults with developmental disabilities: psychosocial outcomes, relationships, and future planning, *Journal of Policy and Practice in Intellectual Disabilities* 7 (1): 16–25 (<https://doi.org/10.1111/j.1741-1130.2010.00243.x>).
- Heslin, R. 1974. *Nonverbal Behavior and Social Psychology*. New York: Plenum Press.
- Hirschfeld, R., Smith, J., Trower, P., and Griffin, Ch. 2005. What do psychotic experiences mean for young men? A qualitative investigation, *Psychology and Psychotherapy: Theory, Research and Practice* 78 (2): 249–270 (DOI: 10.1348/147608305X25865).
- Hodapp, R. M. 2007. Families of persons with Down syndrome: new perspectives, findings and research and service needs, *Mental Retardation and Developmental Disabilities Research Reviews* 13 (3): 279–287 (<https://doi.org/10.1002/mrdd.20160>)
- Hodapp, R. M., Glidden, L. M., and Kaiser, A. P. 2005. Siblings of persons with disabilities: toward a research agenda, *Mental Retardation* 43 (5): 334–338 ([https://doi.org/10.1352/0047-6765\(2005\)43\[334:SSOSEB\]2.0.CO;2](https://doi.org/10.1352/0047-6765(2005)43[334:SSOSEB]2.0.CO;2))

