Niepełnosprawność. Dyskursy pedagogiki specjalnej
Nr 49/2023

Disability. Discourses of special education
No. 49/2023

Diana Aksamit
The Maria Grzegorzewska University
ORCID: 0000-0003-4169-4654
https://doi.org/10.26881/ndps.2023.49.08

Barbara Marcinkowska
The Maria Grzegorzewska University
ORCID: 0000-0003-2022-7141
https://doi.org/10.26881/ndps.2023.49.08

Jennifer Kurth
Kansas University
ORCID: 0000-0002-5947-7642
https://doi.org/10.26881/ndps.2023.49.08

The experiences of fathers of adults with profound intellectual disabilities. A qualitative study

Little is known about the experiences of fathers who care for adults children with profound intellectual disabilities. The aim of this study was to explore these experiences from their perspective. The information was shared during the participant interviews using analytical methods, based on theoretical and methodological concepts developed within the biographical sociology framework outlined by Fritz Schütze (1977, 2012). The respondents were asked to share their thoughts about their experiences as fathers from past, present and future perspectives. Gaining a better understanding of and uncovering details about the fatherhood experiences of men with adult children with profound disabilities is important so as to better understand ways to better support fathers in such situations. It is especially important to know about the ways in which these fathers perceive their experiences and to understand the social context that impacts their experiences and perceptions.

Key words: father, profound intellectual disability, experience, support

Doświadczenia ojców osób dorosłych z głęboką niepełnosprawnością intelektualną. Badanie jakościowe

Nadal niewiele wiadomo na temat doświadczeń ojców dorosłych osób z głęboką niepełnosprawnością intelektualną. Celem podjętych badań było zbadanie tych doświadczeń z ich perspektywy. Dane uzyskano w wywiadów z ojcami i przy użyciu metod analitycznych, opartych na koncepcjach teoretycznych i metodologicznych opracowanych w ramach socjologii biograficznej nakreślonej przez Fritza Schütze (1977, 2012). Respondenci zostali poproszeni o podzielenie się swoimi przemyśleniami na temat swoich doświadczeń jako ojców z perspektywy przeszłości, teraźniejszości i przyszłości. Lepsze zrozumienie i odkrycie szczegółów dotyczących doświadczeń ojcostwa mężczyzn dorosłych osób z głęboką niepełnosprawnością intelektualną jest ważne, aby lepiej zrozumieć sposoby ich skutecznego wspierania. Szczególnie ważne jest poznanie sposobów, w jaki badani ojcowie postrzegają swoje doświadczenia oraz zrozumienie kontekstu społecznego, który wpływa na ich doświadczenia i postrzeganie.

Słowa kluczowe: ojciec, głęboka niepełnosprawność intelektualna, doświadczenie, wsparcie

Introduction

In scientific research on the family of a child with profound intellectual disabilities, "mother-centrism" has dominated for years. This means that researchers were more likely to focus on the mother than the father (Ganong et al. 2003; Fathi et al. 2011). This is not only a direct result of the researchers' interest in the mother, motherhood, but above all, as we assume, of certain empirical difficulties, in particular: reaching the group of fathers, or obtaining their consent to participate in the study. An analysis of the literature indicates that until the 1980s, fathers were referred to as "invisible" in most studies, were not a frequent group of interest for researchers or were omitted from analyses of the family (MacDonald et al. 2010; Boström 2012). Recently, however, there has been a growing number of research in the group of fathers that highlights the importance and role of the man in the process of raising a child with a disability (Swallow et al. 2012; Braunstein et al. 2013). Still, little is known about the experiences of fathers of children with profound intellectual disabilities (Dunn et al. 2019; Aksamit 2021). Research on fatherhood in relation to a child with disabilities, including a child with profound intellectual disabilities, indicates that there are two distinct research perspectives: **(1) pessimistic** – brings together researchers and presents results showing painful, trajectory-laden suffering experiences of fathers as well as individual family members; **(2) optimistic** – brings together researchers aiming to show the value and importance of fatherhood for individual biographies of men, positive aspects of fatherhood taking into account the disability of a son, daughter. Theoretical and empirical analyses in an **optimistic perspective** – show a new image of the father, often socially unknown, remaining in the shadow of still prevailing negative socio-cultural stereotypes about: inter alia, a man's involvement in the care and therapy process of a child with disabilities, behavioral mechanisms and ways of thinking of fathers. Therefore, it is important to highlight the results of research which indicate that the involvement of fathers in the care of a child with disabilities results in a reduction of depressive symptoms, stress levels resulting from the care of the child in the group of mothers (Laxman et al. 2015). One cannot help but point to research showing that fathers' participation in family support programs results in positive outcomes in terms of the resolution of behavioral problems and increased levels of communication in children with disabilities (Bagner 2013). We conclude that it is particularly important to understand and show not only the negative experiences or negative aspects of fatherhood towards a child with a disability, but also those of a positive nature, because they can be seen as a form of coping by and for other parents, and a buffer against stressful experiences over the years (Folkman 2008).

