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# The present and future vision of siblings of adults with intellectual disabilities

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**ABSTRACT**

*The present and future vision of siblings of adults with intellectual disabilities*

Siblings play an important role in the lives of individuals with intellectual disabilities, as typically developing children can serve as role models and have a positive influence on everyday functioning. As they reach adulthood, non-disabled siblings may become caregivers for their intellectually disabled siblings, taking part in decision-making and assuming increased – or even sole – responsibility for siblings who require support due to the ageing, illness, or death of their parents. This study presents the findings of a semi-structured interview survey conducted in Hungary on the experiences of siblings in adulthood, at a time when their roles within the family are changing or are expected to change. One aim of the broader survey was to explore the responses of 11 siblings in order to understand how they perceive the future: the care of their intellectually disabled sibling and, importantly, the impact of this responsibility on their own personalities. One of the most important findings, which may offer a lesson for the social care system, is that – due to negative societal attitudes and the characteristics of the institutional system – siblings do not view institutional care as an opportunity to support independent living. According to the participants, the influence of their intellectually disabled siblings on their own personality development was positive, making them more accepting and more supportive of other people's difficulties.

**KEYWORDS:** adulthood; intellectual disability; siblings; relationships; vision for the future

## The relationship between people with intellectual disabilities and their siblings

Throughout our lives, our relationship with our siblings is among the most complex and longest-lasting bonds, in which a shared past plays an important role. The sibling relationship is normally accompanied by ambivalent feelings arising from conflicting personality traits, jealousy, alliances, and quarrels, but also from happy and precious moments. After gaining some distance as a result of adult responsibilities, siblings may provide support for one another when caring for aging parents and, later, when facing their own challenges associated with old age (Armbrust, 2013).

The relationship between parents and their non-disabled children is shaped by the multitude of tasks related to the disabled child, concerns about the disabled child's development, and other responsibilities; therefore, parents generally have less quality time with their typically developing children. In connection with this idea, Kálmán and Könczei (2002) emphasize that the difficulties associated with raising a disabled child can lead to the healthy child developing an adult-like attitude and being expected to be understanding, empathetic, and willing to make sacrifices. According to Radványi (2013), typically developing siblings may develop feelings of jealousy and fear of being different during childhood, a desire for information during the school years, and then, during adolescence, they may become a source of support for their parents in caring for and providing for their sibling with special needs.

Experts agree that one of the important elements of the family relationship system is the relationship between the disabled person and their non-disabled sibling(s). Within the family, all relationships have multiple reciprocal effects on one another: actions and reactions shape expressions and emotions between siblings, forming the basis for cohesion or estrangement in adulthood (Gallagher and Bristol, 1989, cited in Radványi, 2013).

## Factors influencing sibling relationships

The factors determining sibling relationships can basically be divided into two types. From the perspective of personality development, biological characteristics and genes play an important role in determining gender, appearance, phenotype, and the individual's physical and mental health (Cole and Cole, 2006), as well as birth order, age differences between siblings, and gender. On the other hand, personality development and the formation of social relationships are influenced by experiences within the family, interpersonal models, and experiences gained in a more immediate socialization environment (Stipkovits, 2017; Leman, 2019).

Families raising children with disabilities may, because of an imbalance in family functioning, neglect their typically developing children and spend little time with them. This can result in various behavioral symptoms or school-related problems as children try to draw attention to themselves, expressing accumulated tension and feelings of exclusion. In fortunate cases, recognizing inappropriate parenting attitudes can shift the family's balance toward positive change (Kálmán, 2004).

