

GABRIELA DOBIŃSKA

University of Łódź

ORCID – 0000-0003-3629-5210

KATARZYNA MIŚKIEWICZ

University of Łódź

ORCID – 0000-0001-8707-2063

## “(UN)KNOWN PARENTHOOD” – ON THE PROCESS OF BECOMING A PARENT OF A CHILD WITH INTELLECTUAL DISABILITY\*

**Introduction:** A child with intellectual disability significantly impacts the existing model of the family and the parental, fraternal and marital roles assumed by its members. The experience of new situations filled with fears, anxiety and ignorance determine the direction of the actions taken by parents in order to regain the lost balance.

**Research Aim:** The aim of the project was to reconstruct the process of parents getting used to (coping with) their child's intellectual disability.

**Research Method:** Personal experiences of parents collected in the form of unstructured interviews served as research material. Data analysis was performed in accordance with procedures of grounded theory.

**Results:** Based on the conducted research we were able to present and reconstruct coping process of parents of children with intellectual disability, at an early stage of diagnosis. Within it, we identified strategies for coping with the new life situation in which our research participants found themselves.

**Conclusion:** The following considerations are centred around the Polish perspective, and take into account the political, cultural and social contexts. The coping process of parents of children with intellectual disabilities consists of the following stages: experiencing a crisis, seeking control, trying, discovering potentials, familiarization.

**Keywords:** intellectual disability, parenthood, family, the process of “becoming”, interviews, (un)known parenthood

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## INTRODUCTION

The problems of the parents of children with intellectual disability are a recurring subject in social sciences (see Obuchowska, 2005; Twardowski, 2005; Dyk-cik, 2006; Karwowska, 2008; Minczakiewicz, 2008; Palęcka and Szczodry, 2011; Konieczna, 2012; Stelter, 2013; Hoetal., 2013; Matczak, 2016; Tomczyszyn, 2016, 2018; Aksamit, 2017, 2018, 2019a, 2019b; Barłóg, 2017; Cytowska, 2017; Edwards, et al., 2018; Niedbalski, 2019; Aksamit and Kruś-Kubaszewska, 2021; Aksamit and Wehmeyer, 2022; Barłóg et al., 2022). When we write “(un)known parenting”, we mean that although there are many scientific studies on the topic of being a parent of a child with intellectual disabilities, this is an area that is still current, undertaken and requires further analysis (see Aksamit and Kruś-Kubaszewska, 2021). For parents, it is “unknown parenthood”, or as Bakiera and Stelter (2010, pp. 136–137) wrote, “different parenting”.

The existing studies lead to the conclusion that the birth of a child with intellectual disability is an immensely difficult moment for parents (Karwowska, 2008; Minczakiewicz, 2008; Barłóg, 2017; Edwards et al., 2018; Aksamit and Kruś-Kubaszewska, 2021). The new situation affects the existing family model, marital, family and fraternal relations, as well as the model of sharing responsibilities (Karwowska, 2008; Palęcka and Szczodry, 2011; Bakiera and Stelter, 2010; Orlikowska and Bołtuć, 2018). Family members – usually parents – assume various strategies of coping with their children’s intellectual disability, in order to regain the lost balance and normalize family life. An interesting and universal analogy was presented by Rembowski (1986), who wrote that parents can be compared to a membrane or a specific coating that performs protective, filtering functions enabling communication between family members and people from outside this social group (Rembowski, 1986). It can be safely said that a child’s development is largely determined by the quality and condition of the family in which they grow up (Mrugalska, 1995). This corresponds to the research results presented in this article, the aim of which is to present the process of “becoming used to” (coping with) the child’s intellectual disability, at an early stage of diagnosis and the selected strategies for coping with the new life situation in which the participants of our research found themselves.

## RESEARCH ON FAMILIES WITH A CHILD WITH INTELLECTUAL DISABILITIES

We are aware of numerous foreign studies about parents of children with intellectual disabilities (see Hassall et al., 2005; Chadwick et al., 2013; Budak et al., 2018; Dave et al., 2014; Gauthier-Boudreault et al., 2017; Oti-Boad, 2017)



but our research was conducted in Poland, and therefore covers the situation of parents in a specific socio-cultural context. Therefore, in this article we will refer to research involving parents of children with intellectual disabilities living in Poland. It is worth adding that the literature on the subject mainly includes studies involving both parents (Karwowska, 2008; Ho et al., 2013; Orlikowska and Bołtuć 2018; Barłóg et al., 2022) and mothers themselves (Pałęcka and Szczodry, 2011; Aksamit, 2017, 2018, 2019a, 2019b; Aksamit and Wehmeyer, 2022). By far the least amount of research involves fathers themselves (Cytowska, 2017).

