



„Wychowanie w Rodzinie” t. XXXI (2/2024)

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## Selected aspects of the functioning of siblings of blind children

### Wybrane aspekty funkcjonowania rodzeństwa dzieci niewidomych

#### Abstract

**Introduction.** A contemporary approach to disability cannot focus solely on the disabled persons themselves, without reference to the wider context in which they function. Blind children are constantly and continuously affected by their family environment, which shapes their attitudes towards themselves and others. As the family is a united system, the relationships between non-disabled and disabled siblings affect other members of the family. Typhlo-pedagogical literature is rather poor in studies related to the experiences of blind children's siblings. Meanwhile, the issue is worthy of attention because of the specific situations arising from both being a brother or sister of a blind child and being part of the family system.

**Aim.** The aim of the article is to emphasise the need for an in-depth look into the functioning of siblings of children with visual impairment.

**Materials and methods.** The text is a theoretical overview based on an analysis of Polish

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and foreign source publications.

**Results.** Awareness of the needs of siblings of visually impaired children can deepen the insight into the functioning of a family which a blind child is a member of. Learning about the perspective of sighted brothers and sisters may accentuate certain issues that have yet to be comprehensively tackled by contemporary typhlo-pedagogy. A positive effect might be the enhancement of knowledge of visual impairment and its consequences, as well as the improvement of educational and rehabilitation practice, as the acquired knowledge should help develop clear guidelines for providing interaction support to siblings from the earliest years of life.

**Keywords:** blind child, siblings, family.

### **Abstrakt**

**Wprowadzenie.** We współczesnym podejściu do niepełnosprawności błędem jest skupianie się jedynie na samych osobach z niepełnosprawnością bez odniesienia do szerszego kontekstu ich funkcjonowania. W przypadku dzieci niewidomych środowisko rodzinne oddziałuje na nie w sposób stały i ciągły, kształtując postawy w odniesieniu do siebie i innych. Ponieważ rodzina stanowi jeden system, stosunki między pełnosprawnym i niepełnosprawnym rodzeństwem wpływają na pozostałych jej członków. W literaturze tyflopedagogicznej można zauważyć deficyt opracowań dotyczących problematyki przeżyć rodzeństwa dzieci niewidomych. A tymczasem ich sytuacja warta jest pogłębionego spojrzenia z uwagi na swoją specyfikę, zarówno bycia bratem czy siostrą dziecka niewidomego, jak i częścią układu rodzinnego.

**Cel.** Celem artykułu jest zwrócenie uwagi na potrzebę pogłębionego spojrzenia na funkcjonowanie rodzeństwa dzieci z niepełnosprawnością wzroku.

**Materiały i metody.** Tekst ma charakter teoretyczny, poglądowy, oparty jest na analizie źródłowej publikacji polskich i zagranicznych.

**Wnioski.** Wiedza na temat potrzeb rodzeństwa dzieci z niepełnosprawnością wzroku może pogłębić spojrzenie na funkcjonowanie rodziny, której częścią jest dziecko niewidome. Poznanie perspektywy widzących braci i siostr może zwrócić uwagę na pewne wątki jeszcze nieobecne lub szczątkowo obecne we współczesnej tyflopedagogice. Może to zarówno przynieść pozytywne efekty w aspekcie wiedzy na temat niepełnosprawności wzroku i jej konsekwencji, jak i ulepszyć działania z zakresu praktyki edukacyjno-rehabilitacyjnej, dając konkretne wytyczne dotyczące wspomagania wzajemnych kontaktów między rodzeństwem już od najwcześniejszych lat życia.

**Słowa kluczowe:** dziecko niewidome, rodzeństwo, rodzina.

## **Introduction**

In the contemporary approach to disability, it is impossible to focus only on people with disabilities themselves without reference to the broader context of their functioning. In the social model, disability is primarily a result of the interaction between the person and the environment in which they live. With regard to children, this is primarily the family, peer and school environments. The family environment interacts with the child in a constant and continuous way, shaping his or her attitudes towards self and others from an early age. And it is in this environment that the non-disabled child encounters his or her brother or sister's disability for the first time. This is usually not an easy situation for him or her, having to deal with all sorts of negative emotions, activate ways of coping with a difficult situation, find ways of meeting his or her needs and sometimes find his or her way back into the family. As the family is a single system, the relationship between siblings without disabilities and siblings with disabilities affects the other members of the family, and can either support or interfere with the process of its proper functioning.