Family relationship patterns undergo constant and regular transformation and mutually shape one another, much like changes in family life cycles, when parents are forced to take on new roles as their children develop and grow (Kálmán, 2004; Radványi, 2013). Based on psychological and social studies of siblings of persons with disabilities, the prevailing view in the 1970s (Farber, Gath, cited in Rossiter and Sharpe, 2001) was that the diversion of parents' attention away from the personality development of their typically developing children was clearly detrimental, leading to narrower social relationships and isolation from peers. Later research (Bagenholm and Gillberg; Cuskelly and Gunn; McHale and Gamble; Rodrigue, Geffken, and Morgan, cited in Rossiter and Sharpe, 2001) identified several negative factors; for example, higher rates of depression, more behavioral disorders, and lower perceived acceptance by the environment – findings that were more typical among sisters. Regardless of gender, healthy siblings spent more time doing household chores and were assigned more caregiving tasks, which may explain their less frequent participation in community activities.

In the early 2000's, several research findings were published (McHale, Updegraff, and Feinberg, cited in Shivers and Dykens, 2017) describing similar characteristics among typically developing siblings of children with intellectual disabilities, most prominently in social-emotional competencies. According to these studies, siblings of children with disabilities are more empathetic and understanding, more helpful with household chores, more caring, and better at adapting to different situations; however, depending on social, environmental, and family patterns, they may also be more prone to deeper feelings of unhappiness and sadness. During social interactions and shared activities, conflicts between siblings are less common, and siblings of children with disabilities tend to handle them more flexibly. In most cases, they treat their siblings with higher support needs in a protective, caring, and loving manner, but they may suppress negative feelings – mainly toward their parents – and this can influence their personality development (Kálmán and Könczei, 2002). Typically, at the beginning of the sibling relationship, they treat their sibling with higher support needs lovingly and gently, even though jealousy and fear of illness and difference may develop during childhood (Hannam, 1985, cited in Radványi, 2013).

## Characteristics of sibling relationships in adulthood

In the case of siblings with intellectual disabilities, a different developmental trajectory may alter personality development during adolescence, which can manifest as delays in planning, partnering, and career choice. Often remaining in a childlike role, the parents make decisions about their disabled child's life after school, including employment, the possibility of forming and/or maintaining social relationships, and placement in an institution (Hatos, 2012).

Because of inequality in abilities and opportunities, the competition that typically develops may not occur; instead, growing responsibility and the desire to care for the sibling, as well as maternal and paternal behavior, become decisive factors in the sibling relationship (Kálmán and Könczei, 2002).

In the non-disabled population, sibling support is strongest in older age; because of changes in memory, childhood events may be easier to recall. Even in the context of narrowed social relationships, siblings can represent the most secure point and the closest bond (Hammer, 2016). According to Petri (2015), not only loneliness but also an increased need for reconciliation and closure of past grievances and disputes can bring siblings closer during a period marked by loss and farewells. Successfully resolving earlier conflicts and reconnecting after reconciliation can provide strong emotional support, and a peaceful, loving relationship and mutual support can bring siblings closer.

Researchers have found mixed results when examining the emotional bond between siblings with intellectual disabilities and their typically developing siblings. Some findings (White and Riedmann, cited in Doody, Hastings, O'Neill, and Grey, 2010) suggest that physical closeness and genetic similarity strengthen emotional bonds, while other experts (Floyd, cited in Doody, Hastings, O'Neill, and Grey, 2010) conclude that the degree of contact and family changes – such as parental loss or the birth of a child – determine emotional bonds. A survey conducted around the millennium (Orsmond and Seltzer; Pruchno, Patrick, and Burant, cited in Doody, Hastings, O'Neill, and Grey, 2010) found that adults generally have strong bonds with their siblings with intellectual disabilities; this bond tends to be stronger among female siblings due to close emotional ties during adolescence and supportive parental behavior. In contrast, high support needs and challenging behavior can weaken the bond between siblings. Notably, in typical sibling relationships, intellectual disability does not significantly affect the frequency of communication or the degree of emotional closeness in everyday life. The number of conflicts increases with age, although in the case of individuals with intellectual disabilities, the level of intellectual functioning must be taken into account (Doody, Hastings, O'Neill, & Grey, 2010).

