SOCIAL EXCLUSION OF MOTHERS OF ADULTS WITH PROFOUND INTELLECTUAL DISABILITY. PERCEPTION OF THE QUALITATIVE RESEARCH IN POLAND

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Abstract
Maternity is a frequently undertaken topic of research both in Poland and around the world. However, the mothers of the adults who require support in any aspect of their lives, i.e. people with profound intellectual disability, remains a kind of "research gap". The same also applies to various types of legal and social welfare solutions, which, although addressed to the people with disabilities and their families, do not meet the needs of individuals with profound intellectual disabilities or their caregivers. Therefore, the question arises in what way it is the main objective of the study was a theoretical, empirical, methodological and practical analysis meant to answer the following question: do the mothers of adults with profound intellectual disability feel socially excluded? And if so, in what way? Does the sense of social exclusion affect their motherhood? The research in a group of the mothers of adults with profound disabilities (where adults mean people over 25 years old - the threshold is the age when any form of education, such as revalidation classes, is no longer provided to such people), conducted in 2016-2018, shows that they feel socially excluded and that this affects and intensifies the social marginalization of their adult daughters and sons. The research group consisted of 34 women. The respondents (mothers) were from 50 to 78 years old. The women were from different regions of Poland, both single mothers and divorced. Their economic status was very diversified. Some of them did not work professionally all their lives because they had to take care of their children. Each interviewee signed a written consent to participate in the study. The analysis concerned their various experiences over the years and their impact on their role as mothers through the key question: What is it like to be a mother? The interviews lasted from 120 to 240 minutes and were recorded on a voice recorder. I used a narrative interview which is similar to in-depth, free conversations. Through follow-up questions, I was trying to encourage the interviewees to tell a story of their experience of social exclusion. I analyzed the information shared during the participant interviews using analytical methods that align with a grounded theory because it involves building a theory on the basis of systematically obtained data that directly relate to the observed aspect of social reality. My analysis of the transcribed interviews was guided by GT principles, which include limiting the researcher’s preconceptualisation and focusing on theoretical sampling. I divided the data into smaller units, called incidents, which I then conceptualised and related to other incidents. My general analytical procedure was to constantly and iteratively compare incidents. The analysis of their statements showed that the women had to deal with social marginalization for many years, and that they experienced it even from the closest family members, neighbours or people from their communities. It had a huge impact on the their entire motherhood, psychological well-being, and, more importantly, on their social identity. The sense of exclusion had an impact on the current image of motherhood in the respondents. It had also a huge impact on the formation of their psychosocial identity. Over the years it has led to a number of phenomena, such as self-exclusion of these women from their communities, avoidance or unwillingness to build social relations.

Keywords: profound intellectual disability, social exclusion, mother.

1 INTRODUCTION
Many scientific articles on the functioning of the families with a child with intellectual disabilities have been written in Poland as well as abroad. However, analysis of the available literature both Polish and foreign indicates that family with a child, and in particular an adult with deep intellectual disabilities, is still beyond the discourse of theoretical and scientific considerations. Hence the question arises whether, being outside, the needs of people with profound intellectual disabilities are secured? Can anyone, including a person with profound intellectual disabilities, as well as her family benefit from existing legal, social and social solutions? The research presented in this article was conducted in Poland in 2015-2018 in the group of mothers of currently adult children with profound intellectual disabilities (people over 25 - when the opportunity of education ends in Poland). Already in this point it should be noted that until 1997 people with profound intellectual disabilities were excluded from school obligation. It was not
until 1997 that the Bill on the rules for the organization of remedial classes came into effect with its subsequent amendment in 2013[1]. The moment when the possibility of implementing broadly understood education for people with profound intellectual disabilities ends is also the period when the question arises: what next? Lack of the institutions (and lack of the possibilities to attend those already existing) adapted to the needs and abilities of people with profound intellectual disabilities is often a factor that makes a child stay outside of social life and live only with a mother who has many roles, being a caregiver, rehabilitant, nurse...

