

# Mothers with Intellectual Disabilities Raising Children with Intellectual Disabilities

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**Abstract:** The article describes the results of research involving mothers with intellectual disabilities. The aim of author's own study was to learn about maternal experiences related to raising children with intellectual disabilities. The experiences were described in greater detail in relation to the diagnosed disabilities of their children, early stage of their upbringing, problems emerging during their development, involvement of significant (supporting) persons. In addition, issues addressed in the study included description of maternal competences, the subjective meaning and essence of motherhood, and perception of the role of one's own disability in acting as a mother. Moreover, factors related to life situation of mothers, their previous experiences, especially experiences in their families of origin and personality features significant for the quality of motherhood, were identified.

**Keywords:** Mothers with intellectual disability, child with intellectual disability, motherhood, personal experience.

## INTRODUCTION

Issues related to mothers raising children with intellectual disabilities have been investigated in numerous studies. Their perspective has been changing over time, from focus on negative experiences (such as stress, burnout) towards a more positive approach rendering parental satisfaction and its multiple contexts. Problems explored in previous studies referred to parents' experiences at diagnosis and those related with adaptation to raising a child with disabilities [1-6]. Intensity of parents' experiences related to diagnosing child's disability has been shown, with their diversification in the context of environmental and personal conditions. Significance of circumstances in which a child was diagnosed, attitudes of the specialists and people in the immediate environment (spouses, grandparents) was indicated. The diagnosing period serves as a preparation to taking up the role of a mother of a child with disabilities, recognized by many researchers as parental adjustment. A stage-based model of this adjustment reflected phases, determined by the quality of psychosocial experiences, such as shock, emotional crisis, apparent adaptation and constructive adjustment recognized as parental achievement of the optimum welfare and balance in the fulfillment of child's and family needs [6]. Some researchers have construed adjustment as acceptance of child's disability; others would never speak about acceptance, as the term "acceptance" is not able to reflect the abundance and variability of parents'

experiences faced across their children's lifetime [2]. Rather, the term paradox should be used, characterized by: having conflicting opinions about the child, loving the child as he or she is but at the same time wanting to erase their disability and maintaining hopefulness while being given negative opinions of other people. This paradox involves conflicting emotions: pain, despair, suffering, and sorrow but also hope, joy, happiness and optimism [6]; ambiguous information, advice and prognoses, being in conflict with their own observations [7]. The paradox consists in accepting the child and their disabilities, with simultaneous desire to be able to change the situation, willful rejection of the disability and aspiring to be a "typical, normal" mother. Mothers' perception of their children's possibilities does not match the reality, but at the same time they undertake the daily caregiving effort knowing their offspring's limitations like no one else. Tension created as a result of confronting the reality with one's hopes and desires becomes the source of strength to pursue solutions, face the daily routine, and therefore, do possibly anything that is good for the child [2]. Optimism allows to overcome difficulties and get the feeling of control in the fulfilled role of a mother. Together with hope, optimism creates a positive picture of the future life; mothers experience personal development. Therefore, this paradox is a highly complex phenomenon in the mental functioning of mothers of children with disabilities, determining their well-being [6].

Empirical evidence has shown that parents need to continually adapt to the fact of raising a child with a disability. In the course of child's development, as well as in the functioning of the entire family, there keep on emerging various situations that require adaptation.

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Successive problems, natural in a family life cycle (children growing up) and specific in raising a child with a disability, require ongoing revisions of the manner of thinking about oneself and about the child [4]. Therefore, the role of a mother or father of a child with disabilities brings about swings of emotions, feelings, beliefs and behaviours. This role involves fulfillment of a range of tasks common for all parents, as well as those specifically stemming from special needs of a child with disabilities (e.g. participation in child's rehabilitation, provision of proper education), often requiring specific competences (knowledge and skills) from the parents.

Considerable caregiving burden does not preclude parental development and growth. Challenges related with raising a child with special needs may contribute to a more mature approach in looking at the world and one's own life [8]. Parenting children with disabilities may be the source of positive personal experiences. Mothers have a chance to feel satisfaction, acknowledge their own value, improve their competences and make their role more successful, which allows them to cope with problems more effectively and increase their level of parental satisfaction [6, 9, 10].

The study investigates maternal experiences of women with intellectual disabilities raising a child (children) with the same disabilities. Issues related to motherhood in this group of women have been increasingly recognized by researchers, and they have changed over time. A tendency has been observed to broaden the perspective of difficulties, limitations and risks assessed by others (e.g. by specialists), with parental possibilities and subjective experiences reported by the stakeholders themselves.

The study helps identify some trends characteristic for families of individuals with intellectual disabilities, such as living in or bordering on poverty due to lack of employment, poor ability to compensate for the insufficient budget via social benefits (including but not limited to social pension) and inability to cope by taking action, despite frequently being aware of a difficult situation. Absence of a stable relationship, and very often failure to make the relationship formal, is a typical feature of such families. Studies have shown relatively frequent instances of lone mothers living with one's family of origin, cohabitation and changing partners combined with raising more than one child [11-16]. Studies conducted worldwide (UK, Netherlands, Australia, Sweden) have reported a high number of

