FUNCTIONING OF ADULT SIBLINGS OF PEOPLE WITH INTELLECTUAL DISABILITY IN THE AREA OF PARTNER AND SOCIAL RELATIONSHIPS

K. Kruś-Kubaszewska

The Maria Grzegorzewska University (POLAND)

Abstract

The functioning of a family with a child with intellectual disability is exposed to the centralization of life around the needs and difficulties resulting from developmental problems of the child. Parents experience the problem of disability from the adult perspective, meet with it at a certain stage of life and from that moment it affects their system of values, social life, organization of time, and parenthood. Meanwhile, able-bodied siblings raise from the early age in the awareness of the disability of a brother or sister, in the daily duties and restrictions connected with this fact. It is growing up marked by the experience of social perception of the intellectual disability of a loved one, diversified parental attitudes towards able and disabled offspring.

It is also a life in the shadow of rehabilitation, therapy and support system targeted in Poland especially for the needs of the disabled person, sometimes its parents. The question then arises, is the support for non-disabled siblings also? The issues of growing up of able-bodied siblings, its social and partner relationships seem to be overlooked in the light of numerous scientific publications about support for families raising children with intellectual disability in Poland as well as abroad. The siblings of people with disability are called "invisible children", which is a depressing picture of the marginalization of their needs and insufficient scope of support offered to this group.

The aim of the study was to learn about the experiences of adult siblings of people with intellectual disability in terms of its social functioning, social relationships and partner relationships. A qualitative research methodology based on narrative interviews was chosen. The interview was given by 15 adults aged 22-43 who are siblings of people with intellectual disability. The selection of the sample was determined by the fact of raising up with siblings with intellectual disability and the age of the interlocutor. Using interview as a main method allowed to get detailed and individualized knowledge about the experiences of the group being researched, at the same time giving the interlocutors the opportunity to decide independently which aspects of social and partner life are the most important for them. Based on the analysis of the content of interviews, the article is an attempt to answer the question on how adult siblings of people with intellectual disabilities perceive their partner and social relationships and what kind of reaction of the environment towards the intellectual disability of a brother or sister have they experienced? The reflection was whether, and if so, how, the intellectual disability of siblings affects the social life of able-bodied brothers and sisters.

The interviewees' perspective presented in the article is a picture of "other", sometimes difficult, but valuable experiences of able-bodied siblings. Research has revealed that growing up with disabled siblings affects the interviewees' expectations toward partners and their perception of relationship. In addition, it shapes the specificity of social relations of this group, shows which traits and behaviors are expected from good friends by them and which social attitudes they value.

Keywords: sibling, relationship, social relations, intellectual disability.

1 INTRODUCTION

Research on the functioning of the family of a child with intellectual disability focuses to a large extent on the needs and difficulties of the child and its parents. Looking at the problem of disability only from the perspective of parent- disable child or mother- father relations is a partial approach, in which there is no room to identify the needs of able-bodied siblings. In families of people with disabilities, life must often revolve around caring of the disabled child. Such a situation leads to the marginalization of the needs of an able-bodied child, because parents lack time, strength and sometimes- money. Moreover, the sufficient system of support for siblings of people with disabilities does not seem to exist in Poland. The legal basis for supporting families of people with disabilities marginalises the problem of
organising support for siblings. Due to the place of a child with disabilities in the family and legal system, the research group is often called "invisible children" [1].

The awareness that siblings of people with intellectual disabilities are a risk group in terms of emotional and social functioning seems to be stronger in foreign discourse. There are initiatives to support this group. The first form of support is a workshop called "Sibshops". They have a formula based on the activity of the participants, so that they can play a supportive and therapeutic role. They are especially dedicated to young people who, who by engaging in common activities, gain psychological help at the same time [2]. In the opinion of siblings, well-organized support should include the creation of support groups, but also assistance in taking care of disabled siblings. It should provide psychological support in difficult situations, access to information about services and support places in order to secure the future of the disabled person. Workers of the institutions within this system should also inform about possible additional financial resources for the family, enabling the sibling to obtain rest and housing for the disabled.[3].