The process of becoming a parent of a child with intellectual disability is very complicated and multidimensional (Dobińska, 2019). Disturbance to the order of social roles may result in constraints to the developmental potential of a family, perceived as a system in intra-family relations and in a broader context with people outside the family (Przywarka, 2003; Skórczyńska, 2007). Bakiera and Stelter wrote that:

In the case of a family with a child with intellectual disability the effective functions of the family are usually upset, and the fulfillment of more difficult roles requires a particular effort, and carries with it a significant mental burden. A child with limited intellectual capacity is a shock for parents, something outside the realm of dreams and plans connected with happy parenthood. (2010, p. 135)

In the literature on the subject, researchers draw attention to the following problems faced by parents of a child with intellectual disability: everyday care of children (Aksamit, 2019b; Aksamit and Kruś-Kubaszewska, 2021), disintegration of family relations (Karwowska, 2008), providing health care and rehabilitation for children (Tomczyszyn, 2016; Cytowska, 2017), unfriendly treatment of children by social environment (Tomczyszyn, 2016; Aksamit and Wehmeyer, 2022), social isolation (Aksamit, 2018), low quality of formal and informal support (Aksamit and Wehmeyer, 2022), loneliness in the SARS-CoV-2 coronavirus pandemic (Barłóg et al., 2022). As a result of them, a crisis is experienced and actions are taken in order to restore the lost balance lead to changes in the scope of defining parental and marital roles, which are created and modified anew in a processual fashion (Karwowska, 2008; Pałęcka and Szczodry, 2011; Bakiera and Stelter, 2010; Orlikowska and Bołtuć, 2018). As a result of experiencing many difficulties which exceed their capabilities and mental resilience, parents undergo a crisis of parental role and a disintegration of identity (Aksamit, 2017, 2019a, 2019b, 2021; Barłóg, 2017). At first they experience fear, anxiety and uncertainty resulting from their lack of knowledge and unpreparedness for such a situation. Over time, parents of children with intellectual disabilities learn a new reality. Parents try to regain balance by taking various actions. In this context, it is worth mentioning post-traumatic growth understood as a positive psychological change

experienced as a result of successfully coping with effects of a negative event (see Byra, 2015; Byra et al., 2017).

It is worth highlighting that whether or not the birth of a child with intellectual disability has an adverse effect on the functioning of the family is determined mainly by the personality traits of family members, their emotional relationship with the child, their attitude towards upbringing and their vision of the future (Stelter, 2013). That is why source literature includes many research projects devoted to emotions which accompany the parents of children with intellectual disability (see Aksamit, 2017, 2019a, 2019b; Aksamit and Kruś-Kubaszewska, 2021; Barłóg, 2017). Important for our research are the conclusions of Kościelska (1995), who draws a cross-section of various affective states which accompany the parents of children with intellectual disability. The author focuses on maternity which is entangled in a series of fears, anxieties and thoughts characterized by emotional lability (Kościelska, 1995). In her description of emotions connected with coping with the disability of the child, Kościelska describes the following: fear of hostility, concern over lost opportunity, fear of confronting the child with (various) new situations, anxiety concerning the future. Another equally difficult emotion which parents experience is “mourning”, i.e. “the mental state of parents which arises as a result of losing the child they have dreamt of and of being confronted with the child that was born” (Kościelska, 1995, p. 52). This range of emotions includes despair, apathy, depression, sadness and despondence. Some parents experience a feeling of “being deficient” as a result of having a child with intellectual disability, which may lead to a crisis of identity (cf. Aksamit, 2017, 2019a, 2019b; Aksamit and Kruś-Kubaszewska, 2021). As a result parents experience hostility not only towards themselves but also towards their immediate social environment (Kościelska, 1995). That is why it is so important to constantly increase social awareness of the situation of parents of children with intellectual disabilities.

We would like to point out that in this article we focused on studies which were important from the point of view of our research project. We are aware that this is not a closed review, but we had to select material due to our research interests and due to the size limitations of the article.