The picture of the functioning of a family with an adult with profound intellectual disabilities, which I found as a researcher and also an analysis of the research, indicates that the reality in which my respondents functioned was different over the years. It was based on the exclusion of women from various areas of social life, and also- of her child. The selected research group deserves special attention due to constant mobilization, life on the verge of burning out own strength, feeling the full responsibility for caring for and bringing up a child with such a complex and specific intellectual disability. One of the main factors determining the undertaking of research in this area is the phenomenon of identifying mothers with their disabled child. This is confirmed by the research conducted by Zaneta Stelter: "a child with a disability who deprives the mother of the possibility of being herself, causes that the mother accepts the identity of a disabled person who she is not"[2]. Everyone has the right to participate in social life, regardless of his / her current personal situation, level of functioning or experience. An inseparable condition of interpersonal contacts taking place in the social life and forming its basis is the desire to make them in social relations and to perceive another participant in this process as a unique, original and unique element[3]. This results in the right of every person to actively participate in social life. No reason can justify marginalization or exclusion of people from social life at any stage of their life, neither of members of their family. It should be noted that families of people with all kinds and degrees of disability have always been and still are the groups at risk of social exclusion. It is dictated by lack of understanding of the situation in which they are found over the years, with which they struggle with difficulties and problems.

It should be pointed out that a phenomenon of "automarginalization" by families with children with disabilities occurs very often. The conducted research in a group of mothers of people with profound intellectual disability shows that this is due to the powerlessness of women, the desire to avoid unpleasant experiences. It is a kind of defence mechanism against misunderstanding of the society. Thus, motherhood and its image are shaped in the conditions of social rejection, a feeling of non-belonging to a group. The specificity of profound intellectual disability has great importance here, characterized by a very diverse, complex clinical picture, which causes in people from outside: misunderstanding of one’s behaviour (often behaviour that deviates from commonly understood social rules: making noises, screaming, behaviours taking a form of autostimulation: swaying, rhythmic tottering[4] and a strange facial expression[5]. Such person very often is deeply misunderstood, without the possibility of individual narration, which is one of the main reasons for being "out". So how it is connected to the social situation of the mother of a person who is "deeply misunderstood"? At the beginning the reality in which they function and with which every day the interviewed women struggle shall be briefly described.

Motherhood brings essential values and experiences into a life of every woman. Sometimes, the very fact of the appearance of one's own child, can give the mother a sense of fulfillment. The child often deepens or reveals the meaning of woman's life. According to Aleksandra Maciarz, the problems faced by a single mother can be classified into following categories: material, psychological, protective, and educational difficulties[6]. Reports on the economical situation of the surveyed group shows that single mothers have lower income, which can also lead to burnout and social exclusion. The implementation of caring tasks helps women to avoid reflection on their difficult life situation, because they focus on care and household duties, they take over the duties of other family members at the cost of their own needs. A child with profound intellectual disability is completely "reliant" on the caregiver, which means that: "the mother, in contact with her child, may have a feeling of injury because of the limited opportunities to self-realization"[2]. Often the mother accepts then the identity of a disabled person- although she is not disabled. This influences the fact that she feels lost among people around her who are unable to understand her suffering, which leads to a sense of difference and exclusion. The feeling of being "different" as a mother and the feeling of difference of her child through years leads to the categorization process. It is a process in which "we" is changed into "others" by members of the group, which includes the mother of a person with profound intellectual disability. Therefore, it is possible to describe this process as follows: categorization consists of determination by others to which category a person or an object belongs to[7]. In other words, categorization involves the recognition of a group of people as a separate entity that differs from other groups or from one large group. As an example, there may be a
According to Erving Goffman, in today stigmatization is not manifested in a physical stigma, but this anchored in society regarding people with disabilities are a result of social stigmatization. The to social stigmatization and exclusion. It should be noted that the negative stereotypes, prejudices through interactions that are symbolic, because using stereotypes, people mark people who cannot be process is carried out by symbolizing and marking selected people. The stigmatization is expressed the senses, intellectual and communication capabilities - which is a feature that differs from other functioning of people with profound intellectual disabilities allows to indicate many deficits in the field of the individual and groups. In turn, this is the reason for generalization as "others" - "we" - "strangers". The functioning of people with profound intellectual disabilities allows to indicate many deficits in the field of the senses, intellectual and communication capabilities - which is a feature that differs from other individuals and groups. In turn, this is the reason for generalization as "others" - "we" - "strangers". According to Erving Goffman, in today stigmatization is not manifested in a physical stigma, but this process is carried out by symbolizing and marking selected people. The stigmatization is expressed through interactions that are symbolic, because using stereotypes, people mark people who cannot be included in the "we" category and are included in the "they" group[12]. Social stereotypes can affect a person in different ways through negative social attitudes, by isolating disabled people, by influencing their identity or lost sense of identity.