People with profound intellectual disabilities from childhood to adulthood require round-the-clock care, including the use of specialized equipment: feeding tubes, respirators, rehabilitation lifts. This is a group of children with multiple disabilities. Due to the type and combination of disorders taking place in the group of people with profound intellectual disabilities, we are not able to list them – however, it is important to emphasize that this is associated not only with reduced cognitive, motor, emotional, social functioning but also with a health condition that deteriorates year by year (e.g., epilepsy, gastro-esophageal reflux, muscular atrophy) (Van Timmeren et. al. 2016). The functioning of these people includes problem behaviors: hitting, jerking, spitting, aggression, self-aggression, which as research shows negatively affects the mental health of their parents in particular (Kopeć 2013). Literature shows that fathers of children with profound intellectual disabilities are confronted with many psychological challenges, revisit past emotional crises and, being in this state, often have to meet the social demands alone: of being a good father (Gohel et al. 2011). Due to the nature and complexity of a child's profound intellectual disability, fathers often do not feel competent in caregiving activities – thus seeking to have the mother take over the majority of caregiving activities – which in turn often leads to problems in the marriage and the family as a whole (MacDonald et al. 2010; Aksamit 2019). On the part of fathers, this is dictated by the specificity and complexity of profound intellectual disability, but on the other hand, also by the lack of time resulting from the fact that they need to work several jobs, so that men cannot acquire as many parenting competences as mothers (Aksamit 2019, 2021). It is important to note, however, that fathers who undertake nurturing and caring activities have a greater sense of involvement and empowerment in their fatherhood and higher levels of satisfaction with their parenting (MacDonald et al., 2010). Contemporary research shows that fathers do not spend less time on caregiving activities compared to mothers (Luijkx, van der Putten, Vlaskamp 2017). Therefore, the primary research aim of this study was, using a biographical method embedded in the context of qualitative research, to explore and understand the experiences of fathers of adults with profound intellectual disabilities and to provide information about the expected and possible ways to support this group of men in different periods of parenthood.

Method – procedure for obtaining narratives

The selection of the study group was purposive. Two criteria were used: the first was the profound intellectual disability of the respondent's offspring, the second was the age of the child (the sons or daughters of the studied fathers were over 25). The use of such criteria was dictated by the specific situation of this group of fathers, due to the fact that there are still no solutions for their adult children, after the age of 25, in Poland, but also in the world, due to the small number of centers and institutions offering support. The situation is as follows: until the age of 25, people with profound intellectual disabilities in Poland attend remedial classes which are organized by the Ministry of Education and Science (Journal of Laws 2013, item 529); after the age of 25, care for this group of people is mostly provided by parents, legal guardians in family homes. Only a small group of adults with profound intellectual disability can attend the centers, which is dictated by, among others: their place of residence (city-village), material status of the family (the possibility of using the offer of private centers); the possibility for parents to transport their son or daughter to remote centers. Accordingly, (n=15) fathers were informed about the study by the mothers, with whom only (n=7) fathers remained married, the others, despite formal family breakdown, had good contact with the mothers and shared childcare throughout their lives; (n=5) fathers were informed by their service providers, i.e., municipal social services workers, nurses, doctors. (n=4) fathers of adults with profound intellectual disabilities who received a place in day care centers after completing their education were informed by trainers, psychologists, therapists. The remaining (n=6) fathers were recruited using the snowball method (Rubin, Rubin, 2012; Emmel, 2013). The fathers who were interviewed were between 58 and 79 years of age (Table 1).

Table 1. Age range of surveyed fathers of adults with profound intellectual disabilities

Fathers of adults with profound intellectual disabilities			
Age range	58–65	66–73	74–79
Number of people in a given age bracket	13	15	4

Source: study based on own research.

Narrative fatherhood structuring based on Fritz Schütze approach. Interviews

In order to explore and analyze the process dimension of men's biographies and the paternal experiences that comprise them, the theoretical and methodological concepts of Fritz Schütze (1977, 2012) were used. It was assumed that biographical processes and ways of experiencing different events, experiences of fathers cannot be analyzed and explained only by means of the category of action. The aim was to take into account the process of various situations, events and experiences in the biography of fathers. Based on Schütze’s (2012) conception, it is assumed that the history of an individual consists of a sequence of “process biographical structures", which testifies to its individual, unique dimension. Process structures occur in different combinations in every biography. When these combinations are established in the biography of a specific person, it will create the possibility to characterize the life course, to compare individual fates, to look at to what extent and in what way the individual is entangled in social processes. Based on the theoretical and methodological concepts developed within Schütze's (1977, 2012) biographical sociology, the fathers were asked to share their thoughts on their paternal experiences from a past-present-future perspective. A biographical approach was used, which provides an opportunity to explore and learn about the phenomenon of the human life course. The interviews were conducted over a 1-year and 6-month period and were in Polish. Each interview was constructed around a major research question: "How does it feel to be a father of a child with a profound intellectual disability?". The interviews were conducted in respondents' homes and lasted between 120 and 240 minutes. The respondents were informed that they could stop the survey at any time. A written informed consent was obtained from each father prior to the study. The interviews were recorded using a dictaphone, and then through repeated listening to the collected material, the interviews were carefully transcribed. Data from the interviews were coded using Atlas-ti (version 89), a qualitative data analysis software package.