## The issue of sibling care

Due to higher living standards, life expectancy at birth for people with intellectual disabilities doubled from 33 years in the first third of the 19th century to the turn of the millennium, creating serious challenges for care systems. As they age, their health may deteriorate more rapidly than that of the general population, and their mental and cognitive abilities may decline; this, on the one hand, makes access to health services more difficult and, on the other hand, given shortcomings in health and social services, increases the need for intensive care (Pető, 2021).

When parents can no longer provide care, siblings most often assume daily responsibilities associated with increased support needs. The decision between caring in the home environment or institutional placement depends on a number of factors, such as childhood experiences, parental attitudes, and the degree of disability. The extent of care provided for a disabled sibling is influenced by the financial situation of the non-disabled sibling, their career opportunities, emotional relationships within their own family, and geographical distance (Pető, 2021).

Higher support needs among siblings with intellectual disabilities encourage (or force) their typically developing adult siblings to assume greater responsibility for caregiving or administrative matters. The extent of these additional duties – whether voluntary or imposed – can be reduced by a family support network; if someone can help with daily care, responsibilities are less likely to be experienced as burdensome. However, substantial time spent on physical care, challenging behavior, and communication difficulties can weaken emotional bonds and make it harder to experience closeness and affection. Adults caring for siblings with intellectual disabilities face new role demands, often taking a more hierarchical position as substitutes for parents who previously performed caregiving tasks. In addition to their traditional, emotionally based sibling role, they may now be responsible for daily care, support, decision-making, and guidance for personal development. Nearly all siblings caring for adults with intellectual disabilities must navigate multiple role expectations across all areas of life. Most report satisfaction and a balanced, loving relationship with their disabled sibling, but many would welcome delegating some tasks to a professional, a parent, or another relative (Dorsman, Waninge, Schans, Luijkx, & Putten, 2023).

# The survey

## Purpose and method of the survey

The aim of the survey was to assess the relationship between siblings of adults with disabilities and their disabled siblings, focusing on the quality of their relationship in terms of how they organize their daily lives, how they shape or have shaped their living conditions, and how they feel about caring for their siblings in the future.

The survey was conducted using semi-structured interviews and addressed several questions. It was structured around seven topics: (1) the interviewees' personal data, (2) data, characteristics, and abilities related to their siblings with disabilities, (3) childhood experiences, feelings, and memories related to siblings and parents, (4) current living conditions, (5) relationship quality, (6) questions about the future, and (7) the impact of the disabled sibling on the interviewees' personalities and lives. This study focuses on the "present" and reports experiences related to the current situation of siblings (topics 4–7).

## Participants

The survey involved 11 adults (7 women and 4 men) living in settlements in one of Hungary's eastern counties who have siblings with intellectual disabilities. The average age of the respondents was 39.5 years; the youngest was 25 and the oldest 58 at the time of the interview. The average age difference between the disabled and non-disabled siblings was seven years, with a minimum of two and a maximum of 18 years between the births of the two siblings.

Among the disabled siblings of the respondents, eight were male and three were female. The youngest was 25 and the oldest 62, and their average age was 40 at the time of the interview. Based on expert committee opinions, medical documents identified intellectual disability as moderate in six cases, severe in three cases, and mild in two cases. In one case, mobility impairment and hearing loss, and in another case, visual impairment, complicate the condition. Five individuals were in good general health, while six have various chronic illnesses (epilepsy, diabetes, heart problems, thyroid disease, orthopedic abnormalities, and skin disease).

Four of the respondents' siblings with disabilities require only minor assistance with self-care (personal hygiene, dressing, eating), while seven require more assistance with activities (e.g., serving food, using buttons and zippers, and personal hygiene).

## Presentation of survey results

### Assessment of current living conditions

The quality and "content" of the sibling relationship was influenced by current living conditions, as living in the same household and the distance between residences could affect both the quality and quantity of care provided. The number of participants living together with their sibling was almost equal to the number living separately.