## RESEARCH AIM AND QUESTION

The subject of our research was the process of becoming a parent of a child with intellectual disabilities. The aim of the project was to reconstruct the process of parents getting used to (coping with) their child’s intellectual disability.

## RESEARCH METHOD AND SAMPLE CHARACTERISTICS

The processivity and dynamics of the emerging experiences of parents of children with intellectual disabilities suggested the theoretical framework of symbolic interactionism (Blumer, 2007), embedded in the strategy of qualitative research (Babbie, 2013). Symbolic interactionism assumes that a person is a social actor who actively (re)constructs and negotiates the meanings given to the phenomena surrounding him in the course of social interactions (Hałas, 2012). The approach we adopt allows us to reveal the dynamics of changes taking place in the analyzed fragments of the research participants' biographies, in the socio-cultural context indicated by them. It shows the ephemerality of the meanings given and reveals the variability of definitions formulated by social actors.

The research results presented in the article below are the result of many months of analyzes of the collected empirical material conducted according to the procedures of grounded theory methodology (hereinafter: GTM). The choice of GTM gave us space to discover certain patterns, as well as specific mechanisms that give meaning to the actions undertaken by an individual and the relationships in which he is involved (Glaser and Strauss, 1967; Konecki, 2000). GTM assumes the construction of a middle-range theory through theoretical sampling and comparison of subsequent cases (Glaser and Strauss, 1967; Strauss and Corbin, 1990; Konecki, 2000). This enabled us to “control” the acquired data. We coded the collected data in an orderly manner, using focused coding of categories defining causal conditions, intervening conditions, interactions, strategies and tactics undertaken, context and, ultimately, consequences of actions taken (Glaser and Strauss, 1967; Konecki, 2000).

The collected empirical material consists of seven informal interviews conducted with parents of children with intellectual disabilities. We managed to talk to two fathers and five mothers. Taking care of the narrators' comfort and sense of security, the meetings took place on neutral ground, most often in a café or a park. The question initiating the interview with the parents was a request to tell about themselves and their family.

The sample selection was initially determined by the snowball method (Bryman, 2001), which over time naturally transformed into theoretical sampling, which we achieved thanks to regular and thorough category development. Theoretical sampling is a kind of process of collecting data enabling theory generation. As a result, the researcher collects material, codes it, analyzes it and makes decisions about subsequent research steps (Glaser and Strauss, 1967). The moment the study ended was the theoretical saturation of the sample, which is reflected in the lack of “new” data on the basis of which the selected categories could be developed. Therefore, the subsequent narratives obtained do not provide material for specifying or developing the theory (Bryman, 2001). Moreover, it is worth mentioning that the described research, due to the issues raised, was exceptionally



difficult and was characterized by many emotions experienced by the participants sharing their own experiences and by the researchers who became the beneficiaries of these difficult stories.

The participants are parents of children with intellectual disabilities. The children of the research participants ranged in age from 8 to 33. The parents participating in the study were of different ages (from 32 to 67), thus, reconstructing their own experiences from different perspectives. Time was of special importance here. While sharing their story, the narrators drew points on the timeline that marked the most important events in their lives. Moreover, by analyzing the collected empirical material, we noticed that over the years there have been many changes in the perception of intellectual disabilities, greater public awareness has contributed to an increase in the offer of support for families with children with intellectual disabilities, as well as changes in social attitudes towards people with disabilities.

## RESULTS

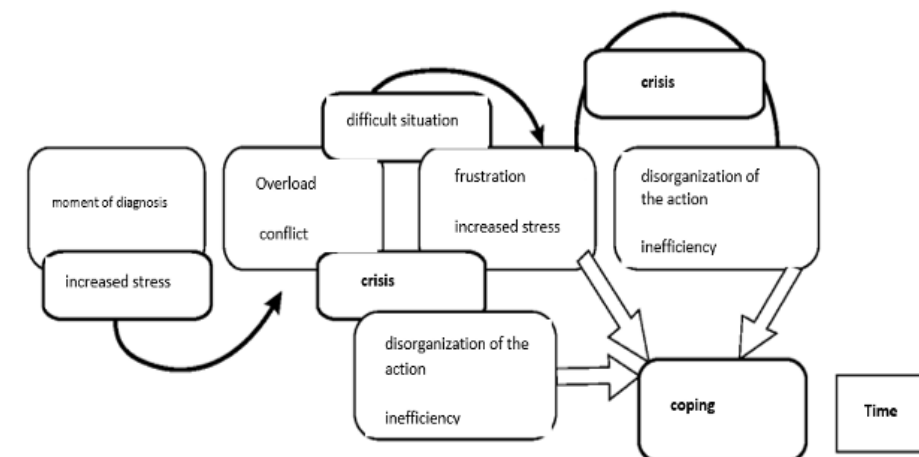
### **Strategies of Becoming Familiar with a Child's Intellectual Disability Employed by Parents**

