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Motherhood of a woman with intellectual disability – retrospection of biographical experiences

Macierzyństwo kobiet z niepełnosprawnością intelektualną – retrospekcja doświadczeń biograficznych[1]

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Abstract: The parenthood of persons with an intellectual disability continues to be a sensitive and controversial issue. Although the concepts of normalization, subjectivity and emancipation are actively implemented, the right to engage in parental roles is denied to such persons. Among other things, this is due to social perception, in which persons with intellectual disabilities are incapable of self-reliant and responsible functioning. Previous studies have demonstrated that such persons do have legitimate needs, including the desire to be married as well as to seek fulfilment as parents. This paper sets out to discuss the findings of studies concerned with subjective interpretations and biography-building among mothers with intellectual disabilities. Such studies were guided by the need to address insufficient knowledge of how such persons define motherhood and the search for answers on what is individual and inimitable from a mother's perspective. The study relied on an interpretative paradigm and took advantage of the biographical method, examining the experience of six women/mothers with an intellectual disability through thematic narrative interviews. A number of categories were distinguished in the course of analysis in order to describe motherhood from the standpoint of subjective experience. The categories distinguished in the course of analysis and interpretation revealed a wide range of individual meanings given to motherhood experienced by women with intellectual disabilities. Based on personal interpretations, the study revealed various facets of motherhood, defined as love, happiness, satisfaction, dream, but also as duty, difficulty, fear, loneliness, helplessness or even failure. Moreover, insights were gained into the social and cultural context in which the mothers interviewed happen to function. The meanings attached to motherhood were rooted in subjective experience and, as such, may be due to the fact that relationships and the parenthood of persons with intellectual disabilities are seldom, if ever, accepted. They may also result from the challenges that the study participants face, struggling with their children's behaviour and growth issues as well as with the aftermath of their own disability.

Keywords: qualitative research, motherhood, intellectual disability

Abstrakt: Rodzicielstwo osób z niepełnosprawnością intelektualną nadal jest tematem wrażliwym i kontrowersyjnym. Mimo wdrożenia idei normalizacji, podmiotowości i emancypacji, odbiera się prawo tym osobom do pełnienia ról rodzicielskich. Wynika to być może ze społecznego postrzegania osób intelektualnie niesprawnych jako niezdolnych do samodzielnego i odpowiedzialnego funkcjonowania. Dotychczasowe badania ukazują potrzeby tej grupy osób, które nie tylko chcą zakładać związki małżeńskie, ale pragną także realizować się w roli rodziców. Celem artykułu jest zaprezentowanie wyników badań dotyczących subiektywnego interpretowania i konstruowania biografii matek z niepełnosprawnością intelektualną. Realizując badania kierowano się niedostateczną wiedzą w zakresie definiowania macierzyństwa przez te osoby oraz chęcią poznania odpowiedzi na pytania, które dotyczyły tego, co z perspektywy matek jest indywidualne i niepowtarzalne. Badania osadzono w paradygmacie interpretatywnym i zastosowano metodę biograficzną. W tematycznych wywiadach narracyjnych wzięło udział sześć kobiet/matek z niepełnosprawnością intelektualną posiadających dzieci. W toku analiz wyodrębniono kilka kategorii, które ukazują macierzyństwo z perspektywy subiektywnego doświadczenia matek. Wyłonione podczas analizy i interpretacji kategorie stworzyły paletę indywidualnych znaczeń nadanych macierzyństwu, którego doświadczają kobiety z niepełnosprawnością intelektualną. Przeprowadzone badania, oparte o osobiste interpretacje matek, ukazały różne oblicza macierzyństwa, które jest definiowane jako miłość, szczęście, radość, satysfakcja, marzenie, ale także jako obowiązek, trudność, lęk, osamotnienie, bezradność czy wręcz porażka. Ukazały także kontekst społeczno-kulturowy, w którym matki zostały usytuowane. Nadane macierzyństwu znaczenia, oparte o subiektywne doświadczenia kobiet, wynikają być może z braku całkowitej akceptacji związków osób z niepełnosprawnością intelektualną i pełnionego przez nich rodzicielstwa. Mogą też być skutkiem zmagań uczestniczek nie tylko z trudnościami wychowawczymi i rozwojowymi dzieci, ale także ze skutkami własnej niepełnosprawności.