There are still few studies in the literature on the experiences of siblings of children with disabilities. Often, studies discuss the situation of parents (mainly mothers) in detail, neglecting other members of the family system, or talk about the functioning of the family without analysing the fate of individual family members. Meanwhile, the position of brothers and sisters of children with disabilities is worth an in-depth look because of its specificity. First of all, sibling relationships may last the longest compared to other family relationships, are built on a common genetic, social and cultural heritage and are based on shared experiences (Pisula, Danielewicz, 2007). Children with disabilities do not so much experience different emotions and feelings in relation to a family member's disability than adults, but have different capacities to exercise control over them. First of all, adults have a greater awareness of feelings than children. They also usually have developed coping strategies and, although sometimes these strategies fail in part, they can rebuild or modify them so that they continue to be helpful. Adults also have a greater knowledge of what help is available and easier access to self-help groups (for example, support groups organised for parents of children with a particular type of disability) or to publications dealing with issues of functioning in the face of a child's disability.

Having a sibling undoubtedly influences the functioning of a child with a disability as well as a non-disabled child. For a child with a disability, the relationship with siblings enables the formation of the first interpersonal bonds outside the parents, modelling ways of establishing and maintaining contact with peers. As far as the importance of having a sibling with a disability is concerned, the impact on non-disabled children in the family cannot be clearly stated. On the one hand, having a brother or

sister with a disability can entail a number of disadvantages, such as not having their parents' need for attention met, feeling less loved by them. At times, it can cause a sense of loneliness, isolation from peers or affect the realisation of one's own life path by having to include the care of a brother or sister in one's plans (Zyta, Ćwirynkało, 2014). On the other hand, however, having a sibling with a disability is an experience that can shape social skills, as well as qualities such as, for example, sensitivity, tolerance, the ability to cope with stress and social involvement (Wojciechowska, Cierpka, 2007).

For their brother or sister with a disability, the non-disabled sibling is not only a colleague, playmate and friend, but also the best teacher, nanny, carer, tutor, interpreter, therapist, and sometimes has to take on the role of mother and father as well (Moraczewska, 2008, p. 291).

The role of non-disabled siblings in rehabilitative parenting is significant, so it is worth paying attention to their needs and identifying opportunities to meet them.

## **Experiences of non-disabled siblings**

When younger siblings are born, the child experiences a variety of emotions and feelings – fear of losing their parents' interest, jealousy of the time they spend with them, uncertainty about how the family will continue, sometimes disappointment with a brother or sister. These coexist with positive emotions and feelings – interest in siblings, joy at the expectation of having a playmate, pride at becoming a big sister or big brother.

A frequently experienced feeling related to a loved one's disability is anxiety, which is usually about the future. Fear of the future can be reduced, for example, by observing the child's progress through the stages of development. In the case of a child with a disability, however, this is difficult as his or her psycho-physical development, especially at the beginning of life, is somewhat delayed. Such anxiety can also be alleviated by observing the behaviour of others, e.g., children with a similar problem attending early childhood development support classes. Parents, by being around other parents and their children with disabilities, taking part in activities together, can reduce their anxiety. Meanwhile, it is rare for a sibling of a child with a disability to participate in such activities. They cannot rely on the predictive power of their brother's or sister's development from observing other non-disabled children around them, and they lack the opportunity to observe the progress of children with the same disability as their sibling, making it difficult for them to reduce their anxiety levels.

Full siblings with disabilities often have a sense of loneliness. This can be associated with low self-esteem, high levels of social anxiety, feelings of alienation. Children need the presence of others, their help and attention. This is the basis for forming a sense of belonging to the social world, bonds with close people, relationships with peers and adults. Already in the first months of life, children exhibit innate bonding behaviour, such as smiling, clinging and crying. In later years, the need for contact does not diminish, although it takes on different forms. In a family with a child with a disability, most of the care effort is directed at the child, which may result in a narrowing of the caregiving function in relation to the non-disabled sibling. Also, the emotional bond with the parents may be disrupted, manifested, for example, by the parents' apparent emotional indifference due to a noticeably greater focus of attention on the problems of the sibling with a disability or their lesser availability, especially in the first months after the child's birth. And even if the biological needs of the non-disabled child are met at these moments, psychological needs may be unmet (Yurkiewicz, 2017).