We need to remember the situation of a family with a child with intellectual disability is immensely difficult, multidimensional and filled with extreme emotions. Each family member experiences the diagnosis and the moment of birth of a child with a disability individually. Therefore, we may observe multidimensional processes of coping with this situation. In the following considerations, we focused on the crisis that accompanied parents in the early stages of dealing with their child's disabilities. What we mean here is the confrontation of the participants with the role of a parent of a child with an intellectual disability. Interestingly, the narrators themselves brought up this topic, giving it great importance, like a "legend" attached to a map. Using extensive descriptions, they tried to reflect the emotions accompanying them. All types and features of difficult situations co-occur and interpenetrate each other, e.g. the reaction to a threat, i.e. a child's disability, affects perception and may therefore cause a state of overload or a conflict situation. Difficult situations are characterized by reduced efficiency of activities, disorganization, emotional arousal, tension, and poor well-being. Constant stress that a person cannot cope with becomes a crisis. Experiencing difficulties generates frustration, and stress is a reaction to it. However, a crisis situation is a specific type of difficult situation (see Tomaszewski, 1975; Farnicka, 2011). This is illustrated in the diagram below:



Figure 1.

*Possible family reactions to a diagnosis of a child's disability over time*



Source: (Tomaszewski, 1975, pp. 17–36).

An analysis of empirical material allows us to distinguish specific strategies of familiarization adopted by parents of children with intellectual disabilities. As described earlier, the birth of a child with intellectual disability bears the hallmarks of a crisis. However, our interviews demonstrate that parents taking part in the studies face the challenges and adopt activities in order to familiarize themselves with the new reality. The derived categories revealed that familiarization was processual. We were able to distinguish the separate stages of this process, and particular strategies as part of these stages.

The first stage was called **experiencing crisis**. It is related to the moment when the information about the child's intellectual disability is revealed. This was not always at birth or during infancy. There were parents who found out about their children's condition prior to birth. However, regardless of whether it was before or after birth, the parents described this moment similarly as burdening, a time during which each parent had to face his or her limits and gradually move them. The accompanying emotions were difficult, and the upset sense of security resulted in anxiety and uncertainty regarding the child's future and development. The parents spoke of their fear of the “unknown parenthood”. It is not a parenthood they expected or observed in others. The narrators found themselves in circumstances, which they had never had a chance to encounter. They felt unprepared for the problems they were to face.

N1: I was a little frightened and scared of all of this (...) I was preparing for a different parenthood, this one was completely unknown, you can't prepare for that.



One of the mothers struggled with postnatal depression. The parents had to face challenges connected with having a child with disability, and problems which concerned them directly. Below is an example which describes these struggles:

N1: at first I struggled with myself, because I couldn't handle the baby, I was afraid to touch it, because it was so tiny and soft after birth; unfortunately, I also had other problems, such as ... after birth. B: Postnatal depression? N1: yes, unfortunately. It got me too (laughter).

At this stage the parents initially adopted a strategy of **avoiding social contact** in order to protect themselves and their child. They sought "asylum" for their family. The parents protected their child and themselves from exclusion, labelling and the resulting consequences. They did not want to confront healthy children or their parents for fear of being judged and rejected. This strategy was not adopted based on speculation – it was the effect of experiences which they had when they wanted to involve the child in social life. This is illustrated by the next passage:

N1: Once we were out, and I couldn't handle it, everyone was looking at us and other mums were not pleased that my daughter wanted to play with others and that she was taking their toys. Honestly, I was more worried about her than about me and that people would talk behind my back. I think this was the best solution. We almost stopped going out, all the looks and badmouthing and name-calling, that was not for me or for her.