The family arrangements of participants living together (five people) were mixed, with most living with one or both parents and non-disabled siblings. Three young adult respondents are not yet married, do not have children, and live in their parents' house, but plan to start a family and move out. One respondent moved back to her parents' home with her young daughter after a divorce, partly for financial reasons and partly to help her aging mother care for herself and her sibling. One man assumed care of his younger disabled brother after the death of their parents, which was an obvious solution for him because he was the only one of the three typically developing siblings who had not yet started a family and he lived closest to his younger disabled brother. In only two cases was co-residence in adulthood motivated primarily by a desire to care for the disabled sibling; for three people, it was driven mainly by developments in their private lives. One person living in the same household does not participate in the care and supervision of his severely disabled brother, as their mother still performs all caregiving tasks. Four people supervise or care for their disabled sibling depending on the sibling's level of self-sufficiency. Official matters are handled by the parents, and the siblings interviewed merely express their opinions or accompany their siblings on outings.

All respondents living in separate households (six people) are married or in a relationship, and their residence is no more than 40 km from their parents. One respondent lives with his children in a separate household but in the same building as his mother and disabled sibling. Five respondents sought accommodation close enough to their parents and disabled sibling to be able to help if necessary. However, according to their responses, those living in separate households (except for one person) do not participate in the care and supervision of their siblings. The choice of residence was not influenced by the need to care for a disabled sibling in only one respondent's life.

Respondents were asked whether the severely limited income opportunities of disabled family members affected their financial situation. The responses indicate that caring for a disabled person does not represent, or represents only to a small extent, a financial disadvantage. However, those living in shared households are more affected by the allocation of available financial resources. Based on their experiences, they are at a slight financial disadvantage because their sibling with special needs requires assistive devices and more medication. They also pointed out that the caregiver parent's inactive labor market status causes financial difficulties. Having a sibling with different developmental abilities does not affect the financial situation of those living in separate households.

Half of the respondents (six people) believe it is necessary or desirable to contribute to expenses related to their disabled sibling. One respondent contributes to regular daily/weekly/monthly expenses (housing and maintenance costs), two prefer to buy vitamins, fruit, or clothing to promote well-being and health, and three contribute in both ways.

## Family relationships among the survey participants

When mapping relationships, the survey focused primarily on the quality of bonds and how they change.

Nearly half of the surveyed adults (five people) reported that their feelings toward their disabled sibling had not changed and described strong attachment, love, and acceptance. According to five respondents, their feelings have changed in a positive direction: they have learned to accept the disability, and negative feelings such as shame and guilt have disappeared. One female respondent is concerned about her younger brother's increasingly frequent behavioral problems, which is new compared to earlier periods, but her sisterly love remains unbroken. In addition to a positive, accepting attitude, five respondents reported the emergence of "responsible thinking" and a sense of "dependency." One respondent described the current relationship with her younger brother as distant, which she associated with moving out of the parental home and spending less time together.

Six people meet their disabled sibling in person or online every day; two of these respondents live separately. One female respondent visits her family several times a week, while three visit once or twice a week. Five respondents stated that they have no specific joint activities, which they attributed to their sibling's condition, while one respondent reported having no need for joint activities due to emotional distance. Three respondents aim to spend quality time together; because of the sibling's condition, this usually means simply being together, talking, and watching television. Only one respondent reported going on trips or to the movies, and one mentioned discussing tasks related to their baby, which they consider a pleasant, adult-like pastime. Comparing responses from participants living together versus separately, no clear relationship emerged between co-residence and the frequency or quality of joint activities.

Sibling relationships can also be characterized by conflict frequency and outcomes. According to responses, arguments and quarrels do not occur or occur very rarely in seven sibling relationships; given earlier responses, this is not necessarily a positive indicator. Relationships without disagreements are typically those in which the respondent does not participate in caregiving; they spend less time together and usually do not have joint activities. Living in the same household – especially when there is a power imbalance due to caregiving needs – creates many opportunities for minor or major conflicts, as reported in the interviews. Disagreements occur more often in co-residing sibling relationships than between siblings living at different addresses, but conflicts are resolved quickly and the disabled person ultimately understands and accepts the sibling's perspective.

