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# Between Care and Overload: Experiences of Siblings of Individuals with Disabilities Who Use Augmentative and Alternative Communication (AAC)

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## Abstract

The aim of this article is to analyse the experiences of siblings of individuals with disabilities who use Augmentative and Alternative Communication (AAC). The study was conducted within a qualitative research paradigm and involved semi-structured interviews with four adult siblings of AAC users. The collected data were analysed using thematic analysis in accordance with the approach proposed by Braun and Clarke (2006). The findings reveal the ambivalent nature of the participants' experiences, encompassing closeness, personal growth, and a sense of meaning in the sibling relationship, as well as emotional overload, limited autonomy, and concerns regarding future responsibility for their sibling. The analysis also highlighted the significant role of AAC in shaping family relationships. AAC facilitated the development of closeness, enhanced opportunities for expressing needs and emotions, and promoted the social participation of individuals with disabilities, while simultaneously requiring additional engagement and patience from siblings. The findings emphasise the need to recognise and include siblings in support services and interventions designed for families of individuals who use AAC.

**Keywords**: siblings of individuals with disabilities, augmentative and alternative communication (AAC), sibling experiences, parentification, family system

## Introduction

The family constitutes the primary environment for an individual's development, where the first patterns of interpersonal relationships, emotional regulation, and social functioning are formed.

Within the family, children experience closeness, acceptance, and support, while also learning to understand themselves and others through everyday interactions. Sibling relationships are of particular importance in this process, as they represent—alongside parent-child relationships—one of the key contexts of socialisation and psychosocial development. These relationships are long-lasting and multidimensional, encompassing elements of cooperation, rivalry, caregiving, and emotional connectedness (Stoneman, 2005; Petalas et al., 2012; Cicirelli, 1995). When one child in the family has a disability, family dynamics often undergo significant transformation. Siblings of children with disabilities function within a unique developmental context in which typical childhood experiences coexist with additional demands, responsibilities, and the need to adapt to altered family-system functioning. Research indicates that these experiences are frequently ambivalent, involving both the development of empathy, sensitivity, and social competence, as well as feelings of burden, frustration, and the marginalisation of one's own needs (Hastings, 2003; Giallo & Gavidia-Payne, 2006; Moyson & Roeyers, 2012). This phenomenon has been described as the *sibling paradox*, referring to the coexistence of positive and negative emotions in the relationship with a brother or sister with a disability (Siman-Tov & Sharabi, 2024).

In families affected by disability, modifications in family roles and boundaries frequently occur. Siblings often assume additional caregiving, supportive, or mediating responsibilities, becoming an important part of the family's everyday functioning. In the literature, this phenomenon has been discussed in the context of *functional parentification*, understood as children taking on responsibilities typically associated with adults while maintaining emotional bonds and loyalty to the family (Jurkovic, 1997). Such experiences may foster responsibility and maturity; however, they may also increase the risk of emotional overload and restrict developmental autonomy. A particularly important context that further shapes family relationships arises when a child with a disability experiences significant communication difficulties and uses Augmentative and Alternative Communication (AAC). The introduction of AAC into family life alters the ways in which relationships are established and maintained, influencing everyday interactions as well as the demands placed on all family members. Siblings of AAC users frequently act as communication partners, participating in the communication process and learning new forms of interaction. While this may facilitate the development of close relationships and a sense of agency, it may also create additional challenges associated with adapting to the specific characteristics of aided communication (Angelo, 2000; Kent-Walsh & McNaughton, 2009). Despite the growing interest in the functioning of families of individuals with disabilities, the perspective of siblings remains relatively underexplored, particularly in relation to qualitative analyses of their emotional, relational, and identity-related experiences. Existing studies have focused primarily on parents' experiences and the effectiveness of therapeutic interventions, often overlooking the everyday and frequently invisible experiences of siblings as active participants in family life. The aim of this article is to provide an in-depth analysis of the experiences of siblings of individuals with disabilities who use Augmentative and Alternative Communication. Particular attention is devoted to the emotional and relational dimensions of these experiences, including the ways in which siblings experience responsibility, tension, and closeness, as well as the significance of these relationships for the development of identity and psychosocial functioning.