The narrative analysis

The study used the steps of Fritz Schütze's (1977, 2012) method of narrative analysis. The narrative recreated the individual biographical experiences of specific individuals, to discover the basic structures of the process of biographical experience, corresponding to the variants of the narrator's attitude toward the essential phases of his or her life (Schütze 2012). According to Susan Chase (2009: 24), "*narrative is the retrospective creation of meaning, giving shape to past experiences or ordering them*". A systematic comparison method was used to analyze the data, looking for another case to answer the questions (Marshall et al., 2013). This was due more to the need to develop than to verify the theory, i.e., it was more about understanding the phenomenon than explaining it. Systematic comparison of interview excerpts allowed for the recognition of category saturation, i.e., the assumption that a subsequent interview adds nothing new to the research (Marshall et al. 2013). The method consisted of six steps: 1. Formal analysis of the text: the text was recorded using a voice recorder, then written down and transcribed. Then the narrative was divided into separable parts, sequences. 2. Sequential structural descriptions of the textual presentation (the sequence of presentational units): the text was divided, and an attempt was made to specify life stages in terms of process structures with particular emphasis on the trajectory of experiences, according to the assumptions of the adopted Schütze theory. Individual situations, turning points, climaxes were sought in each interview. 3. Analytical abstraction: an attempt was made to reconstruct the course of the respondents' fatherhood using selected research categories, taking into account interrelated process structures. 4. Knowledge analysis: the remaining fragments of the text were analyzed, especially those of a theoretical nature. They concerned the respondents' explanations and interpretations of their own life history in the context of full fatherhood. A contrasting juxtaposition of various fragments of the text was used, which were "pushed" into the background by the narrator. 5. Analysis of other interviews with case selection according to minimum and maximum similarity: at this stage, a comparison of the studied case was made with a similar case (the so-called minimal comparison strategy), and then a different case was referred to in order to obtain rich and diverse research material ("Maximum comparison strategy"). 6. Building a theoretical model: at this stage there were biographical patterns in a given group of fathers which were constructed while taking into account different variants of opportunities and constraints in life in the context of fatherhood (Schütze 2012).

Credibility checks

Despite many studies on the methodology used in qualitative research (Brinkmann, Kvale 2015; Maxwell 2012), epistemological questions about its objectivity continue to be raised in science. Therefore, to establish the credibility of qualitative research in this study, several plausibility tests have been conducted to establish that the studies are reliable and credible. The reliability, accuracy, and relevance of the data were examined by the following activities via: a faithful transcription of the recordings (Davidson 2009) which was facilitated by recording the interviews on a dictaphone, which made it possible to listen to them over and over again, revisiting passages already learned; authentication of the interviews by the fathers – the respondents were asked to authenticate the truthfulness, verifying the authenticity of the recorded reflections. The methodological step used was to share the understanding and interpretation of the data with the interviewees to be able to provide an accurate interpretation of their experiences - consensus was reached (O'Brien et al. 2014); the interpretations made by the researchers were checked by inviting three competent judges, who were asked to analyze them. These were fathers of children with intellectual disabilities who were not involved in the research but had knowledge and experience of raising a child with a disability.

Results

The interviews conducted with a group of fathers of adults with profound intellectual disabilities provided extensive information, especially on how paternal experiences fit into the biography, or life history, of the men interviewed. The qualitative research methodology and the applied biographical approach made it possible to take into account many important aspects of fatherhood and thus the course of biography: *masculinity* in a **social perspective:** requirements, norms and in a **subjective perspective**: what meanings and senses do men give to their own masculinity individually, its significance for fulfilling the role of a father, the formation of fatherhood over the years; the events in the biographies of fathers of adults with profound intellectual disabilities can be called critical, marked by the trajectory of experiences, the significance given to it by the interviewees, and how they perceive the future of their adult children with profound intellectual disabilities

Paternal experiences constituting a biography

Fatherhood is part of a man's biography for life. The surveyed fatherhood of fathers of adults with profound intellectual disabilities consisted of many events, situations having the character of a planned event, that is, a normative one, and a sudden one, completely changing the course of life in the mental (psyche) and physical (soma) dimensions. The statements of the respondents were selected to highlight the complexity of their experiences as fathers, which took the form of significant and often critical events in the following phases: the birth of the child, the process of diagnosis, diagnosis: profound intellectual disability, everyday life and the present, support for fathers (Table 2).