parents with intellectual disabilities deprived of their right of custody (30-60%), which is higher than in case of any other disability [17, 18]. Proceedings are frequently instigated due to negligence resulting from adverse housing conditions, including inappropriate childcare and supervision, failure to fulfill children's needs and failure to take action in case of developmental delays [17]. Functioning of parents with disabilities is not always easy to evaluate, primarily due to the absence of a precise definition of "good parenting". I. Weiber *et al.* [19], while reviewing studies exploring the a/m issues, concluded that motherhood in women with intellectual disabilities is a risk factor for a successful development of their children, since such mothers have problems with satisfying their children's basic needs. More recent explorations (since the end of 1990s) allow to clearly conclude that the IQ of mothers by no means determines different children's behaviours, their neuropsychological performance or achievement [Chen *et al.*, in 19; 20]. The explorations revealed that the level of parenting challenges grows significantly, if children have more severe and complex disorders, but also in case of raising many children in a family [15]. This however, is not specific for such families, since a similar trend has been observed in non-disabled parents, which has been mentioned herein. Undoubtedly however, non-disabled parents exhibit higher levels of competences or are more likely to acquire them than individuals with disabilities. Parents with intellectual disabilities often lack positive role models in a family, especially if they had been institutionalized; they have problems with improving these roles on their own through cognitive activity (using various sources of credible and reliable information), they have a less extensive support network and subjectively lower support [21]. Studies have shown positive experiences of mothers with intellectual disabilities, including their considerable focus on their children's needs treated as central to self-assessment of their motherhood. Mothers with intellectual disabilities are happy, pleased and satisfied with their role, but at the same time they are able to reflect on its quality and significance of the supporting individuals [22-24]. Fulfilling the role of a mother strengthens the status of an adult and allows to reduce negative social implications of the "mentally disabled" label [Edmonds, in 25]. Also, it allows to particularly enhance their feelings of womanliness [26]. These women have been shown to realize their limitations. Mothers with intellectual disabilities speak about difficulties with fulfilling their parental obligations resulting from their own cognitive disorders (e.g.

problems with doing homework with the child due to mothers' limited reading skills). They mention the feeling of loneliness in acting as a parent, its source being their own disability [25]. Women with intellectual disabilities realize that their parental competences are subject to criticism, especially by members of their families [22, 24, 25, 27, 28].

Functioning of families of persons with intellectual disabilities in terms of the quality, just as of the non-disabled ones, depends on numerous complex factors. No determinants specific for individuals with disabilities appear to be identifiable. Cognitive impairments, personality or physical disorders, typical for this population, are indirect rather than direct factors [29]. Differences in comparison to families of non-disabled individuals appear to be manifested in a more frequent occurrence of negative circumstances (potential risk factors), such as traumatic experiences of the parents, abuse and negligence in childhood; absence of proper professional support; lack of parental acceptance; social exclusion of families; child's disability; co-occurring physical, sensory or mental health problems of the parents, presence of a non-disabled partner of the mother in the family, his antisocial behaviours; social stigma, fear of losing the child (divestment of parental responsibility), poverty, lone parenthood, violence and harassment, experienced especially from the partner [30-35].

The aim of author's own study was to learn about maternal experiences of women with intellectual disabilities related to raising children with intellectual disabilities. No studies have been found to address this issue and consider the context in which the child's disability was diagnosed, as well as the way mothers with intellectual disabilities perceive specificity of their upbringing. Previous results have shown these women to share many experiences with non-disabled mothers, however this "commonality of experiences" may be referred to only at a very general level, since maternal experiences are determined by case-specific, personal and environmental conditions. On the other hand, little is known about experiences of women raising children with the same disabilities. To what extent we could speak about trends similar to those observed in non-disabled mothers raising children with disabilities? The qualitative study was expected to provide answers to those questions; moreover, it was intended to identify categories of experiences important for the quality of motherhood, favouring or hindering development of a child with intellectual disability. In particular, the objectives of author's own study include the description

of mothers' experiences related with: pregnancy and first childbirth, early child rearing, child's intellectual disability (awareness and diagnosis), the process of raising a child (children), social situation of mothers, self-assessment of motherhood, perception of one's own disability, and description of mothers' experiences important for child's development.

## **METHOD**

### **Instruments**

A semi-structured interview was used. This data collection method allowed to activate the respondents, encouraging them to talk about their experiences and share the related knowledge and opinions. On the other hand, it enabled the researcher to gather data which was essential, in view of the assumed aim of the study. Issues included in the questionnaire are summarized in Table 1. When a mother also had other non-disabled children, apart from the above-listed issues (excluding disability), questions allowing to compare child raising experiences in children with intellectual disabilities and non-disabled children were considered (including but not limited to specificity of child raising methods, parenting problems). Consequently, two versions of the questionnaire were drawn up: 1) for mothers raising a child/children with disabilities; 2) for mothers raising a child/children with disabilities and non-disabled child/children. Mothers raising two children with intellectual disabilities were asked to report on experiences concerning both of them.

