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OWN EXPERIENCES OF SIBLINGS OF PEOPLE WITH INTELLECTUAL DISABILITIES (IN RETROSPECTION OF YOUNG ADULTS)

Abstract

This article addresses a retrospective of siblings' experiences of people with intellectual disabilities. This paper is empirical. A review of selected literature on the circumstances of non-disabled siblings living with a sibling with a disability was conducted at the outset. The methodology of the research was subsequently described. A qualitative research strategy and a narrative interview method were adopted. Three adults who grew up in a family with children with intellectual disabilities participated in the study. The analysis of the data collected revealed that non-disabled siblings of people with intellectual disabilities were much more likely to receive parental attention. This theme is increasingly being described scientifically. However, the theoretical reflections should impact the practical aspect.

Keywords: Intellectual Disability, Family, Siblings, Retrospection

Introduction

In the social sciences, much attention is devoted to people with various disabilities, their psychosocial functioning and their quality of life. However, attention is increasingly shifting toward the support provided to their families. It is highlighted that the disability of one family member affects the functioning of the others. Being diagnosed with a disability for a child is considered to be a difficult situation and one that presents the family with many challenges. One parent sometimes decides to leave work to be able to care for a child with a disability and organise the therapy process. For many carers, it is a time involving high-stress levels and personal sacrifice. It appears interesting to learn how living with a sibling with a disability affects the development and upbringing of non-disabled children. This theme is rarely explored, particularly in retrospect, by adults who have experienced growing up and developing alongside a sibling with a disability. It is interesting to discover how their attitudes towards caring, empathy and the future need to create their own family in the face of a disabled sibling were shaped.

This article illustrates personal experiences from the perspective of young adults raised in a family where one sibling has been diagnosed with an intellectual disability. The authors intend to portray how the surveyed persons recall their childhood. Furthermore, they aim to describe the role that lived experiences have played in creating attitudes towards the need to develop one's own family.

The article is empirical in nature. At the outset, a review of selected literature on the circumstances of non-disabled siblings living with a sibling with a disability was conducted. Subsequently, the research methodology was described. To provide a reliable, detailed, and individualised portrayal of the siblings' situation, a qualitative research strategy was employed, using the narrative interview method. Three adults who grew up in a family with siblings with intellectual disabilities participated in the survey. The article concludes with cited references.

1. On the situation of non-disabled children in the face of a disabled sibling – a review of selected literature

Sibling relationships are described as inseparable and lasting the longest – from early childhood to old age (Hayden, Hastings, 2005). They have a particular role in the child's development since they serve as a means of learning and a model for future interpersonal relationships outside the family environment (Mandleco, Webb, 2015; Jurkiewicz, 2017, 39). During their childhood, sisters and brothers were each other's playmates, best friends, teachers, and carers, and they supported each other. They learn to cooperate, share, help, care for themselves and others, and achieve their chosen goals (Twardowski, 2011, 92).

Relationships between siblings are essential for those in such a relationship (Meltzer, Kramer, 2016). In the literature describing the issues of people with disabilities, the situation of siblings of people with disabilities is considerably less frequently presented. Moreover, the focus is mainly on the parents (Moraczewska, 2008, 289). Satisfactory interpersonal relationships, a positive emotional environment, and close bonds can prevent the family from being disorganised when a child has a disability (Stelter, 2014). It is essential to discover what a sibling of a person with a disability feels and experiences — how relationships between them are nurtured, as the sibling will interact with and be influenced by all family members, including their sibling with a disability (Hayden, Hastings, 2022; Minczakiewicz, 1999, 28). Importantly, it is the non-disabled sibling who is positioned as the solution to future care needs for siblings with disabilities (Leane, 2019).