Słowa klucze: badania jakościowe, macierzyństwo, niepełnosprawność intelektualna

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1. Introduction

The sexuality of persons with intellectual disabilities is a very complex and multifaceted issue. It is still a taboo subject, which is why it is neglected and ignored in many cultural circles. Since this sphere of life of persons with intellectual disabilities is hardly ever admitted or accepted, many countries have opted for segregation as an elementary way to prevent parenthood, as well as resorted to forced sterilization (Żytaye, 2013; Drzazga 2016). Quite often, measures are taken to suppress the sexual activity of such persons (Jurczyk 2018) because there is a persistent notion that persons with intellectual disabilities should not have children due to their poor parental competence (Górnicka, 2015). They are seen as incapable of starting a family and fulfilling parental roles, while their needs for sexuality, intimacy, closeness in relationships, love and the desire to have children are dismissed and disregarded, especially by their immediate environment (Myśliwczyk, 2019a). Once introduced, the fertility control policy remains in effect to this day, as attested by international reports (Frohmader, Meekosha, 2012).

The current perception of sexuality, procreation and parenting of persons with intellectual disabilities remains a highly sensitive issue. It gives rise to substantial controversy, despite the widely propagated and implemented ideas of normalization, subjectivity, emancipation and autonomy (Żółkowska, 2016; Krause, 2010), which nonetheless fail to sufficiently highlight the questions of relationships, sexuality, parenting and the rights of persons with intellectual disabilities to perform socially important roles in these respects. However, Kijak emphasizes that changes in the perception of disability and persons it may affect have brought the issue of their sexuality closer to the fore. It has been recognised by various academic disciplines through publications, conferences and seminars, which should mean that it ceased to be a taboo subject (Kijak, 2016). Broader social awareness of the sexuality of persons with intellectual disabilities should contribute to a greater understanding of their needs, as they not only want to marry but also desire to have children. Why, therefore, is social acceptance of persons with intellectual disabilities who seek to fulfil and realize their parental roles still lacking? Why does their parenthood continue to be a debatable topic?

A number of answers to the above questions may be attempted:

1. From a scientific standpoint, there is a lack of sufficient research on the relationships, sexuality or parental roles of persons with intellectual disabilities, especially in relation to the non-disabled population in Poland (Drzyzga, 2016). This is perhaps due to the fact that "there are few such couples in Poland and it is rare for such persons to become parents, owing to both legal obstacles, the attitude of the environment and the cognitive and social limitations that such persons experience. At the same time, persons with intellectual disabilities often express a desire to have their own family" (Żyta, 2013, p. 60). Empirical research suggests that persons with intellectual disabilities do have dreams regarding, e.g. sex, relationships and parenthood, but as they remain under the supervision of their families, such needs are suppressed. Consequently, persons with disabilities remain in the family as unpaid domestic servants, whose parents prevent them from fulfilling roles that they find important (Mattila, Määttä, & Uusiautti, 2017; Crane, 2018; Myśliwczyk, 2019b). It must be underscored that it is the parents who should take all measures that would enable women with intellectual disabilities to develop a sense of self-esteem and gender identity, which, in consequence, may contribute to self-actualization in roles they recognize as important (Bartnikowska, 2019).
2. The persisting stereotypes and prejudices portray persons with intellectual disabilities as "childish", "immature", or "dependent" (Drzazga, 2016, p. 88). This engenders the notion that they have poor knowledge of child-rearing and lack sufficient competence to ensure their children have appropriate developmental conditions. For this reason, they are perceived to have little parenting experience and are unable to assess hazardous situations in childcare rationally (Wałachowska, 2017). Persons who have actually become

parents are judged to be individuals who do not comprehend their role and do not dispose of the capacity to carry out childcare-related duties (Kijak, 2016). In addition, carers, social workers, parents as well as the wider community see them as helpless, requiring assistance and care, dependent on the immediate environment and hostile (Wałachowska, 2017). Concerns with respect to the parenthood of persons with intellectual disabilities may be attributed to the fact that such individuals are not only taken care of by social services that support families and children but fairly often their children are taken away based on judicial rulings. However, one must allow for the fact that persons with intellectual disabilities are diversified in how they function using their social competencies and life skills, which, in turn, is reflected in varying degrees of knowledge, skill sets and performance of duties involved in responsible social roles (Kijak, 2016).