### **Procedure**

Interviews were conducted with six purposefully matched mothers with intellectual disabilities, exhibiting cognitive abilities and communication skills enabling them to engage in a conversation with the researcher. Functioning of one of the mothers, i.e. her high dependence from her mother, made it necessary to additionally interview the grandmother, i.e. the woman's mother. Each mother was raising at least one child with intellectual disability (of different severity). The women were enrolled in the study with assistance of the principal and teachers from the special needs school where children received their training. Four mothers completed their education in this school. A significant enrolment criterion was mothers' ability to give informed consent, and their willingness to share their experiences. The study was implemented by the author of the paper. Each interview lasted from 1 to 2.5

**Table 1: Issues in the Interview (Thematic Categories) and their Specification**

details concerning the mother and her family	age, education, employment status, family situation, housing conditions and financial standing
details concerning the child/children with disabilities	age, sex, additional disorders
experiences during pregnancy and delivery	life circumstances, emotions and feelings associated with expecting a child and delivery, other people's reactions to their pregnancy, preparation for delivery, attitudes of specialists towards their pregnancy and delivery
early child rearing	emotions and feelings associated with the child, assuming the role of a mother and preliminary preparation, midwife assistance
child's intellectual disability	understanding their child's disability, circumstances of diagnosing child's disability, awareness of the causes of disability, emotions and feelings associated with their child's disability
the process of raising a child (children)	experiences related to stages of child's development: support and assistance, ways of raising the child, taking action in the field of rehabilitation of the child, concern for the child's future, using patterns learned from their family of origin, cooperation with the school
social situation of mothers	social support, experiences in their families of origin
self-assessment of motherhood	comparing child-rearing experiences in children with intellectual disabilities vs. non-disabled children (when the mother had more than one child), evaluation of one's own maternal competences, significance and essence of motherhood, maternal satisfaction
perception of one's own disability	understanding one's own disability, significance of one's own personal disability for motherhood

**Participants**

**Table 2: Presents Details Concerning Mothers Enrolled in the Study**

Mother no. 1	Aged 52, mild intellectual disability/ below-average ability, no organic background, lives in a city, elementary education, currently not employed due to child care (receives carer's allowance), used to work as a (trained) caregiver for the Polish Red Cross, lives with her second husband and the youngest children in a council flat, she has four sons altogether (aged 32, 30, 14 and 12). The youngest son with mild/moderate intellectual disability, autism and cerebral palsy (mild hemiplegia). Average financial standing, very poor housing conditions. Her first husband was an alcoholic, he committed suicide after the woman left him. The oldest son is an alcoholic. He found his father after his suicidal death.
Mother no. 2	Aged 44, mild intellectual disability/ below-average ability, no organic background, lives in rural areas; vocational education; not employed, she never had any job; she lives with her husband and children in her privately-owned house, she has two children: a son with mild/moderate intellectual disability aged 19, and a non-disabled daughter aged 20; her financial situation and housing conditions are good.
Mother no. 3	Aged 39, mild intellectual disability, no organic background, lives in a city, vocational education; she works as a cleaning lady in a public institution; she lives with her parents, her brother's family and three children of hers (aged 12, 8 and 5). All children are with (mild to moderate) intellectual disabilities. She is separated. She finds her financial situation and housing conditions to be average. She lives with her children in one room.
Mother no. 4	Aged 39, mild intellectual disability, no organic background, lives in a city, elementary education (non-completed vocational school). Not employed, she never had any job. Currently, she is unable to work due to health problems. She is planning to apply for a health benefit for herself and for carer's allowance for her younger daughter with intellectual disability. She lives with her children in a cooperative flat. She is married. Her husband spends long periods of time in prison (up to 5 years). At present, he is on conditional release. She finds her financial situation and housing conditions average, although she claims that she had to use social assistance on numerous occasions, as her financial standing used to be very poor.
Mother no. 5	Aged 32, mild intellectual disability, mental disorders, lives in a city, vocational education. Not employed, she participates in occupational therapy workshops. Lives with her parents and her son (aged 10) in her parents' flat. The child has moderate intellectual disability, he is epileptic. She was never married, she doesn't want to have a husband or a partner. Good housing conditions and financial situation.
Mother no. 6	Aged 31, with mild intellectual disability, no organic background, lives in a city, vocational education. Not employed due to child care (carer's allowance), although she would like to go to work. She rents a room where she lives with her partner and her son (aged 8) with moderate intellectual disability. She was never married and is not planning to, as she has a negative attitude about marriage. Despite objectively difficult living conditions and financial standing, she finds her situation moderately uncomfortable.

hours. Questions fundamental for the investigated problems were preceded by a relaxed conversation intended to present the researcher's intention, establish

a relationship with the respondent, collect basic respondent information etc. The women were interviewed at school premises (in a designated

classroom) or at mothers' place of living. Mothers were interested in the study to a various extent, some were willing to participate in subsequent meetings.

## RESULTS

Analysis of the material from the interviews made it possible to describe experiences significant in raising a child with intellectual disabilities and other children (if there were other children in a family). They were put into thematic categories, which served as the basis for the semi-structured interview.

### Theme 1: Experiences during Pregnancy and Delivery

While expecting their first child, mothers were in diversified life circumstances. Three of them were married, two had a partner. In one case (Mother no. 5), the woman got pregnant after she had been raped by a man whom she was "dating". The man used helplessness of the woman (her lack of awareness), and the incident took place in the rehabilitation facility they were both attending.

Life circumstances of three mothers (no. 1, 2, 3) was stable and their children were the expected components of their relationships. In two cases, pregnancy was not planned, and mothers lived in their families of origin, together with their parents and siblings (no. 4, 6). All women gave birth to their first child at the optimal gestational age (20-27) in terms of biological maturity. They expected their children with great joy and happiness. Mother no. 5 was an exception, since her pregnancy was a shock and initially evoked only negative feelings in her, which was reinforced by the context of sexual assault. Two mothers, who were not in formal relationships, mentioned their fears concerning the delivery and their ability to cope with parental responsibilities, however they also stressed transitory nature of such impressions and over time they became more and more convinced of their maturity to take up the role of a mother. Mothers living in formal relationships shared the same views. The women gave an account of the growing responsibility, concern about the child and the feeling of being ready for the role:

"I felt that I was grown-up and that I will handle this". (Mother no. 4)

"Well, simply not like some lass anymore, simply that we will have a child, concern about my child's future" (Mother no. 1).