The psychosocial situation of siblings of persons with disabilities has been described in two distinct ways in the literature (cf. Hayden, Hastings, 2022). On the one hand, it is disadvantageous because this group may experience emotional issues, aggressive behaviour, stress, anxiety and a nagging sense of obligation to look after a disabled sibling in the future (Marquis et al., 2019; Sidor, 2005, 71, after: Jarzębowska-Baziak 1973). Such consequences have long been noted in the literature (Galkowski 1979; Berling, Sowa 1983; Seligman, Darling 1989, 123; Lausch-Zuk 1993, 1999; Koscielska 1995; Kruk 1996; Obuchowska 1999). On the other hand, being raised with a sibling with a disability is perceived as a positive experience because it teaches empathy, responsibility, and support and deepens bonds (Hayden, Hastings, 2022; Richardson, Jordan, 2017). However, it is inarguable that much of the research on siblings with intellectual disabilities positions the healthy sibling as the giver of support and the person with the disability as the recipient in this relationship (Hayden, Hastings, 2022).

When a child has a disability, the family focuses mainly on the disabled child, forgetting about the needs of the non-disabled child (Szarecka, 2013, 77). Consequently, the child may feel anxious and lonely, believe they are unimportant and neglected by their parents, and have poor relationships with their family. Negative consequences of having a sibling with a disability also include isolation from friends and peers and giving up social life for fear of ridicule and stigmatisation. A non-disabled child may be accompanied by shame that a sibling is not developing correctly. This generates difficulties in making social contacts in the future. Concerning their sister/brother with a disability, non-disabled siblings may feel grief, anger, and jealousy for their parents' attention, accompanied by a sense of injustice as to why it is they who have suffered the disability in the family.

Sometimes, parents want the non-disabled child to compensate for the other offspring's disability and impose exorbitant demands on them. Often, achieving them proves to be beyond their strength and capabilities. This exacerbates the sense of uselessness in the family and the feeling of having insufficient achievements to deserve

parental recognition. Satisfying high expectations sometimes requires neglecting the desires and passions of the non-disabled sibling. This includes an increase in the number of duties to assist in the daily functioning of a disabled sister or brother. According to B. Sidor (2005), parents require an attitude of forbearance from their non-disabled children towards their disabled siblings and place the work and responsibilities on their typically developing offspring. From an early age, children are urged to look after a sibling with a disability, take them to school, do rehabilitation exercises, etc. This is a huge burden for children as they must quickly become a 'little adult'. The consequence is a truncation of their carefree childhood in favour of accelerated maturity and responsibility for disabled siblings (cf. Hayden, Hastings, 2022).

On the other hand, some researchers note that having a sibling with disability stimulates the development of non-disabled children and allows them to acquire skills that are unavailable in families without an offspring with disability (Walęcka-Matyja, Przybylak, 2013, 71). A child's thoughts and feelings about their sibling with disability are shaped mainly by their parents and their behaviour. Children learn by imitation, so if they see their parents referring to their disabled child respectfully, they too will respect them (Jóźwik, 2016, 137). According to Stelter (2014), the more positive feelings the non-disabled person shows to their siblings, the less negative emotions and more acceptance they experience from their mother. A study by Konuk, Doğru, and Temel (2013) illustrates that the Sibling Education Programme (SEP) reduced aggressive behaviour towards the disabled sister/brother and an overall positive change in attitudes towards them.

The presence of a disabled sister or brother shapes positive qualities such as tolerance, maturity, sensitivity, gratitude for one's health, and compassion (Church, 2021, 185). It can also contribute to the development of altruism and social engagement. People who have siblings with disabilities grow up faster and are more responsible. It is also indicated that close bonds between siblings with and without disabilities influence increased levels of empathy in the former group (Friedman, 2017, 3, after: Benderix, Sivberg, 2007; Cate, Loots, 2000; Hannah, Midlarsky, 1985; Lobato, 1983; Stocker et al., 1997).