3. Concerns are raised in social discourse about pregnancy in persons with intellectual disabilities and the possibility of defective genetic material being passed on. The risk of intellectual disability in the child of a person with congenital intellectual disability can range from slightly elevated to high, reaching 50%, or as much as 100% in particular circumstances (Latos-Bielańska, 2013). Determining the actual number of children of parents with intellectual disabilities is problematic. Ćwirynkało cites data from Norway, according to which "this group accounts for approximately 0.2-0.9% of all children (depending on the criteria of intellectual disability adopted)." However, it should be borne in mind that these estimates are subject to a certain margin of error (Tøssebro, Midjo, Paulsen, Berg, 2017, after: Ćwirynkało, 2019).

The Polish system of social support, sexual education or other instruction relating to sexuality, procreation and parental roles is hardly sufficient. Persons with intellectual disabilities need education, courses and training to prepare them to perform responsible and socially important roles of the spouse and parent (Tarleton, Puckering, 2017; Wołowicz-Ruszkowska, 2018). Intellectually disabled parents (particularly mothers) require support in gynaecological care and in becoming ready to take on parental responsibilities (Wałachowska, 2017). This goes beyond *ad hoc* assistance in caring for their child as a long-term action to providing specialized support of a subjective nature (Lizoń-Szłapowska, 2012). The necessity to ensure support and assistance enabling one to "make free and responsible decisions about the number of children and the time to have them, gain access to age-appropriate education and information on procreation and family planning, as well as obtain the means necessary to exercise these rights" (Król, 2018, p. 90) arises from an international legal act, i.e. the UN *Convention on the Rights of Persons with Disabilities*, ratified by Poland in 2012. This act guarantees the right to enter into marriage and make decisions with respect to having children and sex education, but it also provides for support in parenting (King, 2018). Research shows that the problems faced by parents with intellectual disabilities are the same as those of other parents whose socio-economic status is equivalent (Wołowicz-Ruszkowska, 2021).

The above problem areas involved in the parenthood of persons with intellectual disabilities preclude an unequivocal answer to the questions posed, but they also show the complexity of the issue addressed in this study. The idea of widely promoted freedom of every person and their unconstrained rights tends to be circumscribed when persons with intellectual disabilities are involved. A large proportion of the public do not allow for, or respect, the rights of such persons to love, procreate or have children. The highly valued social roles of the spouse or parent are no longer as prestigious and translate into difficulties and failures in the case of persons with intellectual disabilities. Given such negative social attitudes, it is difficult to find solutions to change the perception of parenthood of persons with intellectual disabilities. Perhaps further research in this area will foster a positive change.

2. Methodological premises of research

The research conducted by this author relied on a qualitative, interpretative paradigm, and the adoption of the latter perspective was dictated by the awareness that the phenomenon in question is difficult to explore in the objective approach. A qualitative research strategy enables one to understand as well as explain, since one focuses both on the vital experiences of the individual and their social context (Bron, 2017). The qualitative strategy employed here involved three perspectives: a phenomenological-hermeneutic inquiry through questions about the sense and meanings that mothers with intellectual disabilities lend to their maternal experience followed by the interpretation of such meanings, as well as symbolic interactionism to gain insights into how they construct their own unique social reality.

The principal goal was to reconstruct the stories and arrive at the subjective meanings that mothers with intellectual disabilities impart to their motherhood. It was, therefore, investigated how mothers define their parental roles, how they experience it, what meaning they attach to the tasks resulting from their role and how they interpret them in the context of their children's behaviour, how they perceive the difficulties resulting from motherhood and how they define the modes of coping. An answer was therefore sought to the following question: how do mothers with intellectual disabilities interpret their own experience of motherhood?

Having adopted an interpretative perspective, it became possible to employ the biographical method. A biography (constructed by the individuals themselves) is built around the subjects' own, individual and subjective description of life, and it assesses and interprets their lives (Kijak, 2016). As an inherent component of experience, interpretation "reveals the meanings persons give to things, matters, events. The striving to know these meanings is tantamount to understanding the human being, his/her psyche, consciousness and motives, which is a characteristic trait of humanistic cognition" (Kijak, 2016, p. 126-127). In pursuing the biographical method, a thematic narrative interview was used as the immediate tool of research since a narrative enables each participant to tell a story from their own perspective.

The selection of the population sample in this project was a targeted one, seeking to enrol women with a diagnosed intellectual disability (mild and moderate) who have children. Supplementary criteria included experiencing the phenomenon in question and being interested in understanding its nature and meaning, giving informed consent to participate in an extensive, recorded interview and to the subsequent publication of data. The study was conducted in 2020 (February-September) and in 2021 (February-March). The empirical material from 2021 (three interviews) originates from an unpublished manuscript (supervised by this author) by a third-year special education student, who gave her permission to use it for the purposes of this study.