In addition to stereotypes, there is one more negative notion - prejudices. They are defined as "a group of usually negative judgments about persons or groups (national, social, religious or other) based on generalizations derived from false or incomplete premises"[11]. Prejudices are characterized by the fact that they can refer to things, phenomena, objects, and even concepts that for many people do not have the slightest meaning in life. All these processes - categorization, stereotypes and prejudices - can lead to social stigmatization and exclusion. It should be noted that the negative stereotypes, prejudices anchored in society regarding people with disabilities are a result of social stigmatization. The functioning of people with profound intellectual disabilities allows to indicate many deficits in the field of the senses, intellectual and communication capabilities - which is a feature that differs from other individuals and groups. In turn, this is the reason for generalization as "others" - "we" - "strangers". According to Erving Goffman, in today stigmatization is not manifested in a physical stigma, but this process is carried out by symbolizing and marking selected people. The stigmatization is expressed through interactions that are symbolic, because using stereotypes, people mark people who cannot be included in the "we" category and are included in the "they" group[12].

It should be noted that the process of marginalization and social exclusion of a family with a child with profound intellectual disability may also be affected by a difficult financial situation, lack of funds for a person with profound intellectual disability securing basic life needs. The economical situation of families with a disabled person in Poland forces one of the caregivers (mother, father) usually to resign from work to look after the child[13]. It should be mentioned here that when a woman is granted a nursing benefit for childcare, it cannot be combined with incomes from salary - which deepens the problems of the functioning of the family, leads to marginalization in the context of rights. The impossibility of combining paid work with social benefits is linked to the fact that most of the mothers of disabled children do not work, which was also confirmed by the research conducted and presented in this article. This is a situation threatening mental and emotional functioning of women, which is confirmed by Cunningham's research, which shows that non-working mothers of children with disabilities have a higher level of stress compared to mothers who are professionally active[14]. Here I also notice that being a part of a community, a feeling of belonging and acceptance of this community may reduce the level of negative experiences in families bringing up children with disabilities. Both allow to take the rest from daily nursing duties, engage in one's interests, and live not just to meet and secure child's needs and all what is connected to the specificity of a profound intellectual disability. Public opinion has created a picture of a family with a person with a disability as poor and suffering. The situation when such a family begins to function according to the status of the "ordinary" Polish family often raises many questions in society. There is no permission to travel, among others, for holidays, or to function in decent conditions. There is even a social expectation that people with disabilities and their families are supposed to function in an accepted pattern (dependence, limitation of activity, poverty, weakness)[15]. The dominance of the characteristics of the weakness of such a person, and hence its family, means that he / she is neglected in social activities, in decision-making matters of the group of which they form a part. It should be noted that the subjective sense of social exclusion and its increase is the age of the child. Negative reactions from the society towards people with disabilities, and thus their families, increase with age. It intensifies many unacceptable behaviours of persons with disabilities (agression, autoaggression, screaming), while, regarding mothers, it intensifies the sense of otherness, misunderstanding, leads to a feeling of social exclusion and marginalization, which is also marked with suffering.
2 METHODOLOGY