## Siblings of Individuals with Disabilities as Participants in the Family System

From a systemic perspective, the family constitutes a dynamic network of interdependent relationships in which the functioning of each member is closely connected to that of the others (Minuchin, 1974; Turnbull, 1995). Consequently, the presence of a disability in one child is not merely an individual experience but affects the reorganisation of the entire family structure, including roles, boundaries, communication patterns, and interpersonal relationships. Within this context, siblings are not merely passive observers of change but active participants in the family system whose own functioning undergoes significant transformation. Sibling relationships in families that include a child with a disability are particularly complex. Research indicates that these relationships simultaneously serve as sources of emotional support, connectedness, and closeness, while also constituting spaces of tension, conflict, and challenging experiences (Cicirelli, 1995; Stoneman, 2005). In the literature, this phenomenon is often referred to as the *sibling paradox*, describing the coexistence of positive and negative emotions in relationships with a brother or sister with a disability (Siman-Tov & Sharabi, 2024). Siblings may simultaneously experience pride, empathy, and a sense of purpose, while also feeling frustration, jealousy, or a sense of injustice resulting from the unequal distribution of parental attention and family resources (Hastings, 2003; Giallo & Gavidia-Payne, 2006). An important aspect of sibling functioning in families of children with disabilities involves changes in family role structures. In many cases, siblings assume additional caregiving, supportive, or mediating responsibilities. This phenomenon has been described in the literature as *functional parentification*, defined as the assumption of adult-like responsibilities by a child while maintaining emotional bonds and loyalty toward the family (Jurkovic, 1997). In families of individuals with disabilities, such parentification often serves an adaptive function, helping to maintain family-system stability in the context of increased caregiving demands. At the same time, however, it may limit siblings' developmental opportunities and contribute to emotional overload resulting from excessive responsibility. The assumption of additional family roles is frequently associated with accelerated maturation, understood as entering social and emotional roles characteristic of adulthood earlier than is typical in the general population (Moyson & Roeyers, 2012). Children and adolescents growing up under such circumstances often develop high levels of empathy, sensitivity, and social competence. Nevertheless, these gains may come at the expense of the spontaneity of childhood and opportunities to fulfil their own developmental needs. As a result, siblings' experiences tend to be inherently ambivalent, combining personal growth with feelings of burden and responsibility. The literature also highlights that the way siblings experience their relationship with a brother or sister with a disability is strongly influenced by the quality of social support available to them (Hacker et al., 2023; Levante et al., 2024; Wolff et al., 2023). Such support may be emotional, informational, or instrumental in nature and may originate from immediate family members, educational settings, or professional support services. The availability of adequate support facilitates coping with challenges, strengthens feelings of security, and promotes more balanced emotional functioning. Conversely, a lack of support may lead to the internalisation of stress, feelings of loneliness, and withdrawal from social relationships. In light of these findings, siblings of individuals with disabilities should be regarded as significant, although often overlooked, members of the family system. Their experiences provide valuable insight into family functioning as a whole, revealing both adaptive mechanisms and areas requiring additional support. The systemic and relational perspective adopted in this study serves as the framework for interpreting the empirical findings presented in the following sections of the article.