A feeling experienced by non-disabled siblings is also shame which is a highly destructive emotion. The subject's attention when experiencing shame focuses on the whole self, blocking the desire to take corrective action, instead leading to confusion and passivity (Lewis, 2005). When feeling shame, the person focuses on how others judge him or her, often accompanied by a sense of powerlessness, hopelessness, causing a desire to run away, withdraw and hide. Long-term feelings of shame can be adaptively harmful (Kleszczewska-Albińska, Albiński, 2009). Because children feel shame, they avoid talking to anyone. As Joanna Konarska (2019) writes in relation to siblings of blind children, they also cannot rely on similar experiences of classmates, as these are unlikely to have a sibling with a visual impairment. Sometimes, moreover, they are rejected by their peer environment because of having a blind brother or sister, which they see as a humiliation and sometimes blame their siblings for this. Despite the fact that they do not receive help in the family, peer or school environment, they cope because they cannot do otherwise. However, they may feel a sense of rejection and although they make attempts to compete with their siblings with disabilities, they have little chance of achieving their goals (Konarska, 2019).

It is worth noting that researchers agree that a good relationship between a non-disabled child and a child with a disability is influenced by the overall atmosphere in the family, i.e. appropriate parenting attitudes, an atmosphere of love and acceptance, emotional closeness between parents and children, and open communication. Especially in early childhood, relationships between siblings are formed through the parents. Appropriate parental attitudes towards the child with and without disabilities, acceptance of the otherness of the child with a disability are treated as role

models and have a positive impact on sibling relationships (Wyczesany, Ucinyk, 2000). A subjective, individualised approach to all children is extremely important for the proper functioning of the whole family. However, it is sometimes the case that parents focused on the child with a disability count on the non-disabled child to compensate for their disappointed ambitions. This causes them to place exorbitant expectations on him or her and to want total subordination, even at the expense of the child's self-fulfilment. This attitude can cause feelings of hurt and antagonism between siblings (Stelter, 2011).

### **Siblings of a blind child – research, theory and practice**

Analysing the Polish and English-language literature, it can be seen that the problems of siblings of children with disabilities and chronic illnesses have received rather little attention, and with regard to children with visual impairment there are very few such publications. And although some problems are common across disabilities, some are due to the specific nature of visual impairment and require an individualised approach. For example, unlike people with moderate and severe intellectual disabilities, visually impaired people do not usually need constant care during their lifetime. There is therefore often no need to expect a non-disabled sibling to take over their total care in the event of their parents' death or old age. Unlike chronic illness, visual impairment is rarely progressive (except for the group of people with unstable low vision). At the same time, however, a specific problem of blind children is, for example, difficulties with non-verbal communication, which makes it difficult to establish contact especially between children at a younger age, who rely less on spoken words and more on non-verbal messages. The results of a study by Maria Elvira de Caroli and Elisabetta Sagone (2013) highlight the need to individualise the approach to sibling relationships in terms of different disabilities. The scholars studied adolescent siblings of people with autism spectrum disorders, intellectual disabilities and Down syndrome. The research confirmed the hypothesis that siblings of people with autism show more negative attitudes than siblings of people belonging to the other groups, and rate themselves worse in the role of brother/sister than the others. Also, representatives of this group were most likely to feel that their brothers or sisters were a burden on the family. Also looking to the future was the least optimistic – they expressed concern that rehabilitation might not lead to independent functioning. The researchers explain this by the peculiarities of the functioning of people with autism, i.e., the lack of social reciprocity, limited or completely absent communication skills and the presentation of numerous stereotypical behaviours.