Having siblings with disabilities entails a number of emotional and social consequences. An able-bodied brother or sister is often burdened with many household duties, is included in the care and maintenance of siblings, and is required to be fully responsible and mature, sometimes far beyond the actual age. Research on siblings of people with disabilities dating back to the 1980s has shown that able-bodied brothers and sisters are more likely to experience adaptation difficulties, they might have bigger problems with emotional control and social development than their peers raising without disability problem at home [4]. These results have been only partially confirmed in 2012 by the study on the adaptability of siblings of disabled people. The research revealed that in the study group, 30% had difficulties in emotional or existential adaptation, the rest did not. People particularly exposed to the adaptation and social problems are those in whose families other factors, such as conflict between parents or low economic status overlap with the problem of intellectual disability [5]. This proves that the fact of disability of siblings while maintaining balance in the family system is not a determinant of adaptation difficulties of efficient siblings. However, maintaining socio-economic balance in a family with a child with disabilities is often a challenge.

The impact of the disability of one child on the emotional state and functioning of the other able-bodied children was the subject of over forty foreign studies conducted in the years 1970-1995. They were based on the opinions of parents bringing up an able-bodied and disabled children. It has showed that nearly 60% of parents expressed an opinion about the risk of the negative impact of the disability on the behaviour of the able-bodied siblings. 30% of parents paid attention to the positive impact of a brother's or sister's disability on shaping of the behaviours of able-bodied siblings, 10% pointed out good and bad aspects of the behaviours of a able-bodied child due to the disability of the other child [6].

Another perspective of research on the situation of siblings of people with disabilities was chosen by T. Moyson and H. Roeyers. Using in-depth interviews with a group of 50 brothers and sisters of people with disabilities, they focused on the individual opinion of the respondents on their quality of life. The results of the survey showed that siblings assess their lives differently than their parents see this problem. First of all, despite the limitations in functioning of their siblings they are interested in spending time together. Understanding their brother or sister and communicating with each other is important to them. Despite the clear distinction between the activities that respondents would like to do with siblings and their real possibilities, the respondents try to compensate these deficiencies by adapting the activities to the skills of the disabled. They emphasize the role of acceptance, without which relations with the disabled siblings and life satisfaction would be assessed much lower. They express an opinion about the regular need for a temporary isolation from their role of an able-bodied brother or sister. The need for support from relatives and peers and contact to someone who would compensate for the activities that are impossible to do with disabled siblings was also emphasized [7].

In some publications, the social relations of able-bodied siblings are analysed from the "me and my disable sibling" perspective . An individual perspective on the specificity of life with siblings with disabilities is presented in the publication edited by J. Koral entitled: "Siblings of people with disabilities". It quotes the original statements of brothers and sisters of disabled people. Many statements indicate proper relations between siblings. Non-disabled children appreciate the achievements of siblings with developmental challenges, they try to support and protect them. At the same time, the statements show difficulties related to being a sister or brother of a disabled person, such as overload of duties, faster entry into adulthood and sense of loneliness, sadness and shame as a result of negative reactions of the society [8]. Relations with disabled siblings were also the subject of M. Gendek's research. He surveyed a sample of 50 people (25 of whom were siblings of
neurotypical people and 25 more of whom were the siblings of disabled). The results showed that siblings of people with disabilities are more likely to provide emotional and instrumental support to their brothers and sisters which means a greater sensitivity and willingness to help in a wider social context. At the same time, according to the research, siblings of people with disabilities are more prone to experience the feeling of rejection at home, which translates into a sense of loneliness and isolation [9].