The subject group comprised six women/mothers aged 24-46, who had one to four children aged 3 to 21. Four were married and two participants were single mothers. All mothers were involved in running the household. The participants were residents of Olsztyn and the surrounding area. Interviews were conducted in places convenient for the respondents, sometimes in their homes or flats, sometimes in a café. Participation in the research was entirely voluntary, and the women themselves decided on a convenient time and place to conduct the interview. The method described by F. Schűtze (Schűtze, 2012) was employed to analyse the material collected; it consisted in transcribing and titling individual interviews, formal analysis of the text, structural description of the narrative, analytical abstraction, contrastive comparison, and synthesis (Kaźmierska, Waniek, 2020).

3. Analysis

The stories told by the authors of biographies reveal the truth of motherhood as they experience it. It is a reality constructed in the light of subjective experience, to which the women/mothers attached individual meanings and significance. Due to its limited scope, this paper discusses only those categories which proved to have the greatest degree of saturation or, in the objective assessment of the researcher, yield a new perspective on motherhood.

3.1. Motherhood: dreams realized

A number of the participants define their experience of parenthood as an anticipated state that has always been in the realm of their dreams. The women had a great desire to become mothers and fulfil themselves in these roles. The dream of having a child is, according to some narratives, another dream after marriage. One respondent emphasizes that the pregnancy was not planned, yet she realized after giving birth to her child how much she had subconsciously wanted to become a mother. Another interviewee dreamed of becoming a mother in order to pass on the gift of life in this way, while leaving behind tangible proof of her existence. Below are some selected statements:

> "I wanted to leave a trace of myself. (...) To give life and to leave a trace, that's what."

> "Well, that was my dream, wasn't it? When I get married, to start a family. And live for that family."

> "I wanted to be a mother, because I knew it must be nice, that you love this child, and that for them you are the most important. I really wanted that, didn't I?"

> "It's probably every woman's dream, I was young, I had a husband, then it's obvious that you dream of having a baby afterwards."

> "I'll be honest, it came out so unexpectedly, because to be honest it wasn't a planned pregnancy. But when I found out, I was very happy (...) because I really wanted it."

3.2. Motherhood: social pressure

Two of the interviewed women perceive their role of the mother as a duty which has to be fulfilled. Perhaps this sense of duty stems from the social pressure which obligates women to become not only a wife but also a mother. Women living in small rural towns from which the participants come are particularly subject to such expectations:

> "(...) being a parent is both duty and happiness (...)."

> "If a woman can have children, it is a duty to have them because if she doesn't, they look at her strangely."

> "Well, when you are old enough, you have to think (...) about children, you know. You have to have children because then you have a family (...)."

Another participant wanted to have a child as an alternative to going into a religious order. Her parents had designed two paths her life would have to follow, one of which involved taking vows, while the other involved "normalcy", i.e. getting married and having children:

> "I never wanted to become a nun, I just (...) wanted to have children. Very much so. (...) I was afraid that my parents would send me there [to the order - author's note], but I succeeded."

3.3. Motherhood: criticism and misunderstanding

Two of the women interviewed faced criticism, which they found to be a very unpleasant experience. They were not able to enjoy their "blessed state" because they were unfavourably judged by their neighbours, who believed that they were not capable of taking care of their children on their own. The participants had similar experiences in their encounters with various professionals, in whose opinion "handicapped persons should not have children". The negative response from their environment and lack of acknowledgement of their desires and needs was a severely distressing experience. They felt stigmatized because they did want to fulfil their role as mothers despite having been diagnosed with an intellectual disability. The most hurtful were the comments and remarks they received from care personnel who, according to one of the participants, should not judge, but rather offer support and help:

> "Well you know it was hard. Because people think that we should not have children. At the beginning they looked at us a bit strangely, but they didn't later."

> "Sometimes the neighbours would say, 'Alinka, you're alone like a child yourself, why do you need this on top of it? Who will raise this child if you need help yourself?"

> "In the hospital, they told me point-blank that I wouldn't be able to cope with the child, they told me to leave it, that I shouldn't have children, because I'm disabled. (...) they tried to talk me into leaving the child when I gave birth."