Reactions of the nearest and dearest, that is of husbands, partners and parents, to the pregnancy were positive. In case of only one informal relationship, the mother (Mother no. 6) said that her partner was very reserved, but this soon changed into joy and anticipation of the child. Negative reactions of the environment also occurred in case of pregnancy of Mother no. 5. The grandmother – woman's mother – spoke about an enormous shock and strong concerns about the pregnancy, delivery and raising the child, due to the mother's low self-reliance and her co-occurring mental problems. She criticized the attitude of the doctor who confirmed the pregnancy (a gynecologist whom the mother used to visit regularly before) as she made no suggestion to terminate the pregnancy "when there was still something that could be done about it". The pregnancy was confirmed when the woman was three weeks pregnant. She went to see a physician, because she felt bad; she was accompanied by her mother.

In general, first pregnancies were progressing well, however in two instances (Mothers no. 5 and 6), there emerged factors which made the women stay in hospital early in the pregnancy and which resulted in complicated childbirth. In one case (Mother no. 5), this was due to falling down stairs early in the pregnancy and urinary tract infections at a later time. Mother no. 6 was probably at risk of miscarriage throughout the entire pregnancy, which she failed to fully realize and which had not been sufficiently controlled by the specialists. She admitted she wasn't sure whether she had gone to the hospital to deliver her baby within or after her deadline: "But I believe this was the date my gynecologist has given me". However, she has had a strong sense of guilt about her lifestyle which in her opinion contributed to complicated childbirth and child's disability: "When I was pregnant, I smoked, I drank coffee and large volumes of Coke. (...) I heard that I cannot quit smoking completely because my body will produce adverse reactions".

No mother consulted a professional regarding preparation for the delivery, however all of them emphasized that they paid regular control visits during the pregnancy. One mother (Mother no. 2) had a doubt whether anyone is able to prepare for the delivery at all. All women consulted other women in their families who already had children, but most often the source of information were not their own mothers. In case of Mother no. 5, the grandmother of the child tried to prepare the woman to childbirth, being aware that due to her mental problems, the woman will have limited

abilities to control herself and cope with any problems. Before childbirth, the grandmother managed to obtain a psychiatrist recommendation confirming the need to follow a special delivery procedure (Caesarean birth) due to limited cooperation with the mother. This however, was not recognized during the delivery by the obstetrician and midwife.

Childbirth experiences related to the first delivery are diversified. Mothers being in formal relationships never mentioned any medical problems, such problems occurred in the remaining two women (Mother no. 4 and 6). One referred to them generally as a "hard, complicated childbirth", the other woman provided great details concerning the delivery (ultimately, it was the Caesarean birth), since they strictly determined the disability of her only son. Both women, mothers of children with intellectual disabilities only, have highly negative experiences as far as the attitude of the medical staff is concerned. One mother stated that this attitude may be referred to as "moderately positive", however her manner of speaking implied that this doesn't really reflect the essence of the problem. The story of the other mother (Mother no. 6) reveals great tragedy she experienced, which is still very vivid in her memory and sustains her self-blame. She had the Caesarean section as the baby's life was threatened (severe hypoxia). Mother's account reveals an exceptionally negative attitude of the attending doctor and her devastating experience: "The doctor asked me: what do you have at home? What do you mean? - I asked. - A baby bath tub, a cot. - Better if you had a crucifix because your baby will die anyway. I started to scream terribly and I can't remember what happened to me next. I woke up in a hospital room." This experience was crucial for her adaptation to the role of a mother, it evoked strong fear of getting close to the baby who stayed alone at the intensive care department. For a long time, the mother received no support (the baby stayed in the hospital for a few months). Only after some time, one of the nurses assisted the mother while visiting the child, which made her somehow overcome this fear. Negative attitudes were described by the grandmother, mother of Woman no. 5. Here, we are dealing with negligence of the woman's special needs resulting from her limitations and disorders, failure to provide her with information about baby's health, no justification for applying pharmacological post-partum treatment, and ignorance of pathological symptoms that appeared in the newborn according to the grandmother. During the delivery, the woman was not able to cope with the pain: "She was kicking like crazy

and screaming very loud that she wanted to be taken home. (...) And she was kicking with such power that she (the midwife) said that even ten men would not be able to contain her, but I knew it was going to be like that". In the course of the delivery, the woman's mother (grandmother) heard a comment that her daughter should never give birth to a baby. According to the doctors, it was the grandmother who was to blame for "not preventing" her daughter from getting pregnant. The woman's gynecologist never suggested the use of contraceptives. They have been widely prescribed but rather to regulate the menstrual periods, suggested the grandmother.

Other women had no objections to attitudes of the specialists. One woman was accompanied by her husband during childbirth (Mother no. 3). Other women, apart from Mother no. 5 accompanied by her mother, had no loved ones by their side, due to various life circumstances. However, neither of them claimed that their husband/partner did want to be there. One of the mothers emphasized that her husband had to fulfill his professional duties, but he kept calling her during the delivery. Support by their own mothers was not perceived as desirable. One woman (Mother no. 4) concluded: "My relationship with my mother is not that good. I suppose that a daughter should have a better one".