Research shows that the dominant problem in establishing closer social relations by able-bodied sibling is their feeling of being different and alienated. The respondents point that the others do not understand the experienced difficulties, which contributes to the problem of emotional integration with a peer group and limits the comfort of conversation with others. The opinion that nobody really understands how difficult it is to be a sibling of a person with disabilities was quite common. The sense of being misunderstood by peers and the local environment is emotionally overwhelming for the respondents [10]. In comparison to siblings of neurotypical people, siblings of people with disabilities more often perceive themselves as unlucky, marginalised and without a normal life [11].

2 METHODOLOGY

The aim of the research was to analyze the perception of social functioning and partner relations of adult siblings of people with intellectual disabilities. The subject of the research was individual experience of able-bodied brothers and sisters in the field of their social functioning over the years. Getting to know the individual perspective of the respondents brings closer the problems of social functioning of fully able-bodied siblings in emotional, individual and internal dimensions, as well as their wider functioning as members of society. The research problems have been specified in the following directional and supplementary questions:

- Does upbringing with siblings with intellectual disabilities influence the social relations of non-disabled siblings? If so, how?
- How do siblings of people with intellectual disabilities perceive themselves in partner relations?
- What are the social reactions to the problem of intellectual disabilities in the opinion of able-bodied siblings?

In the study qualitative data collection strategies were used. There were 15 in-depth narrative interviews conducted, which lasted between 1.5 and 3.5 hours. The interviews were recorded on a recorder and transcribed taking between 17 and 26 pages. The creation of an interview scenario and its categorisation were abandoned, allowing the interlocutor to greater freedom in addressing the various issues relevant to him or her. In order to ensure the comfort of interviews, they were held in places giving a sense of privacy, most often at the home of the respondent or the researcher. Next, the analysis of the content was carried out, distinguishing the most frequently discussed and important for the interviewees topics. This article presents selected thematic areas discussed during the interviews, such as: self-perception in partner relations, experiences of making acquaintances over the years, social functioning in the local environment and the society's attitude towards the issues of intellectual disability.

In the research, the method of targeted selection of the research sample was applied, based on the principle of availability of the sample, as well as taking into account the key criteria for the research. The selected population consisted of 15 adult interviewees who had siblings with intellectual disabilities. Although interviewing a small group of respondents limits the possibility of broad generalization of results, it increases the chance of devoting an appropriate amount of time and personal involvement to each respondent, and thus obtaining detailed information about the issues of interest to the researcher [12]. The criterion of adulthood, diagnosis of siblings' intellectual disability and living with them during childhood and adolescence was the basis for the selection of the sample. Interviews only with adult respondents were aimed to provide an opportunity to look at the issues raised in the interviews from the perspective of time. Among the respondents there were people of both genders, of different ages, from 21 to 43 years old, with different education, marital status and family structure. Achieving diversity in a group of siblings with disabilities allows an initial orientation whether the simple fact of a brother's or sister's disability may contribute to the occurrence of common points in the respondents' experiences of different spheres of life.

During the selection of the research sample, where the choice is determined by the upbringing of brothers and sisters with intellectual disabilities, it is difficult to apply the principle of key, pictorial or
extreme cases. The reason is that these principles are based on the degree of involvement in a given phenomenon. Selection on the basis of the above mentioned principles is made difficult by the fact that in the case of childhood, as well as adulthood, it is possible to get to know the experiences, opinions and attitudes of the interlocutor only during the conversation. The selection of the sample based on the leading common features, such as the above-mentioned age and previous living with a disabled brother or sister, makes all cases seem typical before the interview. In the study, the criterion of convenience was applied. The sample included people whose geographical access and contact was not difficult. Two respondents were selected thanks to the indications of one of the respondents, thus using the "snowball" method. Thanks to the use of individual contacts and recommendations of one of the respondents, the interlocutors had prior knowledge about the researcher. It allowed them for greater openness, freedom and trust in the conversation. This is very important, as the research included difficult issues, referring to partner relations and problems in social contacts, which in various ways could have affected the well-being of the respondent. For this reason, prior knowledge of the researcher was a factor facilitating obtaining information. In order to protect the privacy of respondents, only the names and age of their siblings are given in the survey results.