Table 2. Requirements and practices of fathers in selected stages of parenting

Period (biographical approach)	**Requirements for the father**	**Mechanisms and strategies of action**
The birth of the child	Maintaining the family; maintaining a good family image: a happy marriage, a healthy child	Wanting to be a good father, unsuccessful attempts to take care of the child (constant crying, incomprehensible behavior, lack of contact, criticism from mothers). The beginning of thinking about oneself in terms of otherness

Period (biographical approach)	**Requirements for the father**	**Mechanisms and strategies of action**
The process of diagnosing the child	Being a good father: understanding, loving, strong and steadfast mentally and physically; acknowledging, understanding and accepting the need for the child's diagnosis; being present during the ongoing diagnoses, supporting the child's mother in this process; talking to the child's mother in view of the women's needs;	Cvering up reality; testing the child's abilities - trying to undermine the opinion of professionals; staying outside the house - escaping into alcohol, parties; being on the sidelines; being silent - not engaging in conversations with the child's mother and other family members about the child; hiding negative inner emotions; downplaying the internally felt need for support. The feeling of otherness
The child's diagnosis - profound intellectual disability	Acceptance of the child's disability; love and acceptance of one's own child; acceptance of the demands and norms of the social role of a father of a child with a disability.	Hiding the child's disability from family and friends; avoiding contact with family and friends; pretending to be happily married; falsifying the real image of the child's functioning by using terms such as: lazy, temperamental; forbidding mothers to talk about the child's functioning with people from closer and further environments; adopting a passive emotional attitude towards the child and towards care and upbringing activities.
The period after the child's diagnosis – everyday life	Supporting the family; supporting the wife; participating in the rehabilitation process of the child; being strong and steadfast emotionally and physically	Working two/three jobs; downplaying one's own negative emotions; escaping into alcohol; withdrawal from household duties and childcare activities, divorce (n=25), starting a new family (n=15)
The present (the period in which the research was carried out)	Supporting the mother and the adult child with profound intellectual disabilities	Divorced fathers: blaming themselves for how their lives turned out; supporting the mother and adult child; constantly revisiting difficult past parenting experiences. Inability to reevaluate suffering from negative to positive. Married fathers caring for an adult with PIMD (profound intellectual and multiple disabilities) together with their mother: continued professional activity despite their age; internal interpretation of the situation in which they found themselves – re-evaluating suffering from negative to positive

Source: study based on own research.

> Father: *"She gave birth to a healthy daughter. She was and still is beautiful. I remember when she came home with her. As a father, I felt I was the head of the family, I did what a man should do. I felt like a father"* (p. 133)[1].

> Father: *"I knew I had to support my family. My wife was supposed to go back to work after raising the baby, but… well… it turned out differently. She had to stay at home with her forever. It was somehow natural, I didn't know how to feed her, change her nappy, I didn't know what to do when she screamed for hours. I knew I had to work, but it was very bad… well… you know, it was not enough all the time. I felt like I had lost something in my life"* (p. 134).

For a child with multiple conditions, the diagnostic process is complex. The prolonged diagnostic processes of the son, daughter caused a feeling of information chaos in the respondents in which they could not find themselves. Already at the stage of diagnosing, the fathers gave it a special meaning, which, according to the assumptions of symbolic interactionism (Mead 1934), caused certain behaviors, actions or lack of them. This generated a lot of negative emotions and experiences in the respondents.

> Father: *"We were going for a genetic test. I remember that it was difficult for me to swallow. I looked at my wife and saw her pain. I was scared… But I didn't say anything"* (p. 137).

From the statements quoted above, it turns out that men were experiencing various information about the functioning and development of their children (n=29) very acutely already at the stage of the diagnosis. In the beginning there was perfunctory information from the wives, e.g., in the form of mothers' dilemmas or their thoughts on child development. Most respondents did not articulate these experiences but needed support particularly during this period (n=26). In addition, the image of a strong man formed over the years did not allow them to outwardly show the negative emotions of fathers.

> Father: *"Everyone thought that I wasn't afraid, that it didn't matter to me. Just because I didn't ask my wife or talk about it doesn't mean anything. I had a thousand thoughts in my head, I wanted a miracle to happen, and it would all go away. I think men are scared, but they don't talk about it"* (p. 138).

> Father: *"It was quite a difficult period in our lives, Basia often asked: "Aren't you afraid?". She would say: "How can you be so calm?". I was scared, I was not calm, I was the most scared person in the world. But what was I to say? That I was scared like a small child? What good would that do? She needed me then, and I needed to understand myself"* (p. 138).

---

[1] The statements in the article represent a fragment of the research, which was published in its entirety in 2021 in the author's monograph: Aksamit D. (2012), *Oblicza ojcostwa. Studium narracji ojców dorosłych osób z głęboką niepełnosprawnością intelektualną*, The Maria Grzegorzewska University Press, Warsaw. In order to maintain the objectivity and integrity of the research, the following statements will give pages as the source of previously posted data. In the article, the material was analyzed in a different scope using different analytical categories.

In the parenting of the interviewed fathers, mechanisms of concealing, "covering up" the disability of their own child took place (n=25). The respondents often denied their son's or daughter's disability by: not keeping in touch with family or friends (n=12), pretending that they have a happy married life and are happy husbands (n=5), fathers, joking: that their children were lazy, temperamental (n=8). However, over time, these mechanisms became ineffective, generating a sense of powerlessness, a lack of solutions as to what to do next – so that the child's disability remains unknown to outsiders, so that it continues to be a secret within the family.