Families with a child's disability have an increased need to provide psychological support (Kruś, 2018, 77). In many cases, the dominant type of family support is that of the other children (Zyta, Ćwirynkało, 2014, 63). This leads to a frequent question in the lives of siblings of people with disabilities as to what will happen to the brother/sister in the future. There are instances when parents require a declaration from a non-disabled sibling that they will take care of their sibling when they (parents) pass away or do not have the strength to care for their child. Disregarding their children's plans and dreams, they expect them to look after their brother or sister for life. Since there is a high level of involvement in caring for a sibling with a disability, the support needs of the non-disabled sibling may increase (Arnold, Heller, Kramer, 2012,

374). Siblings may face constant anxiety concerning the future of their siblings with disability and their own lives. Deciding to care for siblings in the future involves questions, dilemmas, doubts and fears regarding the possibility of pursuing one's life plans. From the moment the parents are unable to care for the disabled brother or sister, the person is dependent on the non-disabled sibling who, on the one hand, may not want to give up the sister/brother to a social care home and, on the other hand, is afraid of what life will be like with a disabled sibling by his or her side. Non-disabled siblings may be troubled by questions such as: will they be able to cope with the role of carer? Will it affect them starting a family? Will they find a partner who accepts the situation they are in? (Kościółek, 2021).

Having a sibling with a disability has positive as well as negative effects. It can result in the development of higher levels of empathy, tolerance, and altruism, as well as all sorts of emotional problems, feelings of loneliness, and constant fear for the future of the sister or brother. The education of non-disabled siblings and the support provided by professionals early in life can support their acceptance of their situation, understanding the causes of their behaviour and the emotions they feel, and mitigating their adverse effects.

2. Methodology of own research

For this article, research was conducted using a qualitative research strategy. A case study method with narrative interviews in retrospect of three adults who were raised with siblings with intellectual disabilities was employed. The subject of the research was a personal experience from the perspective of siblings of people with intellectual disabilities. The study aimed to describe the experiences of non-disabled siblings. The main research question was established: "In retrospect, how do young adults recall their childhoods when faced with a sibling with an intellectual disability?" Specific questions were also developed:

1. How did the respondents learn about their sibling's intellectual disability?
2. Were respondents involved in caring for a sibling with a disability? If they were involved, what would the help be?
3. From the perspective of young adults, how were relationships with parents during childhood when faced with siblings with intellectual disabilities?
4. In retrospect, how do young adults describe their relationships with their intellectually disabled siblings during childhood?
5. How do young adults recall peer relationships and psychosocial life during childhood in the presence of a sibling with intellectual disability?
6. From the respondents' perspective, what was the support system like for them in terms of growing up with a sibling with intellectual disabilities?

7. In retrospect, what role did growing up with a sibling with an intellectual disability play in the life of young adults?
8. From the perspective of young adults, does having a sibling with an intellectual disability determine their future life plans?

The respondents' selection was purposive. They agreed to participate in the interview and were informed of the anonymity of the process. Three people were surveyed, and each survey lasted approximately an hour.

Zuzanna, aged 21, was the first respondent—a third-year special education student. The respondent has a five-year-old sister with intellectual disability due to cerebral palsy (she attends a special school). During the week, the respondent lives in a dormitory and, at weekends, goes to her sister and parents, who share a household. The respondent has a partner who originates from her hometown; they have been together for three years.

Dariusz, aged 24, was the second respondent — a part-time IT *project management* student. He works as an *account manager* for a company that is Poland's largest gadgets distributor. He comes from a complete family. He has a twin brother with an intellectual disability who goes to school. The respondent also has a sister, aged 31, who works in a shop. The respondent lives independently.

The third respondent was Lidia—Dariusz's sister—who already has her own family, a husband and two children. She has a secondary education and works as a saleswoman in a supermarket.

3. Analysis of respondents' replies

The main question concerned how respondents retrospectively recalled their childhood in the context of a sibling with an intellectual disability. The in-depth questions were designed to obtain a complete overview. The first concerned how respondents became aware of a sibling's intellectual disability.