Research focusing on risk and protective factors influencing the adjustment of siblings of children with chronic disabilities has also provided interesting results. Based on these, it can be concluded that factors such as marital satisfaction, absence of parental depression, a cohesive family and warm, non-conflictual relationships with siblings have a protective function in relation to siblings with Down's syndrome (and siblings of children with normal development as a control group), but do not improve the situation of siblings of children with holistic developmental disorders. It is therefore difficult, according to the researchers, to expect that in every case the presence of protective factors will have a positive effect on the siblings of a child with any disability (Fisman et al., 1996). A very interesting study involving sibling relationships when one is a child with a disability was carried out by Carlijn Veldhorst, Anna Luijmes, Sabina Kef, Mathijs P. J. Vervloed, and Bert Steenbergen (2023). They carried out analyses in relation to different disabilities, among other things, they identified statistically significant differences between siblings of children with visual impairments and a control group, which consisted of children with visually non-disabled siblings. In terms of sibling relationships, these appeared to be closer in families where there was a child with a disability (including visual impairment). Siblings of visually impaired children showed more pro-social behaviour compared to the control group, as well as greater maturity. They also tended to take on many responsibilities, such as helping their parents with housework or looking after their siblings. The researchers were able to isolate factors that influenced attitudes towards a brother or sister with a disability. These were: age, the age difference between the children, the availability of parents and good communication with them, and peer support. Younger children tended to cope better with their sibling's disability; the older they were the more often they experienced negative feelings, primarily shame (Berryman, 2002). A small age difference between siblings was a negative factor, although the availability of parents and good communication with them was more important for wellbeing. NAME Lavigne and NAME Ryan concluded from their results that it was more difficult for children younger in age than their sibling to cope with their sibling's disability. This may be due to the fact that the child with the disability, despite their metric age, steps into the role of the youngest sibling, resulting in a role reversal – the younger sibling is forced to take on the role of the older sibling, so to speak. The value of peer support was also highlighted – it was positively related to the self-esteem of the children studied and helped them adapt to the role of a sibling of a child with a disability (Berryman, 2002). It tends to be the case that the oldest children identify most with their parents' preferred values and strive to live up to their expectations. They are the ones from whom parents usually demand more, including in terms of helping younger siblings. Younger children are usually treated more leniently. They are expected to behave in ways that are appropriate for younger



children (Richardson, Richardson, 2001). However, when a child with a disability is older, it is not uncommon for roles to be swapped due to the birth order. In such a case, regardless of age, the blind child may be treated as a younger child in need of care, and the gap between them and their non-disabled siblings may widen over time. This can be a disadvantage for both the non-disabled child and the visually impaired child. One study found that even before the age of two, children were able to recognise that their brother or sister was different and imitated their parent's behaviour towards the older child. It was also not uncommon for them to imitate the behaviour of a sibling with a disability themselves in an attempt to become more like them (Kandell, Merrick, 2003). Young children learn through observation and imitation how to behave in the surrounding reality, including socially. However, they cannot distinguish between socially desirable and undesirable behaviour.

Relationships between siblings are undoubtedly also affected by communication barriers. Malwina Kocoń, Natalia Malik, Anna Michalczyk (2019) conducted research on another group of siblings of children with sensory disabilities – deaf children. Their aim was to identify the quality of shared relationships between deaf and hearing siblings, especially concerning areas related to communication. Hearing siblings perceived their deaf brothers and deaf sisters in a positive way. Although the statements also revealed contradictions and ambivalent feelings (e.g., treating them as “normal” while at the same time feeling pity or shame) or actions (e.g., reporting problems in communication due to lack of or poor knowledge of Polish sign language but not attempting to learn it). As I mentioned above, blind children have problems with non-verbal communication. They tend to use very little body language and do not use conventional gestures that are understood by everyone, e.g., they do not point to the object they want to receive. They also have some difficulties in developing verbal communication, e.g., they start talking later. This is probably due to the fact that the words they hear are not accompanied by images that reinforce their meaning, and this in turn results in a lack of visual stimulation for speaking and role models (Majewski, 2002). When young children learn the pronunciation of individual phonemes, they observe a specific visual image of the layout and movements of the speech organ – the mouth, larynx and mandible. Although this image of the phonetic elements of speech is not always clear, it helps them to perceive and imitate others when pronouncing individual phonemes and words. Once visually impaired children begin to speak, they catch up very quickly so that soon there are no differences between their speech and that of their sighted peers in terms of their possession and use of words, although some researchers point out commonly observed characteristics of blind speech. First of all, blind people speak more slowly and somewhat louder than sighted people, and modulate their voice less. They also



have less vocal variety, and less frequently use body movements, facial expressions and gestures to accompany speech (Kemp, 1981).