3.4. Motherhood: fulfilment and responsibility

When interpreting their motherhood, all authors of biographies use the following terms above all: love and happiness. The women are very happy that—as they themselves emphasize— they can fulfil what they find to be such an important role regardless of their disability. They perceive motherhood as a positive and important experience in their lives which, albeit associated with hardship and sacrifice, brings joy and great satisfaction. For some biographers, being a mother means receiving and giving unconditional love, and the feeling cannot be compared to any other. Some of the interviewees, while defining their motherhood, also referred to the great responsibility and duty that are inscribed in the role of a parent. Some mothers emphasize that raising a child requires great commitment, but every effort pays off because the love of a child is their greatest happiness. Below are some sample statements:

> "To be a parent... Well, happiness.
> In a word, happiness. It doesn't matter if
> the child is sick or healthy, it is happiness,
> it is the parent's love for the child.
> That is happiness."

> "Well, to be a parent..., You just need to be, well, you must love (...)."

> "It's a wonderful experience. (...) It requires sacrifice, but very wonderful. (...) . I am very happy to be a mother (...)."

> "First of all, just being a mum, well, it's a huge love for this child, it's a big responsibility because you know that I'm disabled, but I feel that I'm a mum and that I'm very happy that I have a child (...)."

> "(...) it's probably the happiest thing in the world to be a mum, (...) it's such a different love. You feel that you can give your life, that these are the most important persons for you and that you are a mum, who is also the most important person for the children."

> "It is very beautiful to be a parent.
> Really, it is wonderful (...)."

> "(...) it is a good experience
> me being a mum (...)."

> "(...) But after the delivery, when I looked at my son, I just beamed. I was simply overjoyed, very happy (...)."

> "(...) that motherhood,
> such a wonderful feeling!"

> "This is a very important event (...)."

Next to love and responsibility, women associate the role of mother with sacrifice as well. This category is particularly conspicuous in women whose children are also disabled:

> "(...) it is not easy for a mother who has a child with a disability to fight against this condition, against everything (...). So it is definitely a sacrifice. A heavy sacrifice. And it's worth it, it's worth the sacrifice, so that the child has a happy life."

> "It is obvious that it looks a bit different when there are healthy children, but the fact that they are disabled does not mean that I love them any differently or any less, it just means that I have to sacrifice a lot more because you know that doctors, rehabilitation, various meetings, you know that you have to sacrifice your time (...)."

3.5. Motherhood: worry, anxiety, fear

The participants also acknowledge that motherhood involves negative emotions such as anxiety and fear. These feelings were mainly due to concern for the health of the child, who, according to the women interviewed, might inherit their intellectual disability.

> "(...) at first, it was such a fear that maybe they would be born like Kasia was."

> "We were afraid if the other one would also be disabled, (...). The doctor told us to have some tests done, but I said no, we couldn't change anything if God gave it to us, even if it was handicapped."

> "Someone once told me that if I am handicapped, my child would be too.
> I was afraid (...) I was afraid that the child might be too."

The second reason behind the fears and anxieties was a lack of experience in the role. The women's lack of apprehension of their own parenting competence aroused fear and uncertainty about whether they would be able to handle their responsibilities as carers:

> "(...) there was a fear of how we would cope, how we would manage."

> "I certainly didn't have that experience, (...). Well, huge changes, just the fact that a child came into the world, you have to do your duties (...)."

> "I was afraid that I would hurt him, that maybe I would hold him the wrong way or something, you know. You learn, but you have to learn everything in order not to hurt him."

3.6. Motherhood: helplessness vs. the need for help and support

Motherhood is a wonderful state for all women. Being able to realize themselves as a mother is recognized as incredible happiness. However, some of the interviewees emphasize that both the birth of the child and the subsequent upbringing did occasion situations in which they felt helpless. In the initial stages of motherhood, as well as during the further development of the child, most mothers needed support and assistance. The narratives demonstrate that help was provided by strangers, i.e. teachers, neighbours, other parents. The authors of the biographies admit that they need support all the time and are willing to take advantage of the advice and experience of others:

> "To be honest, I was helpless when Ania was born because I didn't really know what everything should look like, the care, feeding, changing clothes (...). I had a nervous breakdown at that time and I looked everywhere for help, for someone to help me about what I should do."

> “(...) I simply had no help, well, unless it was from strangers. From strangers! That I did.”

> “My husband helps me a bit and my parents from the association where my daughter goes for rehabilitation. They also support me, give me various tips. They direct me where to go. They raise my spirits. So their support is also a great help for me.”