Zuzanna recounted it as follows: *I have no idea when I found out about it. I have a feeling that from the beginning when she came out, my parents told me she was ill. I don't remember a key moment or a particular situation.*

Moreover, as a child herself, Zuzanna recognised the abnormalities in her younger sister's development and the resulting problems for her parents: *When she was tiny, I couldn't notice anything except that she cried a lot. She was tiring for my mum, so I tried to relieve her as much as possible. Mum could not let her out of sight and constantly had to carry her in her arms. Later, when my parents started to go to the doctor, I noticed that she was pretty big, lying down all the time and not moving at all, not turning to the side. Her hands clenched into fists the whole time, giving me food for thought.*

Dariusz, on the other hand, as a twin, independently noticed the differences between his own and his brother's development: *I don't know, to be honest; it happened*

by itself; while growing up, I found out what was happening. It is possible that it was in my pre-school years that I found out what was going on. I don't remember particular situations; if there was one, it was also during this 4-7-year period. [...] Saying. He spoke worse than me, but I never thought he was different, just sick.

Lidia also noticed that her younger brother was not developing correctly, recalled as follows: *At four or five, my brother was still speaking his way despite doctors' assurances that he still had time to do so. This already seemed suspicious to me. Although he understood everything that was said to him, he could not express himself, which made me think he was different. I do not remember the specific conversation.*

The second in-depth question focused on whether respondents were involved in the care of their disabled siblings and, if so, what help they received.

From the interview with Zuzanna, it is clear that, in her view, she was primarily a carer and mother to her sister: *I was significantly involved in my sister's care from an early age. I had to look after her because my parents worked, so I spent practically all my time with her. There was a time when I spent so much time with her that if my sister said something to my parents, I had to explain to them what she was saying because they didn't know her speech, and I was their dictionary. I remember that the most painful moment for me was the holidays because my mum was working and it was in the afternoon, so from 1 pm to 9 pm, we were alone. Dad worked not far from where we lived but was not at home all day. So I watched in despair as my friends played hide and seek and ran around the village, and I had to look after her and sit at home with her. It was challenging, and then a considerable anger built up in me. Sometimes, I would go out with her and my friends, but we often played hide-and-seek, for example, and then you had to run fast. My friends didn't want to adjust too much to me being with my sister, so I had to adapt to them. So I couldn't play with them because she couldn't run that fast.*

Zuzanna recalls that for some extended period, she and her sister shared a room and a bed. She recalls this as follows: *We used to share a room for about 5-6 years. At one point, we even slept in the same bed together. I was 11 then, and it lasted for about 3-4 years because the situation forced us to do it. Then, I felt that I was with her 24 hours a day, looking after her all the time like a second mother.*

Zuzanna did not complain to her parents. It seemed her parents knew she felt uncomfortable about caring for her sister and sharing a room and bed. Still, they were unresponsive, even avoided the subject and made no attempt to resolve the problem: *I remember that I didn't speak, but I thought they could see it. It's just that they don't want to talk about it, preferring to keep it quiet.*

Dariusz was also involved in his brother's care, but to a much lesser extent: *Yes, I was involved. For example, sometimes I stayed with him, although he prefers to be wherever his parents are. He has been dressing himself since he was little and has no problem. Sometimes, we played football on the pitch outside the house or hide-and-seek in the nearby spruce forest.*

Lidia, on the other hand, believes that she was not over-involved in the care of her brother with a disability (nor the other brother, either). Her central role as an older sister was walking her brothers to school daily. However, as she emphasised — she was not happy about it. She described it as follows: *It certainly bothered me because my brothers and I were very different in age, and there was never a close bond between them. I took my brothers on walks.*

The respondent recounted that there were times when she played with her brother with a disability among her peers, but such situations rarely occurred.

The third in-depth question concerned how, from the perspective of the young adults, the relationship with their parents during their childhood when faced with a sibling with an intellectual disability.

Zuzanna described her relationship with her parents accordingly: *It wasn't easy. I had the feeling that I was a shadow. I didn't get as much attention as my sister. Well, I tried to direct that attention to myself in some way. I studied well and tried always to be the best in class and school so that they could be proud of me and that they had something to praise. There were brief moments when they paid attention to me. For example, at the end of the year, the certificate with a distinction, the joy of the parents, "Fantastic, we are so proud", but in a moment, we were back to reality, and it didn't reverberate much. Later, they got used to me studying well, so I would have to achieve spectacular results for them to notice. I remember there was a moment when I was a little girl, and at one point, I came to my mother and asked her, "Why am I even alive"? I was about eight to ten years old at the time, maximum.*"