## Theme 2. Early Child Rearing Experiences

The mothers reported that hardships during the delivery were compensated by the joy of giving birth to their first child:

"When I held her in my arms, I found her absolutely wonderful". (Mother no. 2)

"Experience of becoming a mother. I was very happy because of that". (Mother no. 1)

(What were your emotions after giving birth to your child?) "I felt really nice". (Mother no. 4)

According to women's accounts, taking up the role of a mother did not involve any specific difficulties. If there were any, they rather concerned caring over the baby. In such cases, their own mothers and their loved ones (husband's sisters) were of help. In the initial period, husbands were less useful. Mothers who did not have any non-disabled children concluded they had been prepared for the role, as they previously cared for

other children in their families. As one of them said, she "raised her own brother" (Mother no. 6). Only one woman failed to receive any support from the midwife, although she applied for such assistance to competent authorities (Mother no. 2). In the remaining cases, midwife assistance was short-term and involved provision of instructions and supervision (in line with legal provisions), but it was assessed as useful in coping with early caregiving obligations. Mother no. 5 was in a special situation. All care was provided by the woman's mother, the grandmother of the child. As she emphasized: "My daughter was displeased when I woke her up at night to look after the baby". The woman had limited breastfeeding abilities, as her son refused to suck at her breast. Instructions of the specialists were limited to feeding the child artificially, however the grandmother tried various methods and means to enable her daughter to feed the newborn naturally. It should be noted however, that the bond between the mother and a newborn began to be established, as the woman did not want to leave the child in the hospital alone.

### **Theme 3. Child's Intellectual Disability**

Respondents perceive children with intellectual disabilities in a highly different manner. In fact, only two mothers (no. 1 and 2) used relevant terminology, i.e. mental handicap, providing also its severity, whereas one mother spoke about the co-occurring autism and cerebral palsy. Women's accounts clearly indicate that reception of the certificate of disability and granting of the disability status has served as a confirmation of child's developmental limitations. It appears however, that this legal status given to a child in order to obtain specific benefits or rights, is not fully comprehended by their mothers. They tend to treat their children's disabilities as developmental delays, even of temporary nature, as some idiosyncrasies, learning difficulties and specific difficulties that make the children use specific forms of education and rehabilitation, e.g. "Well, he's got the potential, but he is lazy. Well, he has some disability but I'm not well up in this so I cannot tell precisely" (Mother no. 4). One mother has used the term "illness" while speaking of her son (Mother no. 1). All women, except for Mother no. 5 who is completely unaware of her child's limitations, are strongly motivated to show positive aspects of the development and functioning of children with intellectual disabilities. This is manifested as follows: they emphasize that their children have a very good memory (memorizing street names, dates), describe special abilities in repairing different devices, they speak about their interests

(cars), emphasize their personality traits (persistence in acquiring some skills, courage), they refer to statements of professionals ("Our psychiatrist said that he is a phenomenon of a kind", Mother no. 2). Mother no. 1 asked her son with intellectual disability how old were her oldest sons, which she failed to remember herself. Her youngest son with a disability was also able to give her mobile number, if such need arose (!).

Situation of one woman (Mother no. 3) is quite specific, as when asked about disabilities of her children, she denied this fact, although her older children attend a special school. In fact, she is only able to accept some developmental deviations of her youngest child, however she treats them more as a temporary idiosyncrasy: "That's just the way it is, some children develop faster, whereas other more slowly". This mother experiences a kind of contradiction, manifested in the need to present her children as "normal", but at the same time realizing they have some limitations. This can be clearly seen from her statement: "I think, I hope that everything will come to normal, that all will be well with time. That maybe he will become more active and comprehensible. That he will do better than others".

In no case, child's disability was associated with any other particular disorders that would be manifested in specific and noticeable symptoms. In one case, we are dealing with traumatic pregnancy and childbirth that caused organic changes in the brain (Mother no. 6). As mentioned before, this mother feels guilty about her lifestyle during pregnancy, which in her opinion contributed to development of child's disorders. Mother no. 4, who generally referred to her childbirth as hard, has no knowledge enabling her to associate the delivery with child's injury and disability. This woman also has a younger child with an intellectual disability of unknown etiology (presumably, in both instances we are dealing with a set of social and cultural factors). In one case (Mother no. 2), we dealt with postnatal etiology - it was a disease that damaged the child's brain. However, the mother has no knowledge about the pathological mechanism but rather some suppositions suggested by specialists, which point to negligence of the physicians. In the neonatal period, the boy got seriously ill. He was suspected of having encephalitis and had numerous CSF analyses and skull X-rays performed. His mother stated that physicians proved to be severely negligent in this respect, to include instances of "lost examination results". When 3 years later the child was admitted to another medical facility, the mother was told that she

should have prevented doctors from behaving this way. Until this day, i.e. after more than twenty years, she still feels guilty because of that.

Other women were not aware of possible etiological agents determining their child's/children's disability. Asked straightforwardly, they responded that the specialists did not know the causes. In all cases, including the case of complicated pregnancy and delivery, disabilities were diagnosed in preschoolers or schoolchildren. Some mothers were aware of the specific nature of child's development and functioning. They would search for assistance in this respect, primarily from their GPs, but also directly from the specialists (neurologist or psychiatrist). One mother (Mother no. 1) emphasized her persistence and determination in this respect: "They drove me out with one door, but I was entering with another". It should be noted that mothers' concerns regarding abnormal child development were disregarded by the doctors and the women failed to receive exhaustive information. Only two mothers and one grandmother were looking for information about the disorders/diseases developed by their children: on the Internet, seeking doctor's advice, attending meetings organized at schools.