> “I often take lots of advice. (...) because sometimes I don’t know what to do in a given situation. And I often ask, whether the teachers, the tutor, the teacher, or just anyone (...). Sometimes it’s hard for me to understand how to deal with a child, because, you know, it’s a sick child, and sometimes I just don’t know, I just have no idea.”

> “I just don’t know what solution to find sometimes (...). Sometimes I just don’t know how to solve a problem. (...) I also ask a lot of advice from Ms A. [one of the therapists working with the respondent’s sons], for example, (...). And from the class tutor too (...).”

3.7. Motherhood: the joy of being with children

It may be concluded from the statements that motherhood gives the respondents much joy, not only because of having a child but also because of the opportunity of being with their children and spending time together. It is a very special time for the participants, as they sense that their children feel loved and accepted. The biographers emphasize that children do need quality time, whether playing or doing household chores. According to the mothers, this is the time that brings them closer to their children and enables them to build a relationship based on love, trust and a sense of security:

> “I do have that time for the children. (...). But I am glad that I don’t work because I am glad that I can be with the children. (...)”

> “I would find the time. And for the children (...). In the meantime, whether playing tag or hide-and-seek with the children. Or even going to milk the cows. Then I get to talk to the girls and the boys.

> “The fact that the children are just hugging, talking. They confide (...). It just makes me very happy. I am very glad that they come and say what’s going on there (...).”

> “(...) But for a child you need [to find] that time, it’s got to be (...).”

3.8. Motherhood: daily duties

Pursuing their role as mothers, the women speak of duties—relating to the household, child-rearing, education and rehabilitation—with which they have to cope. The narratives show that the authors of the biographies—especially those who have more than one child—are tired of the daily responsibilities to which they are required to attend. They are happy when the children are at school, which leaves them time for household chores and caring for their younger siblings. Running the house, taking care of children and their upbringing, helping with school duties, attending remedial or rehabilitation classes are a heavy burden for the women interviewed. It should also be noted that only one of the latter is supported in said duties by her husband or parents. The other mothers do not receive support from their immediate environment:

> “(...) the daughter goes to school, so there are fewer duties. She comes back from school, so you know, you have to take care of her, do the homework and take her to rehabilitation sometimes. (...) That’s why

> I'm so very happy that there are those few hours spent at school. Because then I have the time to do some housework and take care of my younger daughter (...)."
>
> "(...). Packing, getting dressed, driving to school. In the meantime, I just tidy up around the house, do the cleaning, cook dinner (...). After four or five hours, I have to get back to school, so I go to pick up the boys from school. And usually, it's at least three times a week that we go to classes, we go straight away to the classes with the special needs association after school. (...) and only then back home. And after the classes, sometimes during the classes, my sons do their homework. (...) The therapists help them there (...). After supper, they take a bath and then they go to sleep. Sometimes I also read them fairy tales. At bedtime."
>
> "Reminding them about household chores. (...) Well, it takes some time for them to get used to it. Because you have to remind them, explain as much as possible, that they have to clean up after themselves (...)."
>
> " (...) all by myself, it's either the school, home, or the yard, everything (...)."

A special sense of duty accompanies the participants who are raising their children alone. The mothers have assumed the entire responsibility for raising their child, seeking to fulfil their role as mothers as best they could, providing their children with a sense of security and love:

> "(...) I felt like I had to replace both the father and the mother. I had to. (...)."
>
> "Above all, support. Supporting, helping. Raising the child's spirits, so that it simply has the support of its parents, so that it can count on them, even though they have it hard. This closeness. Especially when that father is not there, you know, so they can always count on me."
>
> "They need to know that I'm always there, because they cannot count on their father, you know."

3.9. Motherhood: a failure

When talking about motherhood, one of the women interviewed expressed a sense of parental failure. The narrative is very poignant, as the woman speaks of her youngest daughter being sexually abused by her son. Hence, the respondent feels that she was unable to raise her children properly, that she failed as a mother, especially where the boy is concerned:

> "(...) upbringing (...) maybe I didn't manage it with these children, well maybe I just didn't know how to. (...) Well, towards girls, I have nothing. Well, according to that son, it wasn't supposed to be like that, it's so depressing (...)."
>
> "They said out loud to my face that I was handicapped and no one cleaned me as should have been done. Even now, I feel shivers because I always wanted to be a mother, in the hospital they used to say it like I was going to give birth to a doll, not a child. It hurt."