Blind people are also prone to use blinkers, i.e. aimless movements that probably serve to relieve excessive psychophysical tension, are part of defensive reflexes or help to provide themselves with stimuli. These include, for example, shaking one's head, jumping up, shaking one's hands, but also moving on stiffly erect legs, keeping one's arms stationary when walking or lack of facial expression when speaking. There are also blinkers, which are self-destructive behaviours, e.g., squeezing the eyeballs, scratching the hands. Such behaviours are often met with a negative reception from those around them. Sometimes, due to a lack of knowledge, people label people presenting blinkers as having an autism spectrum disorder, intellectual disability or mental illness. This can result, for example, in peers avoiding contact with the blind child or their non-disabled siblings.

The relationship between non-disabled and visually impaired siblings can be analysed in several aspects. These are mainly: bonding, responsibility, acceptance of disability. As far as the family bond is concerned, it is the basic type of social bond, influencing the permanence of the family, providing a sense of security and enabling the development of the children's personalities. It is based on two foundations – the subjective one, which is the sense of belonging to a family and the awareness of connection with its members, and the objective one, which is based on legal, customary and cultural factors, etc. (Lalak, Pilch, 1999). According to research conducted, the vast majority of siblings show a special bond with their blind brother or sister based on unconditional love and willingness to help (Battinstin, Bottan, Reffo, Zanardo, & Mercuriali, 2024). This is a very positive phenomenon, because, feeling a bond, having a need to help, the sighted sibling takes the initiative to play together, involves the blind sister or brother in activities and, through this, awakens in him or her an interest in the surrounding world. For a blind child this is extremely important, because if they cannot see the world, they do not feel the need to explore it, they become inactive in terms of motor skills and cognition, which can hinder their development in all spheres. Playing with siblings is a source of many experiences for the child, providing information about the world (also social), fostering the need for activity, learning about the world, play and relaxation. Spontaneous play based on interest in a part of reality provides the blind child with a lot of information about the world and himself. Playing with sighted siblings is an important complement to the rehabilitation activities undertaken. It differs from adult-directed activities not only in that the time devoted to play by children is longer than by adults, as play is the child's primary activity. In play with siblings, blind children learn the rules of communication, resolve conflicts, sometimes compete, and thus prepare themselves for interaction with their peers. Siblings are usually less likely than parents

to be overprotective of the blind child, allowing the child to explore the world more courageously. At the same time, such joint play is also important for non-disabled siblings. They create a bond with the blind sister or brother, enable them to learn about their limitations and strengths and accept their imperfections, and deepen their knowledge of themselves by providing new information for the self-image they create.

As far as responsibility is concerned, it can take the form of taking care of oneself and others. It is linked to an obligation or a sense of duty towards others in the family. In order for this kind of responsibility to develop, the child must experience a space of freedom and freedom of action. His or her behaviour will then result from a sense of empowerment. Although the reactions of the environment are not a prerequisite for the emergence of a sense of responsibility, if the environment notices the child's efforts, it increases the child's involvement. When caring for others, the child feels pride in his or her duty and, if his or her action is based on an inner conviction, he or she is willing to do something good for others, to care for them, to look after them, to help them as much as he or she can. And although sometimes the results of this action are relatively small (e.g., drawing a drawing for someone, passing a glass of water), they are very important from the point of view of responsibility formation (Samborska, 2019). Responsibility for a blind brother or sister, therefore, does not have to be for non-disabled siblings an unpleasant burden, an unwanted duty, but a source of positive emotions, as long as the environment appreciates any manifestation of it.