Although circumstances evoking factors that contributed to pathologic child development proved traumatic for the mothers, they did not find the piece of information confirming their child's intellectual disability (or autism) particularly devastating. Only one of them said: "It was hard for me to accept that but this is my child. (...) As long as I am able to walk, I will not let anyone hurt him. I'm going to help him as much as I can" (Mother no. 1). The environment also accepted such information, although it was hard to guess what emotions or thoughts were in the heads of the nearest and dearest. One of the mothers was aware of that: "I have not heard or felt it myself, but maybe someone said something (about my child's disability) when I wasn't around" (Mother no. 1). Mother no. 3 said that her family doesn't know about it as the woman never informed them about any disorders of (the youngest) child. Mother no. 6 was rid of any illusions after neurologist's diagnosis: "I was hoping that it will somehow disappear". She observed her child's developmental delays and felt that "something was wrong". "This was hard because everyone wants to have healthy children".

#### **Theme 4. The Process of Raising a Child (Children)**

Mothers have raised their children using various types of support and assistance offered by their

nearest and dearest, such as their husbands, partners or parents. They may be referred to as self-reliant mothers, making decisions and fulfilling practical tasks in raising their non-disabled children and children with disabilities. Early after childbirth, two mothers had a job, therefore it were either grandmothers who looked after the children, or their husbands (combining parental tasks with their career). Only one mother (no. 5) is the sole legal guardian of the child, in practice failing to actually raise the child, however. The predominant role of women in child raising stems in part from the traditional gender roles in families (working husband), and at times is determined by life circumstances (husband staying in prison).

In families where there were non-disabled children, mothers never signalled any special educational impacts caused by child's health. Specification of such impacts (rewarding, punishment) resulted rather from individual child's preferences, interests and character (e.g. limiting child's favourite activity as a punishment). Women emphasized positive educational impacts and avoiding punishment. Mother no. 4 clearly stated that she never used physical punishment in relation to her children: "Sometimes I shout at them, I admit that. But I don't think beating is good. My children have never been beaten, they only know it from television". What is more, women also try to show that their children should not receive any negative impact, that they are obedient and understand what they do wrong: "He is trying. When I explain things to him, he is trying really hard. He comes to me, says he loves me and he apologizes to me" (Mother no. 1).

Most often, mothers are quite active in searching for assistance for their children, using options offered by various institutions and different forms of support. Mothers found various ways to provide their children with access to rehabilitation or education (e.g. by listening to conversations at their workplace about what they were entitled to), as they failed to receive sufficient information from the specialists. Two women resigned from or delayed taking some official steps due to difficulties with preparation of relevant documents (mothers no. 3 and no. 4). Certain problems have been observed however, related to management of the entire process in time. The mothers are not aware of proper ways and procedures. This may partly result from the fact that rehabilitation and child support activities were not comprehensive or process-like. Children with intellectual disabilities were sometimes engaged in various types of activities which, according to the mothers, were not effective however.

Mothers are concerned about the future of their children with intellectual disabilities, however to a different extent, which is related with their age. Their statements reveal their fear about the future - that someone will hurt their child, the concern about their fate when the mother will be gone. There is a belief that some roles will not be available to them: "When I look at boys and their girlfriends, I think that my son will probably never experience anything like that. (...) What I fear the most, is that someone will hurt my children. That someone will hurt my son when my daughter leaves the house for a while" (Mother no. 2). The mothers want a good life for their children, a life that is better than their own: "I think about him, I would like him to finish this school. To find a good job. To have money because I must admit, sometimes I was short of money. I admit that I used social welfare when he was born. I wouldn't like him to be poor, I just want him to have a good life" (Mother no. 4).

Mothers having non-disabled children take into account the possibility that their child with disabilities will be looked after in the future. They appear to establish relationships between siblings to ensure their mutual support and acceptance. Some mothers, aware of what the future might bring, already started to discuss this issue with their families. Mother no. 1, in a more advanced age, is convinced that when she is gone, her younger husband will look after the children or alternatively, her much older half brother who has his own family. In case of woman no. 5, the question of the mother and child being looked after in the future by older parents has not been discussed. Their daughter is completely unaware of this, stating that: "She would like to keep living with her mom".

Study participants take over parenthood patterns from their families of origin to a different extent. Some mothers clearly reject them due to pathology in the environment in which they were brought up (this will be discussed below). Other seem to establish their own child raising practices. They speak about spending more time with their children, about talking to the children more frequently. They emphasize changes in child raising methods introduced over time that may make their parenthood different in some aspects: "Because children used to be raised in a different manner, now it's different" (Mother no. 4).

No mother belongs to any parental organization or association working for people with disabilities, they do not find it necessary.

Cooperation of mothers with educational establishments goes well. Mothers find the assistance they get satisfactory and the environment of the special school beneficial for their children: "My husband said that since he's not managing, it's better to send him to this school instead of having to struggle. I would struggle myself. We decided to put him here. And I don't regret it, I really don't (...) But I think the school is good" (Mother no. 4). What is interesting, this mother denies that her son's disability was the reason why she enrolled him in a special school. As mentioned before, she recognizes the limitations rather as learning problems than as a global delay.