3 RESULTS

The fragments of interviewees' statements presented in this part of the article are taken from the author's unpublished master thesis entitled "Retrospective assessment of childhood and adolescence of siblings of people with intellectual disability". The interviews allowed to divide the interviewees' experiences concerning relations into partnership and social relations, as well as the local community attitudes towards the fact of intellectual disability of the interlocutors' siblings. They create a diverse and unique picture of social functioning and, as a result, emotional state of siblings. On the one hand, the results are full of mature and difficult reflections on the place of the interviewees in social life, in partnership and peer relations. They indicate a feeling of alienation, lack of understanding by the environment, distance and even unwillingness of others. On the other hand, they are an image of disability, which has the power to connect people and helps in making honest and valuable acquaintances. It also favours surrounding oneself with friendly people and building responsible, warm and security-based relationships. The results show that siblings of people with disabilities need full normalization of life in the social dimension, they want to function like other acquaintances and peers. Social functioning and building partnership relations is important for the respondents, but still more difficult due to the social perception of intellectual disabilities.

3.1 Partnership in the siblings' perspectives

In the area of partnership relations, fear is the dominant feeling in the researched experiences. Fear is mainly related to difficulties in accepting siblings with disabilities by a partner. Therefore talking about disability, visiting home, meeting siblings is sometimes postponed in time. The interviewees mentioned about avoiding involvement in the relationship, so as not to be rejected. They tried to protect themselves from love disappointment. Attempts to establish close relationships were accompanied by the feeling that no partner would love or take seriously a person with a future burden of caring for disabled siblings.

"Generally speaking, I have always been very afraid of any relationships. I claimed that nobody would want me with a disabled child. I had promised my mother I would take care of Dominic before she died. I had such stupid thinking about relationship, very shallow, when I look at it from the perspective of time... So I didn't get involved in anything serious, because I was afraid of reactions of the boys... I didn't tell the boys about Dominik, and I didn't invite any of them home either." [a sister of 16-year-old Dominik with Down syndrome].

The interlocutors' attitude towards the relationship was also dictated by previous painful experiences. It was mentioned about rejection because of a brother's or sister's disability. After introducing the disabled siblings to the potential partner, the interviewees experienced from partners sudden emotional cold, distance or even breaking the contact. After surviving the rejection, the interviewees had a problem in opening up to the next relationship, believing that the relationship could not be successful and long-lasting. Many times in the interviews the word "burden" appeared in the context of a brother or sister's intellectual disability. The burden was related to the internal awareness of the future care of siblings. In one case it was also related to a significant risk of a genetic defect during pregnancy as a result of being a carrier of genomic changes.
"I never hid Rafal. When I was in college and started planning life with a guy, Paul was at my house and knew (...) He was dating me until his parents found out that I had disable brother. Since that moment he ended up relation with me in a very ugly way... it was a guy with whom I had some kind of plans for the future, and he told me that he couldn't marry a woman who, I quote, "has a fucking insane brother." This guy hurt me so much... Later I had objections to enter into new relationships, because i memorized this words... I was thinking, that every relationship is temporary, that it will not be a relationship for life, because no one will want me and such a burden for entire life. [sister of 44-year-old Rafal with a genetic defect]

The following statement is an example of the partner's rejection experience after first contact with disabled siblings. A given situation made the interlocutor convinced that potential partners are afraid of being close to someone devoting a part of life to a person with a disability, they are afraid of responsibility. Thus, the siblings of a disabled person do not see any chance for permanent closeness.