> Father: *„I didn't want anyone to know that our child "had (special) papers". That's what people said at that time. I forbade my wife to tell her parents or friends about it. I wanted us to be normal, a typical Polish family. Man is stupid, I did not think at that time how much longer I could hide my own child from the world"* (p. 140).

The men felt that they were not understood by their wives who, in their opinion, for a long time devoted themselves only to the children (n=21). They saw this kind of situation as the beginning of the breakdown of the emotional relationship between them and their wives. Their willingness to come closer, to help with daily activities was associated with criticism from the women (n=14). The issue of intimate relationships appeared in the men's narratives (n=21). This was, according to the respondents, an area of marital life that was particularly neglected by women, but important for men at the time.

> Father: *"We didn't have sex, we didn't sleep together, I stopped having a wife. There were many problems at the beginning, but they did not end, they multiplied. We were young, but there was no more intimacy, just everyday life"* (p. 186).

> Father: *"I wanted her to look at me, to hug me too. A guy needs to release his tension. A woman will cry, scream and she will be ok. It's different with men"* (p. 187).

Men indicated that over the years they felt an inner compulsion to meet social demands and maintain their family. Their statements show that it was a natural division, with the woman staying at home with the child and the man spending his days at work.

> Father: *"I've always had diabetes, it was hard. Sometimes I couldn't work anymore, but I had to. At home, everything was falling apart. There wasn't enough money"* (p. 134).

One of the critical events in the biography of most of the fathers surveyed was the break-up of the family in formal terms – divorce (n=25). Various factors contributed to this: lack of sexual intercourse (n=7), lack of understanding of the husband by the wife (n=19), complexity of the child's disability (n=18), lack of sense of family (n=13), male infidelity (n=5), lack of emotional bonding with the wife (n=22) and child (n=17). All this generated a sense of anxiety, a fear that the respondents would no longer be able to cope mentally or physically. Divorce was a particularly difficult experience fraught with suffering.

> Father: *"I left, I couldn't live like that. I didn't love the child. Yes, I left my wife with a sick son and I agonize over it every day. But no one knows about it, everyone just knows that I left my wife, and how could I. I just couldn't cope, I didn't know how to do it. I had a few relationships after that, but I was never happy again"* (p. 184).

> Father: *"I hesitated, what I should do. On the one hand, all this burden of living with a sick child, I had no friend in my wife, sometimes I felt I was a stranger to them. So I said I wasn't coming back. We fighted"* (p. 185).

In the case of respondents who were divorced at the time of the study (including those who had maintained continuous contact with their ex-wife, their child and who had shared child-rearing and child-care responsibilities over the years), feelings of guilt towards their child and wife emerged in their narratives, which did not give them inner peace. Sometimes fathers did not fully understand whether it was guilt or inner regret about how their lives had turned out.

At this point, reference should be made to the experiences of fathers who managed to preserve the classic model of a full family, that is, at the time of the interviews these respondents were married and together with the child's mother they took care of their adult son or daughter every day (n=7). Their statements show that one of the factors that helped them to maintain their family was mutual understanding between spouses (n=5), support from their wives (n=7).

> Father: *"My wife used to lock herself up with the baby. I couldn't touch it, because it was a baby. But finally I said that's it. I'm the father and it's my baby too. I don't know what got into her then. She acted like a lioness defending her little ones from a stranger. I learned a lot of difficult things, I wanted to be a good father. That's how I broke stereotypes, I went out taking the pram, I took him everywhere. Today everyone knows Olek in our town, everyone knows him at the pool, in the shop"* (p. 191).

> Father: *"If I hadn't stomped my foot then, she would have gone crazy. I told her to go somewhere for a few days. She didn't want to, but she went to the countryside. We were left alone, and it was only then that I felt that I was a father"* (p. 192).

Another factor that helped men to maintain their family (n=7) was a healthy child. This was particularly relevant to understanding one's own paternity, including for husbands who had been divorced (n=25). For both groups of respondents it allowed them to go through and relive the various negative, difficult experiences of parenting a child with profound intellectual disabilities, to understand themselves and sometimes to adopt a different perspective of their "self". This created an opportunity for some fathers (n=13) to experience the fatherhood they wanted.

On the importance of support for fatherhood

The respondents indicated that they needed support in the form of an "invisible hand" which they could always use if necessary. Referring to the past (n=24) the respondents indicated that they had been offered informal support over the years, mainly from their wives/ex-wives (n=18); parents (n=21); friends (n=13). However, it should be noted that (n=8) respondents had no formal support. Considering that (n=24) respondents declared that informal support was offered to them over the years as many as (n=19/24) never used this support. As far as formal institutional support is concerned, the majority of the surveyed fathers (n=27) heard about the possibility of using different types of support, but as many as (n=23) of them never used it. The respondents indicated that it was dictated by a socially shaped sense of shame that a man needs help (n=15/23), due to lack of time, which was most often caused by working several jobs (n=5/23), and (n=3/23) respondents pointed out the formalities involved, which involved time, going to several institutions – which was beyond their capabilities. There were also respondents who declared (n=5/32) that they had never heard that there was formal support for fathers as well, they indicated that they felt this was most often the case for mothers.