4. Appraisal of the findings and conclusions for educational practice

The analysis of the narratives demonstrates that the authors of the biographies distinguish between positive biographical experiences related to the role of a mother, involving love, happiness, and joy, as well as negative ones, which they identify with helplessness, fear, anxiety or even failure. However, love for the child constitutes the most important dimension of the biographical space delineated by the interviewed mothers. In their narratives, they cited various feelings and emotions while imbuing them with subjective meanings, but maternal love was potently manifested and featured in all biographies. This feeling gave the women strength, despite the difficult circumstances or situations in which they found themselves. The participants in the study derive joy and satisfaction from motherhood, in that they see themselves fulfilling the role of a mother.

It follows from personal interpretations of individual experience that motherhood centres primarily around love and happiness. The participants had a strong desire to become mothers and to pursue self-actualization in this role. For most, it was a voluntary, conscious choice, whereby motherhood meant the possibility of "leaving a mark" or a "responsibility to shape a new person." For some narrators, assuming the role of mother was a necessity. Two of the authors of the biographies became mothers under pressure. One interviewee chose motherhood as an alternative to joining a religious order. She was compelled by her parents to make a choice, whereby at the time of taking the decision, none of the options took her own convictions into account. The other respondent was forced to surrender to the prevailing procreative attitude, which presumes that marriage entails the obligation to have children. The pressure of "normalcy" espoused by the parents and the social environment, in which a wife should also become a mother, influenced the woman's decision to conceive.

Furthermore, the interviewees clearly associated motherhood with great commitment and sacrifice. It is crucial to highlight the fact that, apart from one participant, the respondents continue to function without the support of either husbands or their immediate family. In the eyes of the study participants, the sense of responsibility for the development of children and their upbringing implies sacrifice. They carry out a great number of duties related to care, upbringing, education and rehabilitation of children, as well as run the household without the support of their closest relatives. This is corroborated by empirical studies showing that women with disabilities gravitate particularly strongly towards the domestic environment, as they are less likely to pursue their career aspirations (Wałachowska, 2017). One may have the impression that the women's awareness of their own disability and the occasional remarks that, as disabled persons, they require help themselves have led to situations where they tried at all costs to successfully confront the responsibilities of such an important, socially recognized role.

It has been asserted in previous research (Gustavsson, Starke, 2017; Wołowicz, 2021) that persons with disabilities very often require help from others and fail to cope with the responsibilities of parenting. Although research by Lizoń-Szłapowska (2011) showed that parents with intellectual disabilities who had received training in creative parenting did not differ significantly from non-disabled parents, the author also noted that parents with intellectual disabilities receive token educational support from institutions, which may result in the risk of child neglect. According to Wałachowska, this does not necessarily mean that parents are deprived of the chance of parenthood, but the corollaries of lacking institutional support are evident. It should be noted that the social position of women with disabilities in Poland is very difficult; their material status is lower than in the case of men with disabilities. The author observes that they are also less educated and are twice less likely to be professionally active than men. Running households and raising children, they are often left exclusively to their own devices (2017).

The analysed narratives also suggest that women attach great weight to family relationships. They perceive that such relationships are formed by spending quality time with each other as well as during chores. Mothers do not always have this time due to an excess of responsibilities. It should be stressed that most mothers have two, three or four children each, with only one participant having one child. Mothers strive to carve out time during the day to spend with their children, believing that such moments contribute to a unique mother-child relationship based on love and trust as well as promote a sense of security in children, positively influencing their development. With regard to relationships, one of the biographers highlights her parenting inefficiency and describes her motherhood as a failure, in view of the fact that her youngest daughter was sexually abused by her older sibling. She has a sense of having let her daughter down and thus perceives herself as a mother who has failed in this role. Empirical research shows that self-perception in persons with disabilities who assumed parental roles depends on the attitudes towards them, the support and assistance provided, and therefore on how such persons are perceived by their immediate environment (Wiszejko-Wierzbicka, 2018)

The motherhood-related experience of the interviewees can also be negative, resulting from the stress one is exposed to. Women primarily fear that their children will inherit intellectual disabilities (Bartosz, 2002). Particularly acute anxiety was experienced by those mothers who had subsequent pregnancies and whose first children had already been diagnosed with a disability. The participants in the study were aware of heredity—as confirmed in the research by Latos-Bielańska (2013)—which fuelled their anxiety about their child's health. Two of them underwent prenatal testing to gain assurance that their children would be born healthy. Bartosz (2002) emphasized that the categories of stress, crisis, coping and critical life events are closely linked, which the reconstructed maternal experience clearly reflects. As early as pregnancy, women experienced tremendous stress, and the lack of professional support caused this state to persist not only until the birth of the child but also afterwards. This is borne out by the findings in Malouf et al., who showed that women with disabilities experience poorer care during pregnancy, childbirth and the postnatal period (Malouf, Henderson, Redshaw, 2017).