"You know what, once I was dating a guy who met my Ania, it was probably the only one... no, the second one. And this boy who met my Ania was in the center at her boarding school, and that was some kind of beginning of my relationship and then... he brought me there, he drove me back home, he met Ania and... and then the contact has been stopped. And then the headmistress of the school, my auntie, said that he probably got scared and that's why he escaped. Because I lost my boyfriend, that I really cared for him. "[Sister of 24-year-old Ania with Down syndrome]

One of the interviewees noticed that the beginnings of relation are particularly difficult. There is the uncertainty what time is right to tell a loved one about having brother or sister with disability. There is also a doubt whether the person will accept this fact, whether he or she will not change the attitude or withdraw from the relationship. It is difficult to speak openly about the problems related to the disability of siblings. However, talking about it and observing the reaction of the other person is the way to ensure if the partner fulfills the interlocutors’ expectations. They want to see understanding and acceptance in the reactions of the potential partner. It gives them a sense of security, that it is a person who will not retreat in difficult situations, will then be a support. Openness towards disabled siblings favors the feeling that at the moment of starting a family in case of having a child with disability the partner would act as a responsible and loving parent, instead of leaving the family. Among the important features of a partner following ones were depicted most often: tolerance, understanding, sensitivity, responsibility, patience and respect.

"But now I'm a little scared. For example, I'm worried because I don't want to talk about the disability to the new boyfriend again, you know. If I meet someone now, I would like to know that the disability of my sister is not a problem for this person. And this is how I think about it, you know..."Oh, man, I have to say it all over again". And show everything again. (...) For me, for example, it's important to know now that for my boyfriend it's not a problem, because I wouldn't want my boyfriend to divorce me if I had a ill child." [sister of a 10-year-old Ania with autism]

In the statements of the respondents there was often a fear for the necessity of choosing between a partner and caring for siblings. The respondents would never want to be put in a situation of choice. A bond with siblings and love for them is a value that should be understood by the partner. At the same time, siblings try to understand that it can be very difficult to fully accept disability for a person who has never experienced similar problems. The respondents are aware that for a partner, acceptance of disability, especially with a view to future care of a disabled person, is a heavy emotional burden.

"I am afraid how my future partner would react, if he wouldn't be against my choices... He would take a woman in a package and it is a heavy package. That's all I'm really wondering about, that's the only thing that can frighten me anyway. It is hard for me to say that I will give up my partner, but I would prefer not to leave my brother too."[sister of 38-year-old Maciek with severe intellectual disability]

In the opinion of siblings, a good partner should first of all be a good person who offers his presence, time and understanding in difficult moments. And who never forces to make a choice "either myself or a disabled sibling".

"You know, when you're 16, you probably think without stress "I'm alone and I have time". But probably when you're thirty years old and more, you get more fears, you think you're still alone, and you'll stay without parents one day. Then it would be useful to have a good person next to you who will be with you and sibling and who will understand all the problems. Because I cannot imagine being with someone who would make me choose between him or Wojtek. Because it is a brother and it's obvious I would like to have both of them."[sister of 16-year-old Wojtek with Down's syndrome]
Building close relationships is also complicated by low self-esteem, which was mentioned by the interlocutors. For some, the fact of bringing up with disabled siblings contributed to the feeling of being worse and less valuable in the opinion of the society. This in turn was connected with the belief that meeting someone and building a relationship is something beyond the reach of the respondent.

"I mean, I wanted to, but somehow I couldn't find love... I don't know why, I've tried, but I couldn't. Surely, there was a lack of self-confidence, a very low self-esteem. Such a house lowered my self-esteem, everyone knew my problems, it was harder for me. [brother of 22-year-old Angelique with Gregg's syndrome]

All respondents stated that for siblings of people with intellectual disabilities it is more difficult to enter into relationships or build close partnerships than for those who do not experience the problem of a brother or sister's disability. Difficulties in partnership particularly result from the fears of the partner's reaction on disability, uncertainty about the sustainability of the relationship, doubts if the partner's intentions are good and serious. It also results from the low self-esteem and lack of self-confidence.