Another strategy adopted at the first stage was using **social support networks**. The participants initially relied on the closest family (parent or partner/spouse, friend of the family) for support. Regardless of who it was the narrators emphasized that without that person's help they would not have coped at the beginning of their path to becoming parents of children with intellectual disability. This happens at a microsocial level and then reaches the macrosocial level. It corresponds with the earlier strategy of avoiding social contacts. It is possible that the participants reached out to people they had the most confidence in and who would not be judgmental.

N1: I had help from my mum because I was still struggling with my ... other issues after birth.

N1: (...) I managed, thanks to my mum.

N3: Whenever there was something I didn't know I called A., and she would help and explain things to me.



N2: I think what was important was that my husband and I were together in this situation. He gave me a lot of support.

Eventually, the relation with a close person encouraged the parents to reach out to broader social networks, such as Internet fora, communities, other parents in a foundation, daycare or preschool. This was connected with leaving their “asylum” and opening to change, which is characteristic of the subsequent stage.

The second stage of familiarizing oneself with the new reality was **seeking control**. This consisted in learning to care for the child, seeking information, comparing the child's development with up-to-date specialist knowledge and with other children. The parents were trying to manage the situation mainly through acquiring new knowledge on intellectual disability. The knowledge gave them a sense of security and control over their lives. Owing to this the parents knew what to expect and could actively participate in and accompany their child's development. Consequently, parents could implement new activities aimed at achieving relative stability.

N1: I read a lot and I remember that I often compared what I read with K. Whether she behaved like that, acted like that and whether she met the criteria in the book.

The strategy which accompanied this stage was **taking control**. It consists in assuming control over one's life. It is a strategy in which the respondents declared taking active part in family life and making active efforts in order to support the child with intellectual disability. In this strategy the parents began making and implementing plans. Moreover, their actions were characterized by perseverance and efficiency. It is worth highlighting that they did not choose easier solutions but those which deemed most effective and beneficial for their child's development. One example is divorce which resulted from a lack of acceptance of the child's disability. Another situation is obtaining academic education in the area of pedagogy of persons with intellectual disabilities. Other examples include parents dissatisfied with the answers and explanations provided by experts, as these failed to meet his or her expectations or needs. This led to broadening one's knowledge individually and with the help of other specialists.

N1: (...) my ex-husband left when K. was 2. First we found out about the Down syndrome, then about the severe heart condition. He said he wasn't handling it. Even today he doesn't tell anyone that he has a child with a disability. He's embarrassed, so I knew it made no sense.

N2: (...) I keep asking, seeking, I never quit. I'm not the kind of person who just accepts information and that's it. I keep asking, looking for nuance (...)

N3: I'm more task-oriented, I'm not afraid of life. I met a lot of great specialists at this course who work with my child, so this is great for me. This academic program gives you a lot, and it depends on you how much you derive from it.

Another strategy present at this stage of familiarizing oneself with the child's intellectual disability was **reorganization of life**. In this strategy the parent modifies the everyday life of the family in order to support the child and respond to its needs. In the narratives this was connected with sacrifice and resignation from the existing mode of life. Parents – mostly mothers – changed their form of employment or (if they were able to) left their occupations in order to devote their time to their families. Reorganization was oriented towards putting the child and its wellbeing at the center of all activities.

R: Were you working then?

N1: No, I was going to return, but then I quit, I joke that I became a full-time mum.

N2: (...) my husband and I shared responsibilities, I stayed home, he worked. It sounds weird but it works for us, I assure you.

However, it needs to be said that reorganization resulted from a desire to support the child and parents introduced it voluntarily, consciously choosing such solutions. The parents did not express sorrow or longing for their past lives. This is illustrated by the passage below:

N4: (...) the fact that K. entered my life, it was meant to be, because I started a new life. I'm proud of where I am. Today I work with other children (...)

The third stage which we distinguished, as part of the discussed process, was **trying**. This took place on an individual and collective level. It can be compared to crossing personal distances (Hall, 2001). Parents tried to use new, untested solutions, establish contacts with people in various spaces (including virtual) in order to find new solutions to obstacles on the path to their children's successful development.

N2: this small group was a substitute to what could be, the moment I saw there was no hate or drama I thought that it was worth telling other parents about it, so they could join us. I also invited teachers, speech therapy specialists and physiotherapists, who give us specialist advice.