The respondent recalls that her mother tried to comfort her somehow, but she did not remember the words she used. She found no solace or support in her words. She told her parents about the unpleasantness she faced from her peers: *I think I told them about it, although it was difficult for them too. They kept telling me not to worry, that I would get over it. Children have this way of getting fixated on someone for a while and then making fun of someone else.*

Speaking about his relationship with his parents, Dariusz mentioned that he tried to focus their attention on himself: *When I was younger, I was rude and even more badass when it came to getting attention. It was effective because a naughty child needs to be calmed down [...] In the beginning, more time was devoted to my brother. I understood that, and for me, it was fine. From what I remember, my relationships with my parents were okay.*

Lidia described her relationship with her parents: *More attention was paid to my brother. I drive to doctors, do medical tests, take classes, etc.*

When asked how she felt about the fact that her brother was the focus of most of her parent's attention, she replied: *I didn't pay much attention to it and knew I couldn't change that. I was focused on my business, school, and studying.*

Respondents were also asked how, in retrospect, they described their relationships with their intellectually disabled siblings during their childhood. Zuzanna answered this question most comprehensively. The respondent believes she has had a close relationship with her sister from the beginning. At the same time, these do not bear the hallmarks of a typical sister relationship or, rather, a mother-daughter relationship: *My sister mainly spends time at home. Her parents are such that I don't think they would let her go anywhere. Optionally, she has a friend nearby, but the whole family visits him and his parents. We mainly spent time playing, for example, at home. She is 17 but still interested in toys. The worst thing is that she often doesn't want to play with me. She is a loner, but she likes to walk, so sometimes we walk together, go out with the dog, and do something in the garden.*

The other two respondents felt that they had a correct relationship with their sibling with intellectual disabilities, which they thought meant visiting their brother and providing assistance when needed.

The subsequent in-depth research question concerned the psychosocial functioning of the respondents during childhood in the presence of siblings with intellectual disabilities.

When asked about her relationship with her peers, Zuzanna recalls such a story: *The most significant moment for me was primary school. I was showing a kind of rebellion because I started to notice this disability more, and I was ashamed of it because of being teased about it at school. For example, there were times when people who lived in the same village would play a game called 'the plague', meaning whoever I touched would get infected. I think it was about disability. It was painful for me, very much so. I perceived it as not being accepted by the social group and the immediate environment very personally.*

The respondent then describes the accompanying emotions: *At first, this shame turned into hatred and aggression. I asked myself why I was the one with a sister like that and was angry with her for being like that. Later, these feelings began to fade, and I just accepted her. I ignored what others around me said; I accepted her fully. There were also times in middle school, for example, when I was mocked that my sister was going to school number four (special school), and it hurt me a little, although I didn't care too much.*

Dariusz, on the other hand, had a different experience: *Peers wanted to help somehow but couldn't; everyone has more significant or minor problems to deal with. Telling the story of his disability brought tears to my eyes. Knowing that it was a mild intellectual disability, I was able to live with it.*

The respondent felt that he had had different experiences but had not witnessed unpleasant incidents from peers.

Talking about relationships with her peers, Lidia mentioned that she would not want others to know that her brother has a disability: *At first, I felt as if I wanted to hide it. It was the 4th, or maybe 5th, grade of primary school. Later, it was known that this*

had not always worked out. But there was no situation where anyone laughed at it. On the contrary, my brother was liked by my peers.

The parents were unaware of Lidia's emotions that she felt shame and even anger at times: *In front of my peers, I felt anger about why this happened to me and I didn't have a fully healthy brother.*

A further in-depth question explored what the respondents' perspective was of their support system about parenting with an intellectually disabled sibling.