The main technique of gathering information was individual biographical and narrative interviews, which through authentic, subjective statements can provide a retroactive perspective at motherhood[16]. The basic source of the analyzed materials were transcripts of the interviews. Narrative interviews were recorded on the voice recorder, they had one form of in-depth interviews, focused on the topic of motherhood. The obtained information has been analyzed according to the analytical procedures proposed in the methodology of grounded theory (GT)[17]. The reason for adopting this strategy is the development of methodology during the research. Information obtained through the transmission of the feelings by women (with broadly understood analysis or interpretation) was divided into a small fragments[18], which made it possible to learn the meanings resulting from many years of experience. Such a study made it possible to capture the ways of respondents to understand the world. This corresponds with William Thomas's definition of the situation: "If people define a situation as real, it is real in its consequences"[19]. The code in vivo will be also incorporated in the development of the theory-this is the way of thinking of the subjects about their problems. The information was systematically obtained and analyzed, so that the theory that was being formed was working all the time. The women were asked to talk about the experience of being a mother by the key question: What is it like to be a mother? The presented research material is based on 34 completed interviews with women from all over Poland. The aim of the conducted research was the theoretical, empirical and practical analysis of various aspects of the experience of motherhood of single mothers of adult children with profound intellectual disabilities. This article focuses on understanding and analyzing the reality in which the mothers functioned over the years and the answer to the key question:

- Do the mothers feel marginalized and socially excluded, and if so, by what do they think that it is conditioned?

As a researcher, I was particularly interested in the answer to the question:

- How and if one can relate to the feeling of exclusion, social marginalization of the mother, the specificity and complexity of her child's profound intellectual disability?

3 RESULTS

3.1 A mother with an adult child with a profound intellectual disability as a part of a social group- a question: the same (we) or others (them)?

Interviews were conducted in different ways, some of the women spoke chronologically according to the course of events that they had to face over the years. Other respondents started their story from events that left stigma on their motherhood, events full of suffering, which made women feel "out". This article will present subjective statements of mothers illustrating experiences that made them feel excluded and socially marginalized. It is impossible to show this in one article, that is why the selected stages of motherhood will be presented and discussed (diagnosis of disability, the moment when the child should have started education but was excluded from the obligation of education- this situation affected all children with profound intellectual disabilities until 1997). Respondents' statements about the feeling of being a mother of a person with profound intellectual disability will also be presented, which is inseparable from being a caregiver, a therapist throughout the whole period of motherhood, which, as shown by the statements, deepens the feeling of otherness and social exclusion.

3.1.1 Diagnosis of a profound intellectual disability

Acting in the social group already at the moment of birth of a child with disability or at the moment of diagnosis of a profound intellectual disability, women began to feel the otherness. In fact, it can be assumed that it was the moment when women slowly started to experience what disability was, but also began to experience the child's disability subjectively, in person.

A few days after birth, I heard a diagnosis that my child would be a cripple, that it was not known whether he would live at all, that I should think deeply what to do next, whether I wanted to waste my life. I was in the room with other women and I remember that I felt such a sign on myself then. I don’t even know how explain it to you. My child was wrapped in a blanket, small and crying, and I already had the feeling that we were from a different world (Olga, 67).

It was not so easy to do the diagnosis. Nobody knew what she suffered from. I was tired of it, I wanted to hear the diagnosis. A genetic syndrome was suspected, but some professor soon denied it. He said
that I had to accept that I had such child and not any other, that no one could tell me what would happen next, that only time would teach me and life. That I shouldn't believe in miracles. And it was like that. It has always been different, and all in all me too (Malgorzata, 71).

Women pointed out that their first association with the diagnosis of a child's profound disability was related to "otherness". Some of them did not want to acknowledge that it was real, they thought that it was a mistake, they experienced many psychological mechanisms, trying to prove themselves and the community that they gave birth to a "healthy child", that they were mothers like any other woman. Unfortunately, very often, it as a result the women more and more felt "otherness" and social exclusion.

I couldn't believe it, I thought it was not true. I tried to live like any other neighbour with a small child. But they made me realize that Zuzka was different, that I should examine her. The more I wanted to show them that my daughter was healthy, the more I experienced her otherness that other people made me feel. In the end, I stopped leaving the house. I don't blame anyone, it was my mistake (Ewa, 65).