At this stage the sense of community was highlighted. The narrators sought other parents who were in a similar situation to share their experiences and provide mutual support. We called this strategy **“seeking people from the same planet”**. The parents felt a desire to meet (e.g. during rehabilitation stays for their

children), to be in virtual contact (social networking, e.g. Facebook). In their contacts with other parents the narrators did not experience fear of being judged and rejected. They felt at ease, but most of all they felt understood. This allowed them to freely express their concerns, ask questions which they would not ask anyone else, including specialists. This resulted in the creation of support groups, fora and spaces to discuss everyday challenges.

N3: (...) I met a lot of parents, who faced similar problems (...)

N2: When J. was little I started looking for opportunities to meet parents of children who were of a similar age but I couldn't find anyone. I mean, I could, but we would either not qualify or there were no more spots at organized classes. Then we came up with this idea of creating a group of people who trusted and liked each other (...)

N5: We went on this trip organized by (name) and there I met other parents and I realized – they had the same issues. Just uncertain young people, you know? After I returned I started a Facebook group to share photos from the trip, but this group took on a life of its own, there were more and more posts, everyone could share. We asked questions, commented, exchanged opinions on therapeutic toys and exercises. We even discussed specialists, because we were a group from all parts of Poland.

N2: (...) I remember when one girl had a serious heart surgery and we were rooting for her in her fight, and we prepared a package for them with balloons and flowers (...)

R: You finally decided to ask these questions?

N3: Sure, I asked parents in the cloakroom (laughter) and now I have a friend, the mum of A. We've been friends since our children were 3, so we've known each other for 4–5 years. We often call each other and talk.

It needs to be stressed that trying is not equal to a verdict or familiarization. Some attempts were successful, others were not. However, the parents did not give in if there was any chance of providing support for their children. The participants were perseverant, as can be seen in the following passages.

N2: I remember going to a therapist, a pedagogue, I told her about what my child was struggling with and asked if she could help, give me some advice, and she said that I could sign up my child for her classes or enroll in an academic program. I had some bad luck with these people but eventually I acquired knowledge (...)

N3: Sometimes as a desperate parent I get fooled into trying some stupid methods, you hope for something and that goes south.

N2: Then there was the idea to create a group of people we liked and trusted, but I rejected it at the time.

R: Why?

N2: Hmmm, I think I wasn't ready.

At this stage the parents began to notice certain systemic limitations and a lack of reliable sources of information. They themselves were becoming "experts" in the field of their children's development. They made that clear:

N1: There is a lot of stupid stuff there and people reach out for it [the Internet].

N2: I started reading books and I encountered a problem because they were old, out-dated.

N6: You know, I frequently asked myself, there are ACA and AA support groups, there are groups for people who suffered from domestic violence or for those who went through cancer treatment, but no support groups for parents with children with intellectual disability. Damn it! I can't accept this, there is no place to let it out, no possibilities, no options (...)

N1: (...) it is difficult for a mother with a sick child in our country.

N3: I like reading books, but they are passive (...) There is no direct counselling for parents (...)

N4: (...) I bought a book, I think it was by [Name], but I couldn't understand it (laughter) this was too difficult for me (...)

The next stage was **discovering potential**. It could be compared to secondary integration in the process of positive disintegration, according to Dąbrowski (2021). It is a moment in which parents regain their lost balance on behalf of a new order. For each parent who participated in the study it was something different – for one person it was university enrollment and later working as a special education pedagogue, for others it was the creation and active participation in support groups for parents. Regardless of the activities, parents began to notice opportunities for development in the situations in which they found themselves. They experienced a sense of engagement and importance, helped other parents facing the same problems, and other children with intellectual disability.

N4: When I talk about it now, I have tears in my eyes, I feel silly, but I think that the fact that K. entered my life, it was meant to be, because I started a new life. I'm proud of where I am. Today I work with other children; This group was like Ram Das mantra for me, do you know what that is? B: Yes, healing mantra N: exactly, I felt I was maturing as a parent, that I was becoming a parent expert, I know what to do and how, it was our center. We helped each other, we exchanged opinions, addresses, photographs,

I shared everything with them. I realized that my advice was helpful to others and that the group was doing a lot of good (...)