Susanna recalls that she did not have a supportive person in her life to care for her younger disabled sister. She felt lonely. Dariusz said the closest person he could talk to was his grandfather: "The best contact I had was with my grandfather, and he was the one I trusted the most." Lidia recalled experiencing annoyance when her brother was ridiculed by his peers for not being able to speak. She did not mention this to her parents. She did not want to burden them with this and did not expect any support from them. She had a friend whom she confided in: *I had a friend in my school days. She gave me the support I wanted and needed.*

The final two in-depth questions explored the role that, in retrospect, growing up with a sibling with intellectual disability played in the lives of those interviewed and whether having a sibling with intellectual disability, from the perspective of young adults, determined their future life plans.

Zuzanna considers her relationship with her parents to be very unhealthy, and she is unable to separate herself from them: *From Monday to Thursday, I live in the dormitory, and for the rest of the days, I go down to the house and spend the whole weekend there. It was terrible. I always say that I have this unhealthy bond with my parents, which is that I feel like the umbilical cord hasn't been cut all the time. The very fact of the change of environment and the fact that everything was new and unknown to me there. I didn't have friends there because it was the early days of university. I experienced it very severely. I cried a lot. I kept calling home and saying that I wanted to go back, but I didn't get the support I hoped for from them. I was told all along that it would be fine. "Don't exaggerate; it's not that bad at all." I preferred to hear that they understood me.*

The respondent also has problems separating from her sister. She felt as if she was leaving her when she left for university: *I had to adapt to a new situation. This went on throughout my second academic year, and it wasn't until my third year that I overcame these breakdowns. It was challenging for me. I am very connected to her, very close to her. We talked every day, so it wasn't easy. I felt a profound sadness, a huge sense that something was missing, that a part of me was missing. I was heartbroken. It's fine now, and sometimes I'm glad I'm going to university because I feel like I need to rest. I'm here at home, sometimes depressed and overstimulated. This is also linked precisely to my sister. I have the impression that she has become a bit disengaged from me. We are no longer as close as before, and I would still like to spend a lot of time with her, but sometimes I get emotionally tired. I also think a lot and fear what will happen after her death. I think like*

that now, and when I go to university, I cut myself off from those thoughts; it helps me. [...] I feel that because my sister is a person with a disability, I have chosen this field of study. You could say that my parents chose it for me, but I feel that this is it and that I am fulfilled in it and like it. Increasingly now, in this adult life, I find myself with emotional problems. I have great sensitivity. I am a person who takes everything very personally. I think a lot about death, for example.

It is not easy for Dariusz either after moving away from home, but he realises that it would be difficult for him to develop educationally in his hometown: *It's hard, I miss them, but it's hard to develop educationally in the countryside.*

Darek also recognises some of the benefits of having a disabled person in his life: *I've certainly learnt soft skills, such as empathy. I am more understanding of people who have any problem, not just disability-related. This allows me to be a good project manager in the future.*

Lidia moved out of her home at the age of 22. She says she experienced the moment very well. At first, she missed her brother with a disability a little but quickly got on with her own life. She now sees his brother almost every day, sometimes two hours and sometimes five. She believes that having a sick brother has not affected her current life in any way.

Respondents certainly include the presence of a disabled sibling in their life plans while feeling slightly anxious. Dariusz said: *I can't imagine not helping him. I am ready to support him.*

Lidia admits that she sometimes has a sense of anxiety about the future: *What will it be like when the parents are gone later? Someone will have to take care of him. Me or my brother?*

Based on the interviews, Zuzanna seems to be the most mentally burdened. She finds it difficult to project her own future. The respondent approaches it through the lens of her sister's needs and her parents' expectations rather than her own dreams or aspirations.

Concerning motivation, it is worth noting that Zuzanna has taken part in the study because she wanted to highlight, through her speech, the difficulties that affect siblings of people with intellectual disabilities. Dariusz, on the other hand, admitted that this was his first time talking so openly about the problems he had suffered as a child. Afterwards, Lidia revealed that being interviewed was not easy for her, as she does not like to talk about herself.

Findings

The following conclusions can be drawn from the research carried out:

1. Respondents had already noticed their siblings' disabilities as children. They do not recall discussing the subject with their parents, nor were they directly

informed or prepared by them for information about the diagnosis and its implications. This may indicate that parents of non-disabled children are not aware that they may need such a conversation. Moreover, it may mistakenly appear that children can perceive what is happening and that it is not advisable to talk to them and explain.