For positive relationships between siblings with and without disabilities and siblings with visual impairments, acceptance of the disability is also important. The lack of acceptance of the otherness of a brother or sister may also be related to insufficient knowledge of the specifics of the disability, as greater knowledge is associated with a more positive attitude towards siblings (Hamerlinska, 2008). It is not uncommon for sighted siblings to have little contact with other visually impaired people, which may result in the existence of negative stereotypes that they also use in relation to their brother or sister. This is especially true if the blind sibling is younger. In non-disabled siblings, there may be an unmet need to learn more about how a blind person functions, to identify their abilities in different spheres of development, to compare their own experiences in learning about the world (Berryman, 2002). In this aspect, informational support provided by parents or professionals providing educational and therapeutic activities seems important. This can include, for example, explaining the reasons for blinkers and showing ways to respond to them, explaining unusual communication behaviour of the blind child (e.g., turning the head to the side may be misperceived by siblings as an unwillingness to make contact, while in fact it may indicate the blind child's interest in contact and a desire to better receive auditory stimuli). It can also help to un-

derstand the role of unusual behaviour in blind people's exploration of the world (e.g., sniffing different objects in the environment, touching newly met people, hitting the bus window with the hand). This can not only diminish the feeling of shame about the behaviour of a brother or sister, but also identify these behaviours as an expression of mastering new areas of space, improving ways of learning about the world and functioning in it. However, instrumental support by providing information on specific ways of behaving and modelling specific ways of behaving is equally important.

## **Summary**

Knowledge of the needs of siblings of visually impaired children can deepen the understanding of their experiences, help to see the problems and strengths of the family system from their side. Including their perspective in the research conducted can draw attention to certain themes still absent or residually present in today's tylopodagogy. This can have a positive effect both in terms of knowledge of visual impairment and its consequences, as well as improving educational and rehabilitation practice activities by providing concrete guidelines for supporting interaction between siblings from the earliest years of life. The practice of the field of tylopodagogy shows that these are important issues. A few years ago, a magazine dedicated to the problems of the blind published statements from children whose brothers or sisters are blind. The youngest interviewee was six years old and her blind sister was four years old. It was clear from the interview that she mixed the joy of having a sister with the sadness of not being able to see. She enjoys playing with her sister and the fact that she can do many things just like a sighted person, e.g., running, climbing, while she is annoyed by some of the questions posed by her peers at school (e.g., does she love her sister). Another interviewee was a 14-year-old girl and the conversation was about her older sister. She too felt negatively about excessive attention from other people. She felt frustrated in situations where she tried to help her sister and the sister did not accept the help. However, she was always reminded in these situations of how many obstacles she had to overcome to be where she was now. She often thought about the future and how her sister would cope in her adult life. Another interviewee was a 14-year-old boy whose blind sister was 17 years old. In his statement, he mainly emphasised that she is helpful in various situations, e.g., she speaks Spanish better than he does and helps him with his Spanish lessons, she has a great memory and often remembers things that he should also remember. He also noted that they each have their own responsibilities, which he

sees fulfilling as preparation for independent living. He greatly appreciates going on trips together with blind children and their sighted siblings as part of an association activity (Cheadle, 2003).

Given today's knowledge of the issue, it seems reasonable to take measures to strengthen positive relationships between siblings without disabilities and siblings with visual impairments, such as:

- to provide the non-disabled child with information on the specifics of visual impairment adapted to his/her linguistic and intellectual abilities, with particular reference to the possibility of supporting the blind child on various levels;
- including the visually impaired child in rehabilitation activities with the blind child. This can increase his empathy, allow him to understand the value of support, and strengthen competences useful for living with a sibling with a disability. However, it is important that the sibling expresses a willingness to participate in such activities and does not see them as an undue burden on their sister's or brother's problems;
- enable, where possible, siblings of visually impaired children to participate in support groups to create a safe space to share their emotions, experiences, to help them experience understanding and support;
- organising activities in the classroom attended by a child with a visually impaired sibling to learn about the world of the visually impaired, to better understand their needs, limitations and strengths. This can help to break down or prevent peer isolation;
- organising joint activities – e.g., sensory games, which can contribute to the sensory compensation of a blind child, but can also be a great way of playing together. Playing with texture or auditory memories, wooden puzzles, navigating sensory paths, painting with structured paints can also be attractive for sighted children;
- participation of the non-disabled child in spatial orientation activities – this can be a form of play or reciprocal activity, but can help to understand the limitations of a blind brother or sister, making it easier to understand the need to support a blind sibling or to devote more time to him or her;
- assigning age- and developmentally appropriate responsibilities in parenting to each sibling (sighted and blind), which can foster a sense of fair and equal treatment;
- individualising the approach to the needs of all children, paying attention to meeting their individual needs related not only to their level of ability, but also to their age, personality, interests.

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