The final stage was **familiarization**. At this stage parents declare having acquired the tools to cope in their situation. They exchange theoretical knowledge, methods of working with children, contact information to other parents and tested specialists. It needs to be stressed that this is a dynamic stage which bears the hallmark of a process. In their communication, the Narrators often revealed a lack of certainty and the processual character of familiarization. This is not a closed stage. It highlights community which, at subsequent stages of life, helps parents to familiarize themselves with other families in similar life situations. It is sharing experiences with parents at the beginning of their path, however, it also constant discovery along with the progressing development of the child, which brings with it new needs and challenges.

R: Do you feel more self-confidence, thanks to your studies?

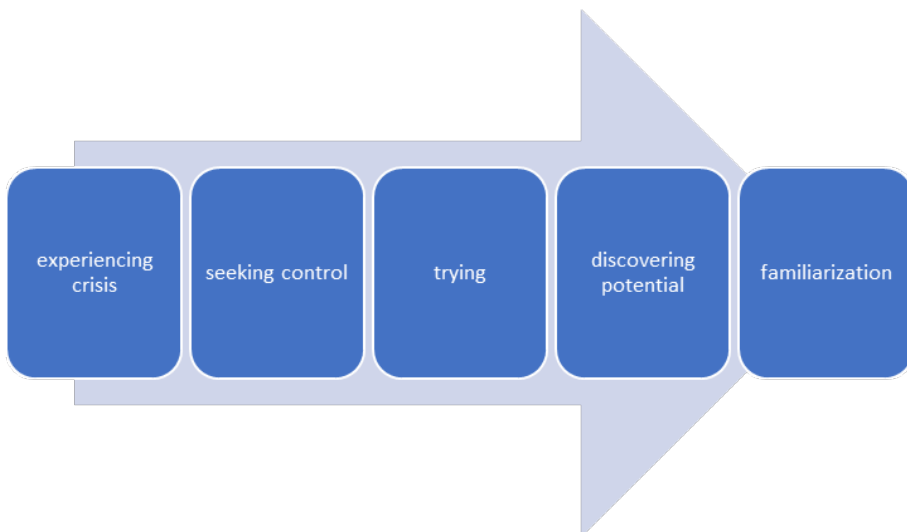
N4: Absolutely, I already know a lot, of course I don't know everything, but I've become accustomed to everything, I joke that I'm used to K.'s disability, because I'm familiar with it, I'm not afraid of it any more. I learned various methods, I have a network of contacts with other parents, specialists. I met a lot of people at university. I wonder what comes next.

The process of familiarization illustrated above has common elements, but its course and dynamics are individual. However, regardless of diversity we were able to distinguish stages common to all participants. First, the parents experience a crisis which is turbulent, filled with extreme, interpenetrating emotions, and is orientated towards isolating oneself from new relationships. Then, when parents begin to leave their comfort zone and open themselves to broader social contacts, we have the control seeking stage, characterized by acquiring new knowledge, skills and competencies regarding child development and its support. The next stage is trying, which consists in establishing contacts with parents in a similar situation, and creating groups, which allow parents to feel more at ease in the company of people who face similar doubts and issues. The next stage includes testing new, previously unknown methods of accompanying the child in tackling developmental obstacles. Then parents reach the moment when they begin to see opportunities resulting from being parents to children with intellectual disability, which foreshadows the stage we called discovering potential. At this stage parents regain balance and take advantage of the benefits resulting from the process of “advancing” at being parents of children with intellectual disability. It is important for the parents to see opportunities for the child's development as well as their own. The final stage in this process is familiarization, which bears the hallmarks of a dynamically changing cycle that is never complete, as its course results from the changes in the child's develop-

ment. Figure 2 presents the described process of becoming a parent to a child with intellectual disability:

Figure 2.

*The process of becoming a parent to a child with intellectual disability*



Source: Authors' own study.

## DISCUSSION

The presented research is a preliminary analysis of the problem, requiring continued exploration. The dynamics of the process of becoming a parent to a child with intellectual disability is not rigid or fixed. However, it constitutes an actual image of the activities undertaken by parents in order to support their child and transmit the best opportunities for development. Aksamit and Kruś-Kubaszewska (2021) wrote similarly about the life cycles of a family of a child with intellectual disabilities. The authors pointed out that they do not appear chronologically but overlap. It is worth stressing that the appearance of a child with intellectual disability significantly impacts marital, parental and fraternal relations in families. This is consistent with the conclusions of other researchers dealing with the situation of families with children with intellectual disabilities (Karwowska, 2008; Pałęcka and Szczodry, 2011; Bakiera and Stelter, 2010). At the same time, the results of our research show that parents achieve life balance and experience personal development. This corresponds to research results regarding the positive aspects of parenting, including posttraumatic growth (see Hastings et al., 2005; Greer et al., 2006; Blacher and Baker, 2007; Beighton and Willis, 2016; Byra et al., 2017).