3.2 Social relations in the siblings' perspectives

In social relations, the respondents emphasized that they have close, trusted people who understand their situation. They indicate that they did not have any difficulties in childhood to have good playmates, but not always friends were open to stay with their disabled siblings. Despite good social relations, the interviewees noticed the distance of others towards disabled siblings, their fear, uncertainty about how to behave in problematic situations. The key to establishing lasting friendships was understanding and openness to each other. The respondents did not feel offended if their friends openly said that they did not know how to behave in contact with disabled siblings and did not feel good in their company. They had a sympathetic attitude, arranged time away from home or explained things that were not understood by their friends. The respondents were aware of the fact that some of their friends' behaviours may be due to the fact that they had not met with the problem of intellectual disability before, not due to their bad intentions. Many close acquaintances, however, had good contact with disabled siblings with the passage of time.

"For example, I have a very good friend, but she said "I'm afraid of your Ania". I'm fine, that's fine for me. She is so nice, she understands, but she says "I don't know what to do, I'm afraid". I'm saying it's OK, so we don't have to meet Ania at home." [Sister of the 10-year-old Ania with autism].

"When I was little, my neighbor was afraid, she didn't like coming to us, because she was afraid of Maciek... she was my age. She was afraid, but my friends, for example, are not and they adore him."[sister of 38-year-old Maciek with severe intellectual disability].

It is important in making friendly social relations to prepare friends for various difficult, atypical behaviours of siblings also by treating them in a natural way. Thanks to this, the world of adolescence with disabled siblings becomes more open and understandable for others.

"But when someone was supposed to come to me, I warned this person that I have such a brother and sometimes he does strange things so that they wouldn't be surprised. (...) But generally everyone accepted it calmly, they didn't make any problems. I don't feel like I have more or less friends because of my brother's disability."[brother of 21-year-old Mateusz with Down's syndrome].

The memories, however, did not lack painful experiences. They focused on the negative attitudes of peers towards a disabled brother or sister. The interviewees remembered the attempts to exclude siblings by others, offensive comments, ridiculing. In such situations they stood up for their brother or sister, which led to conflicts with their peers, as well as to distance from the group that is not sympathetic towards

"I remember the situation when Dominic was 3 years old, I was outside with him for a walk in front of the block and younger friends pointed at him with their fingers... it was common in those times. I always stood up for him so effectively that the situations didn't happen again. [sister of 14-year-old Dominic with Down syndrome]

"These negative reactions are mainly in the backyard. I functioned a little as a defender...(...) Rafal tried to get involved in various games, so he was pushed away and tormented. So I played the role of such a defender a little bit."[sister of 44-year-old Rafal with a genetic defect].

Siblings may have a feeling of otherness in a peer group, they may not feel belonging to a group. Despite the positive attitudes of their peers, it is difficult for them to feel understood. One gets the
impression that fully able-bodied siblings faster grow up emotionally, which makes it more difficult for them to fully participate in the social life of a peer group, to joke carefree, laugh at the same things, to feel comfortable. An inner feeling of being different dominates, even if it does not result from the reaction of friends.

"I did not feel like I was part of this group at all. I was a little alone. I was able to go all the way with them, but not to talk. They said something to me, I laughed, I answered, but actually I wasn't fully present. I went out with them, but I was only such an addition to the group. And so it was for many years, all the time I felt unhappy, I couldn't find a place for myself. I wondered what was going on, I couldn't deal with them, I couldn't talk to them, because they had fun in the group, they didn't understand me."[brother of 22-year-old Angelika with Gregg's syndrome].

Having disabled siblings has an impact on the social relations of the respondents, on the selection of friends, making friends and perceiving interlocutors' own place in social life.

3.3 Contacts with local community

The biggest lack of acceptance of intellectual disabilities was noted by the respondents among strangers, people who are more distant, who do not know well or have never attempted to learn about the daily struggles of families of children with intellectual disabilities. The social stigmatization of intellectual disabilities takes various forms in the experiences of siblings: from distance, through persistent looks, to deliberate malice of the local environment. Not all glances are understood as a manifestation of intolerance, the respondents indicate that they may result from the fact of otherness, curiosity of the society and do not have to exclude friendly behaviour. Siblings grow up in the eyes of the environment with a sense of otherness, every day they have to cope with treating their family differently by the society. However, interlocutors remember also friendly reactions.