> Father: *"I cannot say that we did not have support. I have this feeling that people often say that nobody supports them, that nobody helps families like us. But it is not quite like that. I know my wife would disagree, she's a kind of an activist. The problem, as I see it, is that often people are unable to take it in at that particular moment"* (p. 213).

> Father: *"Friends said they'd stay with Tomek, so that we could go away somewhere, but we always said thank you, and we never did. I also understand, people offer something, they try, and all the time they hear «no». Then it comes to the point that if we need support, we do not have it"* (p. 214).

The respondents started their statement about support (n=28) by emphasizing that mothers in particular needed help: (n=28) at the stage of the diagnosis of the child, 23/28 during the adulthood of the son, daughter. For men, the beginnings of parenthood related to the process of child diagnosis were particularly difficult (n=29), however none of the respondents ever outwardly disclosed this. The interviewed fathers were not able to explicitly state which specific support they needed, and in which form during the different periods of fatherhood, but their statements made it possible to categorize it (Table 3).

> Father: *"I remember the tightness in my throat when we found out that our child was different. My wife was crying, she really needed some stronger drugs then, but also a conversation. It was different in my case. I wanted to run away and hide, to hide what had happened. I wanted someone to help me, but also not to interfere, not to ask"* (p. 210).

Fathers in their narratives showed a certain mechanism of hiding weaknesses by covering up their child's disability. However, as the analyses show, this generated a lot of negative emotions, thus a greater internal need for support, and more and more efforts not to be disclosed. The respondents were engaged in an inner struggle with their "self".

> Father: *"I preferred to make something up when someone asked why I was so silent, why I sat like a shadow. I said that I was overtired from work, that I was doing something at home, that I was fixing the car, that I caught some kind of cold, but I didn't talk about what I was feeling. It's all so complicated. Maybe if I had said that we have a sick child, that my wife and I only argue, that our older son has problems at school, that I feel like I failure – maybe life would have turned out differently"* (p. 211).

Table 3. Options for supporting fathers of children with PIMD (profound intellectual and multiple disabilities)

Period	**Modes of thinking/mechanisms of action**	**Character and types of support**
The diagnosis – profound intellectual disability of the child	Internal feeling of needing support – hiding weaknesses, not naming the need for support.	Support without instructions on how to raise a child with PIMD – paying attention to the socially wounded image of fatherhood/manhood; working on the man's own "self", leaving aside the aspect of fatherhood at this stage; clear messages from the closer and more distant environment – you are not alone (without asking about one's well-being).
The period after the child's diagnosis – everyday life	The desire to escape, the constant mechanisms for hiding the child's disability; masking one's own weaknesses – internally blocking the need to be supported; blaming those closest for the situation in which they find themselves – the desire to defend one's "self". A constant sense of pity rather than real support.	The need to help – without interfering in the men's personal lives, without questioning, the need to listen without asking. Clear messages from the closer and more distant environment – you are not alone (without asking about one's well-being). Paying special attention to men's own "self", taking into account the aspect of fatherhood in second place. Making demands on fathers – taking into account their inner need to give something in return, to be needed, to be important for others in society.
The present (the period in which the research was carried out)	A sense of social stigma: I/my family/child – perceived only as recipients of social support –resulting in reluctance to use formal and informal support. Need for social understanding (without pity).	Raising public awareness of the capabilities of people with PIMD – aiming for broad social inclusion through the expansion of the network of 24-hour institutions, projects that will take into account the capabilities of people with PIMD (as a contribution to the development of society). Raising public awareness of the importance of the father's role in the parenting process. Addressing issues of emotional functioning.

Source: study based on own research.

The analysis of the responses indicates that one of the significant factors determining the use of formal and informal support by fathers: is the social image of the profound intellectual disability of their child (as an individual contributing nothing to society, only as a recipient of assistance), the perception of families raising a child with disabilities (as poor, needy, only as recipients of support). Support for fathers of children with profound intellectual disabilities should be shaped by the experiences of men, their inner needs. The ways, the forms, the type of help and the organization of support, both formal and informal, are implicit in the meanings and senses given by fathers to the experiences that make up the role of the father and the biography of men.