Narrators often highlighted that the beginnings of “(un)known parenthood” were difficult, filled with extreme emotions, and they confronted expectations regarding the role of a parent – one that was taught, planned, dreamed of – with reality filled with fear, ignorance and a sense of loss of the desired parenthood. Kościelecka (1995) also pointed out such emotional states of parents of children with intellectual disabilities. However, it is worth noting, that the author carried out her research in the 1990s and almost 30 years have passed since then. The world has changed, but for parents, responsibility for a child with intellectual disabilities is still a huge challenge. Our research, therefore, shows that over the last three decades, “(un)known parenthood” is still a current and adequate term.

## CONCLUSION

All of the stages listed and the strategies which are adopted constitute the core of the process of becoming a parent to a child with intellectual disability. We need to stress that the rate of changes is individual and depends on circumstances. Moreover, there is a possibility of regression at every stage. However, as we can see in the narratives, the crisis stage would end, thus forcing the parents to choose a direction for their actions: “I had a choice, either to stay still here and now or move and regain balance” (N1). Making a decision to act on behalf of redefining one’s parental role and constructing one’s life balance “anew”, was expressed in the stage seeking control stage. Therefore, we put forward the idea that parents are emerging from the crisis stage and parenting children with intellectual disabilities is no longer merely difficult. However, we emphasize that the beginnings are difficult because no parent is full ready for the birth of a child with intellectual disability.

## STUDY LIMITATIONS

At the same time, we are aware of the limitations that result from conducting research in a specific time, social and cultural context. Perhaps in other circumstances of the research participants’ lives, the change would be visible. However, we decided that a qualitative analysis would show the dynamics of the process of becoming a parent and coping with difficulties. Reaching people willing to participate in the research was also a limitation. We did not reach parents who did not take active steps to regain the lost balance of family life. The devised strategies are not a final and complete catalogue of activities undertaken by the participants of our research, but they constitute a spectrum of clearly emerging elements in the process of becoming parents of children with intellectual disability.



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## „(NIE)ZNANE RODZICIELSTWO” – O STAWANIU SIĘ RODZICEM DZIECKA Z NIEPEŁNOSPRAWNOŚCIĄ INTELEKTUALNĄ

**Wprowadzenie:** Pojawienie się w rodzinie dziecka z niepełnosprawnością intelektualną znacząco wpływa na zachwianie się dotychczasowego modelu rodziny oraz podejmowanych przez jej członków ról: rodzicielskich, braterskich, małżeńskich. Doświadczenie nowych sytuacji przepełnionych obawami, strachem i niewiedzą, wyznacza kierunek podejmowanych przez rodziców działań na rzecz odzyskania utraconej równowagi.

**Cel badań:** Celem projektu było zrekonstruowanie procesu osvajania się (radzenia sobie) rodziców z niepełnosprawnością intelektualną dziecka.

**Metoda badań:** Materiałem badawczym były doświadczenia rodziców zebrane w formie wywiadów swobodnych. Analizę danych prowadzono zgodnie z procedurami metodologii teorii ugruntowanej.

**Wyniki:** Na podstawie przeprowadzonych badań udało się zrekonstruować proces „osvajania się” badanych z niepełnosprawnością intelektualną ich dziecka na wczesnym etapie diagnozy. W jego ramach wyłoniłyśmy strategię radzenia sobie z nową sytuacją życiową, w której znaleźli się uczestnicy naszych badań.

**Wnioski:** Poniższe rozważania skupiają się wokół polskiej perspektywy i uwzględniają kontekst



polityczny, kulturowy i społeczny. Proces radzenia sobie rodziców dzieci z niepełnosprawnością intelektualną składa się z następujących etapów: przeżywanie kryzysu, poszukiwanie kontroli, próbowanie, odkrywanie potencjałów, osvajanie.

**Słowa kluczowe:** niepełnosprawność intelektualna, rodzicielstwo, rodzina, proces „stawiania się”, wywiady, (nie)znane rodzicielstwo