"Well, with Marta I remember staring at her with shock, observing her in the elevator. But there was such a general kindness that remained in these people. I still remember that long after my parents moved out of Warsaw, I met my old neighbors. They always asked me with great kindness how is mom, how is Marta, how is dad."[sister of 41-year-old Marta with cerebral palsy]

One respondent emphasized stigmatizing and excluding role of the peoples' gazes. She says that by experiencing these looks she learnt not to pay attention to various unusual situations, because she knows how rejected and marked a person feels when everyone is looking at them.

"In my sister's case, that's what I said before, the emotional control is disturbed. So as soon as she thought of something, not even just in the church, wherever she was, she started laughing. Nowadays, she still behaves like this, she can cry and immediately start laughing... So usually people were staring. It taught me one thing... first of all, not to worry when someone is watching you. It was an assertiveness school for me, in various areas of life - that I don't have to be like others...". When we sit in some room and somebody drops something, what does a person do instinctively? The first reaction is to look... Or someone enters and it is late, we are focused on this person... and we look. I will never do it. I feel that this is the effect of that time, that I know what a person who is looked at feels like, so I won't do it like that."[sister of 41-year-old Marta from cerebral palsy]

There was an opinion that the reactions of the society make the social integration of people with intellectual disabilities more difficult. Unpleasant reactions, which discourage social activation, take place in the public space, e.g. in a church, a restaurant or a supermarket. The misunderstanding of the problem of intellectual disability, apart from the looks, is also manifested in negative comments.

"I don't hesitate to go to different places with my brother, so I will go to an exhibition with him, I will go to the cinema, to the theatre. What I hate is going to restaurants, I hate it chronically, because it annoys me when people stare and comment and these comments can be heard. And sometimes I'm rude and tell those people what I think. [sister of 44-year-old Rafal with a genetic defect]

Because of many problematic behaviours of people with intellectual disabilities, which can affect the comfort of people living in their environment, families sometimes experience strong acts of intolerance. Instead of offering help and getting to know the situation of the family, the neighbours complain about crying, screaming and noise. They call the police, intimidate, treat the family of a child with disabilities as a problem to be solved.

"We had big problems with our neighbours, because Anna was screaming a lot at night and it was so difficult. And you don't know what you have to do with a child who is screaming, do you? When you know that you've done everything correctly, the baby is not hungry, it's not cold and you still don't..."
know what it wants and he’s still screaming... And we had a lot of violence from our neighbours (...) They knew, but Ania's disability bothered them. And they did terrible things to us, e.g. they called the police, that we beat her and that we were doing something wrong, that she was shouting so much. Then they said that they couldn't see her, that we had her locked up somewhere" [sister of the 10-year-old Ania with autism].

Intolerance of a brother's and sister’s disability does not only concern strangers, it also happens in relations with distant families and determines the whole family relationship. It happens that the otherness of one of the family members is the basis for excluding him from family meetings and taking him into isolation. The siblings once again stand in solidarity with the disabled brother or sister.

"When Arthur got married, he did not want Maciek at his wedding, he said that he did not want to. Well, because he is disabled, he doesn't like it and doesn't want to have someone like that at the ceremony. So I said that I wouldn't come either and I wasn't there. Not a good situation at all. I used to see him every day, but (...) he doesn't have any contact anymore. I didn't even meet his son." [sister of 38-year-old Maciek with severe intellectual disability].

The social functioning of the siblings of people with intellectual disabilities appears in the context of the society's reaction as a battlefield. It is a fight for treating disabled siblings in a just, friendly and tolerant way. It is a fight for acceptance of disability in the public space, its popularization, so that the families with disable children could participate equally and with confidence in the social life. Lack of acceptance in the reactions of the environment influences the sense of alienation of able-bodied siblings.