On the other hand, in some interviews there were statements that indicated that the very fact of diagnosing profound intellectual disability, caused that mothers began to identify with this disability from the early beginning. Speaking of a child as "other", they treated themselves in this way, which came out from their inner sense.

I heard that my child was mentally handicapped, and that it wasn't a light handicap. At that time I didn't feel like a mother, but like a lifeguard, I wanted to save my child at any price. Because of that, I've always been different, I've never been tired, I was always doing things somewhere and I thought it would stay that way. But nobody wants people like me. It'd be better to take us out of the city, give a few hundred zloty’s (Agnieszka, 69).

I wanted to help him, only he counted. I wanted to suffer like him. It was me who wanted to take over the burden of handicap (Aleksandra, 71).

The diagnosis of child's profound intellectual disability was an experience inscribed in the motherhood of the women, and also in their personal biography, not only of their children. For the mothers it was a very personal experience of great individual significance, but it also had a social importance - this diagnosis redefined the identity of the women, their motherhood.

Another event to should be mentioned is the moment in which many parents are in a stage of joy and pride, for my respondents, however, the moment of experience of being a part of a socially excluded group, a group for which there is no place, a group which is accompanied by a "deep misunderstanding" and the lack of social and consent to being "the same".

3.1.2 Question about the possibility of education of the children with profound intellectual disabilities

The mothers' stories show that children with profound intellectual disabilities have always been stigmatized. They felt that even if an outsider had never seen their child, he / she could describe the child in advance by certain features that often were not reflected in the functioning of the person with profound intellectual disabilities. This can be explained by the phenomenon of social stigmatization, which manifests itself in marking, top-down stigmatization of people who belong to the same environment, but there is something that differentiates them. In the case of my respondents' experiences, it was "a profound intellectual disability". As pointed out by the mothers, when somebody mentioned this term, at once in the imaginations of the community appeared schemes on how the functioning, look, and behaviour of a person with profound intellectual disability- unfortunately, it often had a stereotypical character of thinking about this group of people.

There were no schools, my son is 43 today. He couldn't go to school because no school wanted him. I heard that they were accepting "normal children" at school, it was awful how much our children were rejected, no one knows how much I cried. Every friend of mine, was taking his / her child to school and work, but I didn't have such a possibility, I always ask why, because I gave birth to such and not another child? It is so unfair. Today it is the same, it is terrible that the society and the state marginalize us, mothers of children with deep intellectual disabilities (Krystyna, 66 years).

I said that my son is a child with a deep intellectual disability, and a school counselor, an educated person, said: "We cannot accept your child because he is dangerous and will threaten others, what I will tell another parents?" I felt that there are parents and me (Olga, 63).

It was incomprehensible to mothers why many people, perceive their children in this way, by what it is influenced. They felt that their children were unwelcome in the community. It should be noted that the
process of perceiving certain things is influenced by three related components that interact with each other, namely: attribution (assigning permanent features); assigning expectations and evoking emotions. Emotions that are manifested in a relation to the perceived person are usually the result of attributing certain properties and expectations to that person. Depending on what way are the emotions expressed (positive or negative), it can give a direction to assign specific properties to the subject. It causes that some properties are more easily assigned than others [20]. It happened in the case of the experiences of my respondents, that strangers without knowing their children with deep intellectual disability, were assigning certain features to them.

The headmistress told me that she used to be in contact with such children, that she was very sorry for me. Honestly, I didn’t know how she felt for me. I remember her saying that these children were very poor, but at the same time they were not suitable for school (Katarzyna, 73).

When the teacher saw my small but big child, she got scared. Because Olus ran up and hugged her, and because he was really big, she was waiting when he would bite or hit her. She didn’t even want to meet him (Lucja, 59).

In a significant part of the interviews, the mothers were emphasizing that when a small child is being brought up, a mother does not feel that much social "otherness". According to them, the "otherness" was felt in being a mother (no feedback from the child in the case of deep intellectual disability, lack of mutual communication, smile). The moment when the women wanted to send their children to school was the moment when this feeling of "otherness" increased rapidly, when they began to become more aware and experience that they are on the margins of social life.