In addition to disagreements, problems may arise from the physical and mental condition of the disabled person, which can become more common with age. Eight of the disabled siblings of the survey participants showed physical and/or mental deterioration as early as their thirties. These negative changes affect both parents and siblings, as it can be difficult to face age-related decline. However, the sister of a 25-year-old woman with severe intellectual disabilities reported psychological improvement, increased activity, and greater independence, which she attributed to changes in institutional care and a new environment.

Respondents were also asked to describe their role in the life of their disabled sibling. Three described their relationship as that of surrogate parents. One respondent described it as a dependency relationship. All respondents living in the same household mentioned hierarchy, dependence, and assuming a parental role, whereas those living further away more often retained a sibling role.

Respondents generally described their current relationship with their parents as good and improved compared to childhood, with fewer arguments and greater mutual acceptance. This was attributed to changes in mindset and understanding of the reasons underlying behavior. Moving into separate households, starting their own families, and spending less time together also reduces friction and contributes to a more peaceful relationship. In two cases, respondents reported a poor relationship with one parent rooted in childhood experiences: one involved divorce followed by estrangement from the father; the other involved persistent distance from the mother, reinforced by a distressing statement remembered from childhood.

The siblings participating in the survey did not report negative experiences among peers. Four said they kept their sibling a secret at school or work and chose friends who could accept the disability. A romantic partner's attitude was identified as an important factor. One respondent's relationship ended because of his disabled brother, but he maintained that acceptance of his brother was essential for long-term plans.

Regarding having children, respondents typically reported only as much fear and anxiety as is usual, which they explained by stating that their sibling's disability is not genetic. One respondent decided not to have children in her twenties because of caregiving responsibilities related to an injured sibling who is 12 years younger.

## Future issues in caring for a sibling with a disability

Planning for the future – where and how the family member with a disability will live and with whom they will spend adulthood and old age – requires consideration of multiple factors.

All survey participants had discussed their disabled sibling's future with their parents. With two exceptions, families with multiple siblings plan together and discuss the future regularly. The exceptions occurred because, in one case, the respondent already lived with the disabled sibling, while in the other, the healthy sister was too young for such discussions to be relevant.

Information about social services can be important in everyday life and future planning. Nine participants reported limited information and lack of awareness of nearby options, while two were unfamiliar with social institutions because a decision had already been made about their sibling's future. This lack of information may be partly explained by parental attitudes: four respondents reported that their parents – especially their mothers – were determined to keep the disabled child at home and opposed institutional placement. One interviewee reported visiting a residential institution and having a negative view of the care conditions. Respondents were also largely uninformed about day services: only one knew of work opportunities for people with reduced work capacity, three were familiar with some forms of employment, and seven did not consider their disabled sibling suitable for work.

Seven respondents had specific plans for the future, while four were uncertain and had only vague ideas about later circumstances. Those who were uncertain were around 30 years old and had not yet started their own families. Among those with definite plans (seven people), four preferred caring for their disabled sibling at home, while three would choose institutional care due to behavioral problems or high care needs. Decision-making factors included love and responsibility and a desire to ensure adequate living conditions.

Respondents considered the death of their parents a likely milestone for their disabled sibling, bringing major financial changes and changes in their relationship. Two respondents believed such changes would negatively affect the dynamics of friendships and family relationships.

## The impact of a disabled sibling on the respondents' lives and personalities

Respondents summarized how growing up with a disabled sibling affected their lives and personalities. Some described their sibling's disability as natural and not experienced as negative, while others regarded it as a defining factor in their personal development. Most respondents (10 people) described the impact as positive, and six highlighted increased acceptance of and sensitivity toward people with disabilities, noting that their sibling made them more open toward people with different developmental abilities.