Discussion

In all the biographies, the most important factor that gained in importance at different periods of the respondents' lives was the cultural factor. It concerned the vision and characteristics of a strong, steadfast man. This made fathers (n=29) unable to talk about what they feel, what they need, what difficulties they have for many years. They took on the mask of being strong, steadfast, tough, which ended up breaking up the family and usually worsening their health. The majority of the surveyed men (n=26) at different stages of their fatherhood (e.g., when the risk of the child's disability appeared, when the diagnosis could not be made for a long time, when a specific diagnosis of profound intellectual disability had already been made) stuck to the cultural image of a man (masculinity), and therefore of a father, imposed on them in the process of upbringing. The analysis of the research carried out shows that the fathers (n=34) adopted different strategies in order not to show that they were also suffering because of the child's disability, that they wanted to cry, that thinking about their offspring’s health they felt as if „someone had taken something away from them and would never give it back”. They said that they often unconsciously prolonged the period of diagnosis (n=17), reassuring their own wives that there was nothing wrong with their child, that the partial or provisional diagnosis was false, an overinterpretation by various specialists. They stressed that the longer this process went on, the more they hoped that something would change. The research results also point to the lack of adequate institutional (n=27) and non-institutional (n=23) support for men, adjusted to their actual needs, emotional situation, ways of functioning, and ways of understanding reality. Men needed support already in the first stage of their fatherhood, especially in the period when the first information about abnormalities in the child's development appeared (n=29). Fathers needed someone to tell them: what's next, how to live, how to be a good father, how to regain control of their lives. But they could neither ask for it nor accept support when it was offered to them. The respondents said that even when they were able to get support from a specialist, to go with the child and the whole family to an appointment, they still felt blocked.

Most of the respondents had played the role of the father in the classic model of the full family for only a few years. In most of the interviewed stories (n=25) the family was destructurized by the father's departure. As research indicates, marital relationships most often become difficult already at the moment of learning about the risk of disability of the child, which is also confirmed by other research studies (Blacher et al., 2002; Jansen et al. 2012). The fathers said that with the loss of their vision of a fit child, they lost their wives. They felt that women often closed themselves off in a "hermetic world" with a child with a disability and forgot about their relationship with their husband. In many cases there was no intimate relationship between them and their wives. A particularly difficult experience for fathers was the feeling that they were not good fathers, that they were not real heads of the family, that they were not real men. However, when fathers from full families felt unwanted, rejected, it was not them but their wives who held out a helpful hand. They came to the conclusion that the father was important in their and the child's life.

The interviewed fathers pointed to many additional problems they had to deal with on a daily basis, their complexity, and gave particular importance to those arising from the environmental context: the perception and acceptance of disability, the understanding of the situation of parents of children with disabilities. Research has shown that men who could count on the understanding of their situation and that of their children, on the acceptance of the otherness of their children, functioned and coped better in difficult situations; they were quicker to remove the “mask” of a strong, steadfast father in the whole process of adapting to disability. The research conducted has shown how important the environment is for families with a person with profound intellectual disabilities. This is why it should be an important subject of the whole therapeutic process for the person with profound intellectual disabilities and his/her carers. The environment offers resources that no therapeutic facility, family support groups or professionals (psychologist, psychiatrist) can offer (Poppes et al. 2010; Tadema, Vlaskamp 2010). It is about the feeling of being part of a social group, about relationships within the group. Research is therefore needed on the resources of different environments that surround the family bringing up, caring for an adult with profound intellectual disabilities, and in the next stage the results of this research should be translated into practice (in the context of a support system, planning of therapy). The system is meant to support parents on the one hand, but on the other hand, the person with profound intellectual disabilities from their childhood to adulthood.

In conclusion – the research carried out shows and confirms how important the process of supporting fathers is. Above all, it is to be a skillfully planned process, taking into account the actual needs of fathers at different stages of their parenting, and is to be characterized by men's understanding.

Research can help to develop a comprehensive understanding of profound intellectual disability. Fatherhood cannot be understood if the voices of men cannot be heard, so it is important to include in the study young men who are just beginning their journey as fathers of children with profound intellectual disability. The analysis of the interviews reveals a new discourse about fatherhood and about family with an aging parent and an aging child.

References

Aksamit D. (2019), *Kobiety-Matki o macierzyństwie. Socjopedagogiczne studium narracji matek dorosłych osób z głęboką niepełnosprawnością intelektualną*, The Maria Grzegorzewska University Press, Warsaw.

Aksamit D. (2021), *Oblicza ojcostwa. Studium narracji ojców dorosłych osób z głęboką niepełnosprawnością intelektualną*, The Maria Grzegorzewska University Press, Warsaw.

Boström P. (2012), *Experiences of parenthood and the child with an intellectual disability* (Doctoral dissertation), Göteborgs Universitet, Sweden.

Braunstein V.L., Peniston N., Perelman A., Cassano M. (2013), *The inclusion of fathers in investigations of autistic spectrum disorders*, Research in Autism Spectrum Disorders, 7(7): 858–865; doi: 10.1016/j.rasd.2013.03.005.

Brinkmann S., Kvale S. (2015), *Interviews: Learning the craft of qualitative research interviewing* (ed. 3), Sage, Thousand Oaks CA.

Chase S. (2009), *Wywiad narracyjny. Wielość perspektyw, podejść i głosów* [in:] N.K. Denzin, Y.S. Lincoln (eds), *Metody badań jakościowych* (pp. 15–57), PWN Press, Warsaw.

Davidson C. (2009), *Transcription: imperatives for qualitative research*, International Journal of Qualitative Methods, 8(2): 35–52; doi: 10.1177/160940690900800206.