I’ve never felt that way, so different, rejected. It concerned my child’s education, I wanted him not to be alone (Joanna, 64).

There was no place for us anywhere, I even asked if I could go to school with him, so that he would stay with children, but there was no consent from headmaster, and also from teachers. We have always been treated differently, so worse and it has to be said out loud. In fact, when Kuba was small, I did not feel that way, we lived somehow. In fact, the institution that was to help us even more showed us where our place was (Grażyna, 62).

They looked at me as if I was crazy. I fought for her right to study, but no one noticed that it was me who didn’t want to be locked in four walls. When the school closed the door in front of my child, many opportunities have been taken away from me (Monika, 69).

The statements show that the fact of excluding children from compulsory education, and also the specificity of deep intellectual disability did not allow mothers-women to fulfill themselves. Their social position has been and is still dictated by what society can offer for people with profound intellectual disabilities. What social resources (legal system, social attitudes, disability perception and culture model) can be used by people with deep intellectual disabilities is largely a predictor of how women’s motherhood will look like, and first of all, how will personal and social identity develop of a concrete woman who is a mother, but she is also herself. Sometimes it occurs that woman annihilates part of herself, the "I" to meet all the child’s needs [21].

3.1.3 Being a mother, a caregiver, a rehabilitant and being oneself

Over the years, the women had to face many difficulties resulting from bringing up a child with a deep intellectual disability, and from the intensity of care treatments, which, with the age of the child did not decrease, but only increased. They experienced a lot of difficult situations related to the loss of wife status (because of being left by husband), but also the loss of the status of a friend or employee. These are the situations that have influenced today’s image of their motherhood and biography. However, in this part of the article, I would like to focus and consider “being myself” - by a woman, the mother of a child with profound intellectual disability. Because a key question arises: Is "being yourself" possible in such a difficult reality in which women functioned and still function?

Did I stop to be a woman a long time ago? I used to take care of it, but today I don’t have time, I have no motivation, I don’t want to (Joanna, 64).

I always had long, beautiful hair. But I didn’t have time, he was tearing out my hair. I don’t paint nails, I don’t remember when I was at the hairdresser’s. Gray hair, short nails... I’m a mother and that’s it. I had to choose and decided that I would be a mother for whole my life, I had to forget about myself (Ewa, 65).
The specificity of a profound intellectual disability was a factor that required from mothers to think deeply about the situation in which they found themselves. Mothers had to set up new values for their lives. Many of them had to stop their professional activity, forget about their plans and dreams. They had to close certain stages of their lives.

I was always full of energy, I worked in a furniture factory, I was supposed to be promoted. But as you can see life had different plans for me. I've reconciled with it (Agnieszka, 69).

I felt grieve, hatred towards my daughter, because she was as she was, but I loved her too. After those years I think that this love has helped me to make the right choice (Malgorzata, 71).

Everyone was living his life, I had to do so too (Joanna, 64).

The women had to face many changes what created an overwhelming situation for them. Being together with a child with a profound intellectual disability, undertaking a fight for the dignity of life of their children, abandoning their own plans resulted in a change of the way of thinking about oneself.

I had to grit my teeth and every day I had to fight for my child to breathe, these are things that we don't talk about. What matters is what I can offer her still. We are very connected. I think about her day and night (Teresa, 78).

I am no longer the former Jola, I don't know what to say about myself. I can tell you a lot about him, I don't know about myself... (Jola, 64)

The child's disability that lasts for the whole life has caused and continues to cause constant changes in the identity of the mother, what is full of suffering. It should be noted, however, that it was precisely suffering that opened the mother's need to redefine her own life situation.

You know, as the saying goes, there is no evil that does not bring good. It was and still is hard, I'm very lonely- but I have to live. Such continuous tormenting leads to nothing, I've checked it myself many times. If I don't help myself, no one will be able to help me (Joanna, 64).