Four respondents emphasized caregiving, early assumption of a parental role, and learning caregiving skills early in life. One respondent noted that, alongside positive experiences, having a disabled sibling also created excessive pressure to conform. Respondents repeatedly mentioned empathy, acceptance, patience, tolerance, sensitivity, helpfulness, interpersonal skills, child-centeredness, thoughtfulness, responsibility, independence, attentiveness, and flexibility as influences. Two respondents emphasized that in adolescence and young adulthood they might have behaved differently if their sibling had developed typically, but a desire to please their parents overshadowed their personal desires and limited their own behavior.

## Summary

International and domestic experts agree that people with intellectual disabilities share characteristics such as below-average intelligence and adaptive behavior difficulties, but their cognitive abilities, communication skills, and behavior vary widely. Because support needs differ, individualized development and care are essential in childhood, while in adulthood individualized pedagogical guidance remains important.

The living conditions, opportunities for developing abilities, and quality of life of people with intellectual disabilities are strongly influenced by their immediate and broader social environment. The family is the primary environment; dynamically changing relationships among family members have a powerful impact on personality formation and life trajectories. Within the family relationship system, multidirectional, continuous interactions mean that the disabled child affects others, while the parents' marriage, their relationship with the non-disabled child, and sibling relationships may also promote or hinder development.

One of the main objectives of disability policies today is to create a legal environment that ensures the possibility of autonomous living for people with disabilities. Adults with intellectual disabilities may use supported housing, residential homes, or institutional care that provides full care and support, resembling a family home while enabling more independent living.

Families often know best the needs and abilities of persons with disabilities, but as parents age and have less energy to devote to their disabled child, their role is often assumed by typically developing siblings. It has been confirmed that a large age difference reduces the likelihood of forming an intimate, close bond, but in the case of siblings with high care needs, this did not prevent the development of a close, loving, caring relationship.

Five individuals (out of 11) currently live in the same household as their disabled sibling; however, conclusions are limited because three of them are still young adults with many unanswered questions and no concrete plans. For two individuals (aged 45–53), co-residence appears permanent. A hierarchical

relationship has developed in these cases: they play a decisive role in care and support, and the relationship resembles a parent–child relationship more than an equal sibling bond.

Financial resources and their allocation have a greater impact on those living in shared households, who share their income with their disabled sibling to varying degrees. The financial situation of those living separately is less affected, although they are willing to cover certain costs. No connection was found between residence and leisure activities or joint programs; instead, the severity of disability was the determining factor. Respondents living in the same household assumed more tasks related to care, supervision, and administrative matters, but also reported more conflicts due to friction arising from co-residence.

The present state of sibling relationships is largely determined by the disabled person's condition, intellectual functioning, behavioral problems, and communication skills. While relationships with mildly intellectually disabled individuals who have good communication skills can be described as more equal, more severe impairments and greater communication difficulties tend to produce a subordinate relationship in which love becomes more caring and controlling.

Planning the disabled sibling's future poses a major challenge, but all respondents reported acceptance of responsibility and caregiving duties. Younger respondents around 30 years of age had more uncertain ideas about the future, while older respondents expressed firmer views based on experience and knowledge of the family's circumstances. Those whose disabled siblings had lower care needs and fewer behavioral problems were more willing to provide care in their own homes, often citing negative beliefs about institutional care. Those who anticipated excessive strain on daily life, negative effects on social relationships, or barriers to employment were more likely to plan for long-term residential social care.

Overall, the survey results align with expert findings that gender, birth order, and childhood family experiences influence respondents' relationships with their disabled siblings. The disabled sibling's condition, level of intellectual functioning, communication skills, and behavioral difficulties strongly affect relationship quality, caregiving involvement, and future planning. Among those surveyed, negative social attitudes may prevent institutional care from being seen as an opportunity to support independent living. Finally, the reported impact of having a sibling with intellectual disabilities is consistent with recent research indicating that acceptance, tolerance, empathy, and sensitivity may be shaped by such sibling relationships.

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