Doubts about one's own parenting competence constitute the second substrate of fears and anxieties. The women did not know whether they would be able to manage caring for infants, toddlers and, later, whether they could handle the difficulties of parenting. Such fears proved to be well-founded and were further exacerbated by harmful stereotypes, according to which parents with intellectual disabilities are deficient in their parenting skills, while any support provided is ineffectual (McConnell, Llewellyn, 2002). On numerous occasions, the women spoke of a sense of loneliness and helplessness because they were already aware that they did not possess sufficient parenting competence, as evidenced by empirical research conducted by Markut (2020), who demonstrated a poor degree of such skills among mothers with intellectual disabilities. Faced with situations they found difficult, the narrators expected help and support from institutions and professional staff. However, the only help they received was provided by neighbours, teachers and parents of other children. This form of support was vital as they felt alone when confronted with educational difficulties and a lack of professional aid. The mothers attached great importance to support of this kind, because they needed it very much and were thus able to learn how to solve problems and overcome the difficulties involved in such a responsible role. These results are in line with the findings of other authors (Kijak, 2016; Blaszczak-Banasiak, Kubicki, 2017; Koziarek, 2018), who underline that parents and carers of persons with intellectual disabilities themselves note that their children or charges receive no professional/institutional support in their relationships, let alone parenting. The researchers also draw attention to the fact that professionals working with persons with intellectual disabilities express their disapproval of their relationships and having children. Negative attitudes from professionals were experienced by two women who, while in hospital, were not only criticized for choosing to have a child but were even advised to leave their infants in hospital after childbirth. Previous research indicates (Wołowicz-Ruszkowska, 2018) that institutional personnel require more evidence of parental competence than they do from women without disabilities, while their concerns stem from the notion that such women are inadequate and incapable of caring effectively for their children.

The above inquiry warrants a number of cautious conclusions:

- the view of the motherhood of women with intellectual disabilities is changing, but acceptance in this respect is far from complete. Therefore, the identity of women with intellectual disabilities, their roles, independence, adulthood – the elements which determine parenthood – need to be redefined. The current perception of intellectual disability forces these women into patterns based on stereotypes and scarce social acceptance. Approaching intellectual disability from the standpoint of the medical model creates a situation where the social environment either recognizes or does not acknowledge the right of a woman with intellectual disability to carry out the role of a mother;

- various support programmes and strategies have begun to be implemented to support parents with intellectual disabilities and their children; nonetheless, as this study demonstrates, this support is insufficient. In addition, it should be noted that women with intellectual disabilities experience symbolic violence in care institutions, which may indicate that they do not gain thorough self-acceptance of themselves and their own choices. It is, therefore, necessary to enhance the system of support with elements ensuring long-term assistance and to modify it to encourage professionals to show approval towards and recognize the rights of women with intellectual disabilities to education which covers not only intercourse, contraception and intimacy but also the course of pregnancy, diagnostic opportunities and childbirth. Education should also include parenting training sessions, during which women acquire knowledge, skills and competencies in marital relationships as well as care, upbringing and education of children at every stage of their development (Knowles, Blakely, Hansen, Machalicek, 2017).
- women with intellectual disabilities need to be supported as they gain awareness that motherhood is not an obligation. Fostering a sense of autonomy and decision-making agency will promote informed choices about procreation and the roles pursued. Such knowledge will also enable women with intellectual disabilities to overcome social stereotypes concerning their sexuality, femininity, and parental competencies, as well as encourage striving for equal rights. It will also empower them to shape their identity independently of social pressure and existing stereotypes.

One should avoid generalizations with respect to the above conclusions, but they do recommend certain changes because, as Sulik writes: "all kinds of attempts to capture the experience of motherhood may yield a certain picture, reveal shades and colours, but just when we think we have arrived at a complete depiction of motherhood, another novel perspective emerges while our picture seems to be an optical illusion" (Sulik, 2017, p. 88).

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