- Johnson, E. D. 2000. Differences among families coping with serious mental ill adults: A qualitative analysis, *American Journal of Orthopsychiatry* 70(1): 126–134 (<http://dx.doi.org/10.1037/h0087664>).
- Kacperczyk, A. 2006. *Wsparcie społeczne w instytucjach opieki paliatywnej i hospicjach*. Łódź: Wydawnictwo Uniwersytetu Łódzkiego.
- Konieczna, A. 2012. Dążenia rodziców do aktywizacji zawodowej dzieci z niepełnosprawnością — lęk o przyszłość, in: D. Tomczyszyn, W., Romanowicz W (eds.), *Aktywność zawodowa osób z niepełnosprawnością*. Białą Podlaska: Wydawnictwo PSW, p. 277.
- Kowalik, S. 1989. *Upośledzenie umysłowe. Teoria i praktyka rehabilitacji*. Warszawa–Poznań: PWN.
- Kościelska, M. 1995. *Oblicza upośledzenia*. Warszawa: PWN.
- Kowalik, S. 2001. Pomiędzy dyskryminacją a integracją osób niepełnosprawnych, in: B. Kaja (ed.), *Wspomaganie rozwoju. Psychostymulacja i psychokorekcja, Tom 3*. Bydgoszcz: Wydawnictwo Uniwersytetu Kazimierza Wielkiego, pp. 36–58.
- Mikołajczyk-Lerman, G. 2011. *Między wykluczeniem a integracją — realizacja praw dziecka niepełnosprawnego i jego rodziny. Analiza socjologiczna*. Łódź: Wydawnictwo Uniwersytetu Łódzkiego.
- Miltiades, H. B., and Pruchno, R. 2001. Mothers of adults with developmental disability: change over time, *American Journal on Mental Retardation* 106 (6): 548–561 ([https://doi.org/10.1352/0895-8017\(2001\)106<0548:MOAWDD>2.0.CO;2](https://doi.org/10.1352/0895-8017(2001)106<0548:MOAWDD>2.0.CO;2)).
- Orsmond, G. I., and Seltzer, M. M. 2007. Siblings of individuals with autism or Down syndrome: effects on adult lives, *Journal of Intellectual Disability Research* 51 (9): 682–696 (<http://dx.doi.org/10.1111/j.1365-2788.2007.00954.x>).
- Phyllis, S., and Draine, J. 1995. Subjective burden among family members of mentally ill adults: Relation to stress, coping and adoption, *American Journal of Orthopsychiatry* 65 (3): 419–427 (<https://doi.org/10.1037/h0079695>).
- Pisula, E., and Dąbrowska, A. 2004. Doświadczenia matek związane z otrzymaniem informacji o zespole Downa u dziecka, *Pediatrics Polska* 79 (6): 460–466.
- Pokorska, O., and Pisula, E. 2013. Temperament matek dzieci z zaburzeniami rozwojowymi a pozytywna percepcja doświadczeń rodzicielskich, *Psychologia wychowania* 46 (4): 7–24.
- Popielecki, M., and Zeman, I. 2000. Kryzys psychiczny rodziców w związku z pojawieniem się w rodzinie dziecka niepełnosprawnego, *Szkola Specjalna* 1: 15–19.
- Richardson, S. S. 2012. Developmental Trajectories of Marriage, Coparenting, and Parenting Stress for Parents of Adolescents and Young Adults with Intellectual Disability. Psychology Dissertations. Paper 100, http://digitalarchive.gsu.edu/psych_diss/index.html.pdf (data dostępu: 17.05.2017).
- Riemann, G., and Schutze, F. 1992. „Trajektorja” jako podstawowa koncepcja teoretyczna w analizach cierpienia i bezładnych procesów społecznych, *Kultura i Społeczeństwo* 36(2): 89–110.
- Rzeźnicka-Krupa, J. 2009. *Niepełnosprawność i świat społeczny. Szkice metodologiczne*. Kraków: Oficyna Wydawnicza „Impuls.”
- Sałkowska, M. 2015. *Matka Downa. Piętno — Znaczenia — Strategie*. Kraków: Zakład Wydawniczy “NOMOS.”
- Scheff, T. J. 2003. Goffman’s Elaboration of the Looking Glass Self, (American Sociological Association) Atlanta (<http://www.soc.ucsb.edu/faculty/scheff/19a.pdf>).
- Schutze, F. 1997. Trajektorja cierpienia jako przedmiot badań socjologii interpretatywnej, *Studia Socjologiczne* 1: 11–56.
- Stelcer, Ż. 2013. *Pełnienie ról rodzicielskich wobec dziecka niepełnosprawnego intelektualnie*. Warszawa: Difin.
- Seltzer, M. M., Floyd, F., and Greenberg, J. 2005. Life Course Impacts of Mild Intellectual Deficits, *American Journal on Mental Retardation* 110(6): 452–468 ([https://doi.org/10.1352/0895-8017\(2005\)110\[451:LCIOMI\]2.0.CO;2](https://doi.org/10.1352/0895-8017(2005)110[451:LCIOMI]2.0.CO;2)).
- Strauss, A. L., and Corbin, J. 1990. *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*. Thousand Oaks (CA): Sage.
- Strauss, A. L., Corbin, J., Fagerhaug, S., Glaser, B. G., Maines, D., and Suczek, B. 1984. *Chronic Illness and the Quality Life*. St. Louis–Toronto: The C. V. Mosby Co.
- Strauss, A. L., and Glaser, B. 1965. *Awareness of Dying*, Chicago: Aldine Publishing Co.
- Twardowski, A. 2008. *Sytuacja rodzin dzieci niepełnosprawnych*, in: I. Obuchowska (ed.), *Dziecko niepełnosprawne w rodzinie*. Warszawa: WSiP, pp. 18–54.
- Wojnarowska, A. 2010. *Niepełnosprawność intelektualna w publicznym i prywatnym dyskursie*. Kraków: Oficyna Wydawnicza Impuls.
- Zakrzewska-Manterys, E. 1995. *Down i zespół wątpliwości. Studium z socjologii cierpienia*. Warszawa: Wydawnictwo Naukowe Semper.

- Zakrzewska-Manterys, E. 2010. *Upośledzeni umysłowo. Poza granicami człowieczeństwa*. Warszawa: Wydawnictwo Uniwersytetu Warszawskiego.
- Żyta, A. 2011. *Życie z zespołem Downa. Narracje biograficzne rodziców rodzeństwa i dorosłych osób z zespołem Downa*. Kraków: Oficyna Wydawnicza Impuls.

Biographical Note: Jakub Niedbalski, Ph.D., Associate Professor in Sociology of Organization and Management Department, Faculty of Economics and Sociology, University of Lodz, Poland. Author, editor, and co-editor of 12 books and about 90 articles and book chapters in Polish and English related to his main research interests: sociology of disability, sociology of sport, qualitative methods and computer analysis of qualitative data.

ORCID iD: <http://orcid.org/0000-0002-2803-7628>

E-mail: jakub.niedbalski@gmail.com