4 CONCLUSIONS

The research has shown that growing up and bringing up with siblings with intellectual disabilities have an impact on the perception of the partnership and social relations between adult siblings of people with intellectual disabilities. Entering a relationship, building partnership relations is associated with fear of being abandoned and the partner's lack of acceptance towards disabled siblings. Non-disabled brothers and sisters have a sense of emotional burden and responsibility for the future of disabled siblings. When thinking about the future and taking care of a disabled brother or sister after the death of parents, it happens that interlocutors believed that their relationships were temporary, that they would not be able to build a long-term relationship. For my interlocutors entering into relationships was stressful. It was full of uncertainty and emotionally difficult. It happens that my interviewees felt otherness and lower self-esteem. The expectations towards the partner were also different, the respondents paid attention to whether they would accept disabled siblings and they wanted to avoid a situation of choice between caring for siblings or a happy relationship. Another important issue was the sense of security and certainty that if the disability problem occurred after starting a family, the partner would be a responsible person ready to stay with the family and to love the disable child. Among the respondents there were people who experienced painful disappointments in relationships, breakups after introducing the disabled siblings, resignation from marriage due to the fact of disability in the partner's family. There were also people in happy relationships who pointed out that having disabled siblings contributes to building partnership relations full of sensitivity and mutual trust. They emphasized that they could count on the partner's support in decisions concerning the future of their siblings, and that the partner's attitude towards a brother or sister with disabilities was full of warmth and respect. This indicated a great importance of the attitude towards disability in building positive partnership relations.

The experiences of social relations were very diversified. On the one hand, the interlocutors pointed to close relationships, having good friends they could count on and understand well. Some did not notice the negative impact of adolescence with disabled siblings on social life. The respondents talked about having a group of friends who also experienced disability of siblings, what made it easier for them to laugh and cry together. Again, the problem of alienation and a sense of otherness in comparison with peers appeared. It was a difficult experience in social relations to defend disabled siblings from verbal violence of their peers, as well as to observe the isolation of a disabled brother or sister in children's games. Social exclusion and stigma were observed mainly in relation to the attitude towards a disabled brother or sister. In social life, interlocutors saw themselves as different from the group, sometimes more adult, not fully understood, but not excluded.

Equally difficult experience were the social reactions towards intellectual disabilities of siblings in the local environment. Strangers reacted with exaggerated observation, aversion. They showed their
distance, fear, and also lack of understanding. The respondents remembered views full of mercy, but also embarrassment and reluctance. They spoke about the annoyances caused by neighbours, lack of support from the society. They stressed that peoples’ sights that they felt while walking with their disabled siblings made them always feel "different".

The experiences of the interlocutors show the problem of integration of people with disabilities and their families into social life. Stigmatization of intellectual disabilities, growing up in the shadow of disabled siblings and centralization of life around their needs may have a negative impact on the self-esteem and adaptability of able-bodied siblings. The group may experience problems in social integration and in establishing close partnership relations. For this reason, it is particularly important to take action to organise support for able-bodied siblings of people with disabilities. It is crucial that these actions are regular, available and implemented since childhood, covering all stages of life. In Poland, solutions concerning support for siblings of people with disabilities are not sufficient. They are limited to informal, spontaneous actions on a small scale and initiatives of non-governmental organisations. It is proposed to organise free individual psychological support for children, young people and adult siblings of people with disabilities, as well as group forms of support based on regular meetings, workshops and trainings. It is important to create intervention and prevention programmes aimed at, among others, preventing depression and disturbance of social relations among able-bodied siblings [13]. Moreover, it is worth noting the supporting role of online support groups, which are a valuable platform for exchanging experiences and are often the most accessible and close source of information.

AKNOWLEDGMENTS

Thank you very much to all my interlocutors for their time and openness. I am aware that recalling some memories was difficult in emotional terms, I appreciate the fact that I could get to know them. Your experience has allowed me to look at many issues related to the functioning of the family of people with intellectual disabilities from a new perspective.

REFERENCES