An exception here is the attitude of mother no. 3 who ignores all notifications from the teaching staff about improper behaviour of her children (meetings with the teacher are concluded by the mother leaving the classroom and slamming the door). This mother's behaviour and most probably messages she communicates affect her son's attitude who, not willing to subordinate, threatens the teacher she will be dismissed at his mother's request (he is aged 8!).

#### **Theme 5. Social Situation of Mothers**

Mothers come from various social backgrounds. This determines the nature and degree of support they can obtain from their families of origin. The support involves emotional and practical assistance to the women, as well as affirmative support towards their children with intellectual disabilities. Their parents - grandparents of the children - assist mothers in difficult situations but also accompany children's development while trying to transfer their knowledge and skills. Importance of the relationship with grandparents was expressed by Mother no. 2: "My father is not very affectionate, he does not speak about his feelings, but he once said to my son (with intellectual disability) that he was his favourite grandson". Sibling relationships were not described in greater detail; mothers usually claimed that they are positive and full of mutual assistance. Some women had traumatic or overwhelming experiences in their families of origin, such as alcoholism of their parents, early bereavement or experienced humiliation and violence. They speak about these experiences as if they wanted to clearly emphasize that they were able to oppose them and achieve a lot in their lives: "I must say that right now I have a really good life. Although my child is not healthy (...) At the moment, I can say that my dreams came true. The child is not healthy but I simply feel fulfilled. If only we could get a flat, then we would not lack

anything because we have money to buy food" (Mother no. 1). "I grew up with two alcoholic parents. I promised myself that I will never let something like that happen again" (Mother no. 6).

Involvement of people other than one's relatives, colleagues, friends, neighbours was not expressly acknowledged. Their assistance, as it follows from accounts of some women, is rather occasional, only in case of a clear need.

Only one mother spontaneously mentioned reactions of random people to a child with disabilities, signaling the problem of coping with negative behaviours. She stressed: "I care more about the child than about some comments behind my back" (Mother no. 1)

### **Theme 6. Self-Assessment of Motherhood**

Women favourably assess their maternal skills, in relation to their non-disabled children and children with disabilities. Two have clearly admitted to be over-protective, being aware of linking this to the guilt they feel (Mothers no. 2 and 6). Mother no. 3 is over-protective in relation to her youngest child. She makes a lot of effort to provide him comfort and satisfy his whims, e.g. she picks him up from the kindergarten when he doesn't want to stay there and she makes all necessary arrangements during her day together with the child. She also tends to control the child all the time, maybe due to his hyperactivity, and carries him in her arms all the time (e.g. during a school trip of older kids).

For mothers, their maternal skills are confirmed in their children's opinions: "I'm a good mother, my children acknowledge this by saying: Mom, you are such a loving mom, you are so good" (Mother no. 4), and by providing the mother with gifts, worrying about her and attempting to look after her (when she is ill). The "good motherhood" criteria refer to specific signs confirming child's physical and mental well-being, as well as social and moral condition: "For me, good means that he is somehow... good but not too good, in order not to exaggerate with goodness, so that they didn't abuse it. In order to raise children well, meaning that they don't end up as some underclass you can see around – drunkards, thieves" (Mother no. 1). They also refer to competences: "To be a mother who will be able to listen to any child and give them advice" (Mother no. 2). Only one mother (4), while self-assessing her motherhood, referred to external opinions – of neighbours and teachers: (Do you find yourself a good

mother?) "I am. They praise me". (Who?) "My neighbours, acquaintances, here at school".

The source of satisfaction for them is child's love: "My son's love when he tells me that he will never leave me, his caring for me" (Mother no. 2). "He is my beloved child (...) That I'm a good mother, which is confirmed by my children when they say: Mom you are so dear, you are so good to us" (Mother no. 1). They associate the essence of motherhood with their own well-being: "It's much better (to be a mother) than to be single. There is someone to whom you can open and talk to" (Mother no. 3). Mother no. 5 who, due to her dependence from her mother, is not able to function independently and express her thoughts, said at the end that her son "Makes her life worth living".

### **Theme 7. Perception of One's Own Disability**

Mothers usually fail to identify themselves as individuals with disabilities. Just as in the case of children's disabilities, its recognition criterion is possession of a certificate. In case of absence of such a certificate, the mother rather tends to speak of herself as of someone "resourceless in filling in documents, making formal arrangements". The fact of finishing a special school is not significant for acknowledging one's disability. Only one mother (Mother no. 6) is convinced that her disability affects her child. This however, does not concern any child raising difficulties, but rather some kind of biological determinism, inheritability (?).

### **Mother's Experiences Important for Child's Development**

Any personal mother experiences determine the specific nature of her motherhood:

Mother no. 1, she was bereaved early and therefore received no support from her own parents, she had an alcoholic husband who committed suicide; her child is autistic; she is very nervous while looking after the child, she treats it as if it was ill (anticipates his treatment?), expects the child to be competent (the mother was irritated when her son was not able to quickly and properly give her phone number); constant fight for her child's rights, feeling of bitterness towards the specialists; potential burnout of the mother (also due to her relatively advanced age).

She wishes to build positive relations with her older half brother, she has great support in her husband, and a deep feeling of satisfaction in the relationship.