Each of us has to cry, we must shout out what we bear inside. You can not forbid it, we must allow ourselves to suffer so that we can enjoy what the destiny offered us (Katarzyna, 73).

I had to tell myself, listen, Goska it is this way, and not the other, and it won't be any better. Either you die or live. Nobody knows what thoughts mothers like me have. It's terrible, but ... (Malgorzata, 71)

What appear in the above statements, is that the mothers had to face the situation in which they found themselves, they had to analyze it themselves and make a choice what to do next. Most of them gave up part of themselves to be able to guarantee the possibility of life for their children. Profound intellectual disability is a highly complicated phenomenon, because it is difficult to have a specific characteristics of the functioning of such a person, what the women had to face.

No one was able to tell me what would happen next (Monika, 69).

One day was it good and the next day I couldn't recognize my own child. Marek was beating, biting. I couldn't leave him, I had to be with him. Sometimes I was screaming because of my powerlessness. I couldn't go anywhere with him, because I was ashamed, I was ashamed of that (Grażyna, 62).

She was always screaming when she was happy, that the whole trolley was moving. But other people didn't understand it. I knew I wasn't welcome in the playground, I stopped worrying about it (Anna, 72).

Those conversations, those starring, talking about him as if he didn't understand it (Lucja, 59).

According to the respondents the period when their children entered into adulthood was and still is one of the most difficult periods in their motherhood, the moment when their feeling of "otherness" increases. It was deepened by the misunderstanding of the society that a person in which all spheres of functioning are disturbed to a greater or lesser extent can and has a right to be recognized as an adult. Their statements show that there was no social consent for the adulthood of people with profound intellectual disabilities.

He sees a woman in a wheelchair and says "poor child". She is 42, she is not a child anymore- I told her that. I have no idea how to show, how to prove that she is an adult person, enough of these "eternal children". Everyone always talks to her as to a child, treats her as a child. How Marysia can play with children? Marysia turns 34 this year. But, you know, my sister comes to me once in a while and asks her children: "Will you play with Marysia?"(Anna, 72).
There is no place for an adult with profound disabilities in the world of today's norms and values. It is true that a lot is said about people with disabilities, but not about our children. Does anybody wonder who deals with such a person? (Lucja, 59)

Due to the fact that there are no institutions that adults with profound intellectual disabilities could attend, people over 25, when they no longer have the opportunity to participate in the classes in the education system, they can only depend on their parents who are already very old. In their opinion, they are a forgotten and neglected group.

4 CONCLUSIONS

The mothers of adult people with intellectual disabilities function in a social reality which despite many changes taking place in Poland and throughout the world is still a reality burdened with stereotypical thinking about people with disabilities. Social categorization of "us" and "others" is still used. The research shows that in different periods of motherhood, women experienced "otherness" and thus the feeling of being a group of mothers of people with profound intellectual disability - a socially excluded and marginalized group. It should be noted that despite the fact that this social stigmatization concerned in particular their children, what happened due to a profound intellectual disability, it also affected them as mothers. On the one hand, it was dictated by the symbiosis that connects mother and child, while on the other hand, mother made a choice of living for a child at a certain moment of their lives. Therefore, what was relevant to their children they took over as "their own" regarding their identity. It can be concluded that mother and child with profound intellectual disability constitute one system. The mother, by redefining her own "I", partly takes over the "I" of her child. It should be noted that the existing support models for the families with a child with a disability do not protect enough them, which in particular causes a feeling of exclusion and social marginalization in the group of mothers. While creating multidimensional support systems what should be taken into account is not only what an intellectual disability is. We should consider what conditions should be created so that each person functions in proper external environment and, what is the most important, in decent internal conditions.

ACKNOWLEDGEMENT

I would like to thank all mothers of adults with profound intellectual disabilities who agreed to share with me a difficult but beautiful world of motherhood experienced over the years.

REFERENCES

[1] Regulation of the Minister of National Education from 30 January 1997 on the principles of organizing revalidation and upbringing classes for children and youth with a profound mental disability-[Polish Bulletin of Acts and Decrees]