Dunn K., Kinnear D., Jahoda A., McConnachie A. (2019), *Mental health and well-being of fathers of children with intellectual disabilities: Systematic review and meta-analysis*, BJ Psych Open, 5(6), e96: 1–10; doi: 10.1192/bjo.2019.75.

Emmel N. (2013), *Sampling and choosing cases in qualitative research: A realist approach*, Sage Publications, London.

Fathi D., Zolfaghari A.R., Hashemi M. (2011), *The contrastive study of mental health status of the mothers of exceptional children (deaf and blind) in special educational system with combined educational system*, Procedia – Social and Behavioral Sciences, 30: 1817–1822; doi: 10.1016/j.sbspro.2011.10.350.

Folkman S. (2008), *The case for positive emotions in the stress process*, Anxiety, Stress, and Coping, 21: 3–14; doi: 10.1080/10615800701740457.

Ganong L., Doty M.E, Gayer D. (2003), *Mothers in postdivorce families caring for a child with cystic fibrosis*, Journal of Pediatric Nursing, 18(5): 332–343; doi: 10.1016/s0882-5963(03)00105-2.

Gohel M., Mukherjee S., Choudhary S.K. (2011), *Impact on the parents of mentally retarded children in Anand District*, Healthline, 2(2): 62–66.

Jansen S.L., van der Putten A.A., Vlaskamp C. (2013), *What parents find important in the support of a child with profound intellectual and multiple disabilities*, Child Care Health Development, 39(3); 432–41; doi: 10.1111/j.1365-2214.2012. 01381.x.

Journal of Laws (2013), *Regulation of the Minister of National Education of 23 April 2013 on the Terms and Methods of Organization of Revalidation and Education Activities for Children and Young People with Profound Intellectual Disabilities* (Journal of Laws of 2013 item 529).

Kopeć D. (2013), *Rzeczywistość (nie)edukacyjna osoby z głęboką niepełnosprawnością intelektualną. Zbiorowe instrumentalne studium przypadku*, Adam Mickiewicz University Press, Poznań.

Luijkx J., Van der Putten A.A.J., Vlaskamp C. (2017), *Time use of parents raising children with severe or profound intellectual and multiple disabilities*, Child: Care, Health, Development 43(4): 518–526, doi: 10.1111/cch.12446.

MacDonald E.E., Hastings R.P., Fitzsimons E. (2010), *Psychological acceptance mediates impact of the behaviour problems of children with intellectual disability on fathers: Psychological adjustment*, Journal of Applied Research in Intellectual Disabilities, 23(1): 27–37, doi: 10.1111/j.1468-3148.2009. 00546.x.

Maxwell J. (2012), *Qualitative research design. An interactive approach* (3rd ed.), George Mason University, Virginia.

Mead G.H. (1934), *Mind, self, and society*, University of Chicago Press, Chicago, IL.

O'Brien B.C., Harris I.B., Beckman T.J., Reed D.A., Cook D.A. (2014), *Standards for reporting qualitative research: A synthesis of recommendations*, Academic Medicine, 89(9): 1245–1251, doi: 10.1097/ACM.0000000000000388.

Poppes P., van der Putten A.J.J., Vlaskamp C. (2010), *Frequency and severity of challenging behaviour in people with profound intellectual and multiple disabilities*, Research in Developmental Disabilities, 31: 1269–1275, doi: 10.1016/j.ridd.2010.07.017.

Rubin H.J., Rubin I.S. (2012), *Qualitative interviewing: The art of hearing data* (3rd ed.), Sage Publications, Thousand Oaks.

Schütze F. (1977), *Die Technik des narrativen Interviews in Interaktionsfeld-studien – dargestellt an einem Projekt zur Erforschung von kommunalen Machtstrukturen*, Bielefeld University Press, Bielefeld.

Schütze F. (2012), *Analiza biograficzna ugruntowana empirycznie w autobiograficznym wywiadzie narracyjnym. Jak analizować autobiograficzne wywiady narracyjne* [in:] K. Kaźmierska (ed.), *Metoda biograficzna w socjologii* (pp. 141–278), Nomos Press, Cracow.

Swallow V., Macfadyen A., Santacroce S.J., Lambert H. (2012), *Fathers' contributions to the management of their child's long-term medical condition: A narrative review of the literature*, Health Expectations, 15(2): 157–175, doi: 10.1111/j.1369-7625.2011.00674.x.

Tadema A.C., Vlaskamp C. (2010), *The time and effort in taking care for children with profound intellectual and multiple disabilities: A study on care load and suport*, British Journal of Learning Disabilities, 38(1): 41–48, doi: 10.1111/ j.1468-3156.2009.00561.x.

Van Timmeren E., Van der Putten A.A.J., Schrojenstein Lantman-de Valk H., Schans C.P., Waninge A. (2016), *Prevalence of reported physical health problems in people with severe or profound intellectual and motor disabilities: A cross-sectional study of medical records and care plans*, Journal of Intellectual Disability Research, 60: 1109–1118, doi:10.1111/jir.12298.