Mother no. 2, her son's disease and accident caused a serious brain damage, great concern about the child and fear of the social environment; high emotional dependence of her adult son from his mother, no possibility to establish relationships with his peers; limited possibilities of further education (confined to lower secondary school, he is not willing to learn); potential son's inability to cope with bereavement when his mother will be gone.

Highly favourable environment in the family of origin, considerable support from close relatives, significant degree of emotional integration in the family, establishment of good relationships with her sister.

Mother no. 3, negative experiences in her family home, no family support, separated with her husband; denying children's disabilities, negative attitude to specialists; mother is burdened as she needs to cope with all obligations alone; children are not aware of their abilities and limitations; children find it hard to socially adjust due to their disobedience and lack of respect – reactions provoked by their mother.

Relatively active and resourceful (she is employed, she has no problems with making any formal arrangements).

Mother no. 4, weak bond with her mother (no father); her husband is absent due to his stay in prison; ill health (visible high physical exhaustion), she is careless and not aware of the problems; she is not aware of the essence of her children's disabilities; potential child raising problems (especially, with her son) due to father's absence, his negative example and lack of sufficient physical and mental strength of the mother.

Mother no. 5, she was raped which resulted in an unwanted pregnancy; she is by no means self-reliant but completely dependent from her mother; mental disorders are manifested through aggression towards the environment; potentially, the mother and her child will have to be placed in institutional care; the mother may be deprived of her rights of custody (in fact, she is unable to care for the child herself); severe epilepsy of the child results in periodic stopping of development.

Highly favourable environment in the family of origin, which is the source of ongoing support.

Mother no. 6, her parents were alcoholic, fatal disease of her brother, she changed her partner; extreme poverty; strong sense of guilt and huge

determination evoked by this guilt to take any possible measures intended to improve the child's health; potentially, she is mentally and physically burdened; she has no motivation to keep her relationship stable, she may change her partner again.

## CONCLUSION AND DISCUSSION

In every case, motherhood is woman-specific, which to a significant extent is determined by their previous life experiences, including their experiences in the families of origin, specific events/incidents and their personal choices. To a different extent, it is composed of positive and negative aspects. The former are related with their relationship with the child/children, be it non-disabled children or children with disabilities. Mothers love their children unconditionally and their participation in the process of child's development gives them happiness, satisfaction, fulfillment and reward for their efforts. Negative aspects of motherhood primarily stem from relationships with other people, especially with the specialists, but also with their life partners or family members. In this aspect, women have to deal with negligence, disregard and fear about the child, ignorance of their special needs; failure to receive support, or rejection and abandonment. Just as in the case of non-disabled women, support and preparation for the role in the process of integration into society, significantly determine the quality of motherhood. Women respondents, just like other mothers of children with disabilities [4, 5, 36, 37], had problems with obtaining a diagnosis of their children's health status from the specialists and with putting rehabilitation activities on the right track. They are strongly determined to find effective help for their children, they are able to evaluate its quality in terms of the progress in their development. Mothers participating in the study have presented a specific trend of not acknowledging/not realizing the meaning of their children's disabilities and emphasizing children's possibilities or even special abilities. On the one hand, mothers may be believed to have problems with understanding the essence of disability; due to their own limitations, they are not able to find and interpret information in widely available sources, such as publications and Internet sources. They fail however, to receive sufficient professional support. On the other, it cannot be ruled out that this is a manifestation of the paradox referred to in the introduction [6]. A similar trend in mothers with intellectual disabilities raising children with developmental delays was reported by M. Starke [38]. Mothers interviewed in the study primarily emphasized

positive aspects of their children's functioning and the fact that child raising was the source of their personal growth.

Specific attitude to intellectual disabilities in their children may be related with mothers' approach to their own disability. As shown, mothers in both cases, i.e. in their own case and in case of their children, in the first place acknowledge the formal criterion, that is the certificate. The literature has shown that individuals with intellectual disabilities recognize their own disability to varying degrees, however they usually find it to be something very specific, e.g. reading or writing difficulty etc., and not something global [39]. Failure to comprehend the essence of intellectual disability may lead to mothers' inability to make their children realize the resulting limitations or actual possibilities, and to take far-fetched optimization actions, which requires some lifelong planning. Failure to acknowledge one's disability or realize its significance by study participants makes them fail to consider it in the self-assessment of their motherhood. Just like in the case of non-disabled women, the self-assessment criterion is child's well-being.

Studies have shown that problems described in the literature, such as violence by the nearest and dearest, lone motherhood and living with the family of origin, co-habitation and changing partners combined with raising more than one child, poverty, differently affect mothers participating in the study [11-16]. The above-mentioned factors appear to strongly determine the quality of mothers' parental competences, knowledge, skills and attitudes. Complex dependencies between mothers' experiences and their competences, provide factors potentially disturbing and preventing development of children with learning disabilities. Configuration of such determinants is however specific for each mother, due to the personal nature of their experiences.

Further analyses should offer a more in-depth investigation of the issue examined in the study. Further explorations may examine such problems as fulfillment of family functions and tasks, sources and quality of social support, evaluation and self-assessment of parental competences, quality of relationships between spouses, analysis of parenting attitudes, participation of mothers in the rehabilitation of children with intellectual disabilities; maternal satisfaction and its sources; personal identity of mothers in view of their disability. Respondents enrolled in the study were of different age and their

children were at different stages of their development. Future studies should consider both variables, that is mother's age, child's age, and additionally type of disability (co-occurring disorders) or child's functional status.

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