2. Respondents were involved in helping their siblings to varying degrees. One respondent was involved in helping her younger sister to such an extent that it took on the character of taking over adult functions and exploitation. The other two respondents did not feel that they were as preoccupied with caring for their disabled brother – it was more like support given to a younger sibling. From the interviews, it can be concluded that parents find it challenging to organise and reconcile the care of a child with a disability and their non-disabled siblings. Sometimes, healthy siblings are exploited in extreme ways. It also happens to the contrary that non-disabled children are not exploited to care for their disabled siblings. However, they are given less time and feel less important, alone, and unwanted.
3. Respondents felt that, as children, their parents' attention was more focused on siblings with disabilities. In the case of the respondent, who had a younger sister with an intellectual disability, there was a lack of support; as a child, she felt invisible, unnecessary and unimportant. The respondent thinks these bonds are toxic for her, and she remains entangled in the relationship. Moreover, she cannot become independent, autonomous and free. In contrast, in the memories of the male respondents, neglect was also present in the child-parent relationship. The respondent recalled that he tried to focus his parents' attention on himself through naughty behaviour that needed correcting. At this point, the respondent finds living with the fact that he has left the family home challenging. However, he has decided that this is the best solution for him. The third respondent felt she needed to focus on herself. Simultaneously, she thinks that she cannot ask her parents for any help in dealing with her problems due to their custody of her brother with a disability. From the perspective of those already adults raised with siblings with intellectual disabilities, the relationship with their parents was burdened by the constant stimulation of anxiety about the health of a brother or sister. Moreover, a sense of loneliness in the relationship with the parents was noticeable in each subject.
4. An emotional bond has been established between the subjects and their siblings with intellectual disabilities. However, it has different dimensions. In the case of the student interviewed, the relationship between her and her sister goes far beyond a sisterly bond, more like a mother-child relationship. The respondent has problems leaving her sister and difficulties creating her own life and planning a family. In contrast, the respondent feels that he has a close relationship

with his brother, and it is a brotherly bond. Their older sister seems to be the least emotionally connected to her brothers. However, her brother, with intellectual disabilities, is in her house almost every day and is treated simply as a resident. It seems that creating a healthy relationship between non-disabled and disabled siblings is a complex and challenging process.

5. Respondents' stories included memories of being bullied and ridiculed by peers due to the presence of a disabled sibling in the family. Children who have siblings with intellectual disabilities are at risk of rejection and feeling isolated in their peer group. They are also more sensitive to social judgement and take the behaviour of others more personally.
6. Respondents talked about the support they received during their childhood. It can be observed that providing support to non-disabled siblings is also difficult: either there is no or minimal support, and it is obtained from outsiders (e.g., a friend).
7. Growing up in a family with siblings with intellectual disabilities, from the respondents' perspective, developed higher levels of empathy, understanding and patience. It is noticeable that this complex (family and health) situation and the experience gained impinge on future planning. People who have siblings with intellectual disabilities are afraid to create their own families; they harbour fears about whether their life partners will accept the situation; they feel obliged to care not only for their parents but also for their disabled siblings.

Summary

Siblings with a brother or sister diagnosed with a disability should receive exceptional support and pedagogical and psychological assistance. Furthermore, such support would have to be provided to the parents — because it is the parent's behaviour, values, and emotions — that will largely determine the environment in the family. What professionals can do for non-disabled siblings is to make parents aware that all their children should receive as much support as they need and that non-disabled children should not be left to fend for themselves. Parents mustn't burden non-disabled children with the care and responsibilities associated with a disabled sibling. A distinction should be made between teaching the child to be caring and supportive towards his/her brother/sister and imposing a fixed care schedule. Childhood is a time of learning, fun, and carefree play through which courage, self-esteem and confidence are formed in the child. It is essential to take care of the mental condition of non-disabled siblings from childhood onwards, as they confront many social difficulties (and more). Moreover, "they will enter adult life with everything they received in childhood".

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