## Methodology

The study was situated within a qualitative research paradigm aimed at gaining an in-depth understanding of the experiences of siblings of individuals with disabilities who use Augmentative and Alternative Communication (AAC). The choice of a qualitative approach was determined by the nature of the phenomenon under investigation, which is complex, multidimensional, and deeply embedded in the individual meanings that participants attribute to their lived experiences. The purpose of the study was not to generalise findings to a broader population but rather to reconstruct the ways in which participants experience, interpret, and understand their relationships with a brother or sister who uses AAC. The main research question concerned how siblings of individuals with disabilities who use AAC describe their relational, communicative, emotional, and identity-related experiences within the context of family life. The study was grounded in an interpretivist framework drawing upon the assumptions of phenomenology and social constructivism. It was assumed that social reality is co-constructed through human interaction and revealed through individuals' experiences and the meanings they assign to them (Schutz, 1967; Charmaz, 2014). The study had an exploratory character and employed thematic analysis following the model proposed by Braun and Clarke (2006), which enables the identification and interpretation of patterns of meaning within participants' narratives. A purposive sampling strategy was adopted based on the criterion of living in a family in which one child used AAC. The study involved four participants—three women and one man—aged between 18 and 45 years, who were siblings of individuals with Down syndrome or cerebral palsy using various forms of AAC. The communication methods used by their siblings included tablet-based communication applications, eye-tracking technology, communication books, alphabet boards, and symbolic communication systems. The sample size reflected the qualitative nature of the study, whose purpose was not statistical representativeness but an in-depth exploration of participants' experiences. Recruitment was discontinued when additional interviews no longer generated new meaningful categories relating to communicative, relational, and emotional experiences. Recurrent themes and patterns were identified across the data, indicating that thematic saturation had been achieved in relation to the study objectives. Despite the relatively small sample size, the empirical material demonstrated considerable depth and diversity, enabling the identification of key aspects of the experiences of siblings of AAC users. Participants were recruited through foundations, therapeutic centres, and organisations supporting individuals with disabilities and their families. Participation was voluntary. All participants received detailed information about the purpose, scope, and procedures of the study and subsequently provided informed consent. Empirical data were collected through semi-structured interviews. This method was selected because it facilitates access to participants' personal experiences, interpretations, and meaning-making processes. Interviews were conducted individually in settings that ensured participants' comfort, safety, and freedom of expression. The use of open-ended questions enabled participants to construct their own narratives concerning growing up and functioning within a family that included an AAC user. The interviews addressed topics such as sibling relationships, experiences related to AAC, emotions accompanying everyday family life, perceptions of responsibility, experiences of support and burden, relationships with parents, and reflections on the future of their sibling with a disability. Interview duration ranged from 25 to 90 minutes. All interviews were audio-recorded with participants' consent and subsequently transcribed verbatim. Data analysis followed Braun and Clarke's (2006) six--phase thematic analysis procedure. Initially, the transcripts were read repeatedly to gain familiarity with the dataset. This was followed by initial coding, during which meaningful segments relating to communicative, emotional, relational, and identity-related experiences were identified. The resulting codes were then organised into broader categories and subsequently grouped into themes representing the principal areas of participants' experiences. Particular attention was paid to the role of AAC in shaping family relationships and to the ambivalent nature of siblings' experiences. Data interpretation was conducted with consideration for researcher reflexivity, understood as awareness of the researcher's own assumptions and their potential influence on the analytic process (Finlay, 2002). To enhance the credibility of the findings, a member-checking procedure was employed. Participants were invited to review selected interpretations and confirm whether they accurately reflected their experiences. The study was conducted in accordance with ethical principles governing social science research. Participants' anonymity was ensured through the use of pseudonyms and the removal of identifying information relating to them and their families. Particular attention was also given to participants' well-being, ensuring that participation in the study did not involve excessive emotional burden. The adopted methodological approach enabled an in-depth exploration of the experiences of siblings of AAC users and facilitated an understanding of the meanings they attribute to their relationships, communicative experiences, and functioning within the family system.

## Results

The analysis of the empirical material revealed a complex and multidimensional picture of the experiences of siblings of individuals with disabilities who use Augmentative and Alternative Communication (AAC). Participants' narratives portrayed everyday life as deeply embedded in relationships, responsibility, and emotional involvement, where care, closeness, and a sense of meaning coexist with experiences of burden, tension, and restricted autonomy. Thematic analysis identified five major areas of experience: shared responsibility for a sibling, communication and relationship-building through AAC, the emotional dimension of sibling bonds, relationships with parents, and responsibility for the future of the sibling with a disability.

## Growing Up in the Shadow of Disability: Between Helping and Shared Responsibility

One of the most prominent themes emerging from participants' accounts was their early involvement in caring for a sibling with a disability. Such involvement was generally perceived as a natural part of family life rather than a personal sacrifice. Participants emphasised that from an early age they were actively engaged in their sibling's daily life, assisted their parents with caregiving responsibilities, and assumed a variety of household duties. Several participants described gradually taking on responsibilities that extended beyond typical childhood expectations. In some families, these responsibilities included not only supporting a sibling with a disability but also helping other family members experiencing health difficulties. Participants frequently reported that growing up in such circumstances accelerated their sense of maturity and responsibility. At the same time, these experiences were not viewed solely in negative terms. Many participants emphasised that they had fostered perseverance, independence, empathy, and sensitivity to the needs of others.

## Communication Between Closeness and Frustration

Daily communication with a sibling using AAC constituted a particularly significant aspect of participants' experiences. The narratives revealed that communication evolved over time alongside the development of the sibling's communicative competencies and the introduction of new AAC methods and technologies. Initially, communication often relied on interpreting facial expressions, gestures, body language, and other non-verbal cues. Participants described attempting to infer their sibling's intentions and emotions through observation and careful attention to subtle signals. These communication difficulties were frequently accompanied by feelings of helplessness as well as observations of the frustration experienced by the sibling with a disability. The introduction of AAC was commonly described as a turning point in family life. Participants reported the use of a variety of communication methods, including Bliss symbols, communication books, alphabet boards, communication applications, tablets, and eye-tracking systems. The implementation of these tools required the involvement of the entire family. AAC was perceived as significantly enhancing the communicative independence of individuals with disabilities by enabling them to express their needs, emotions, thoughts, and interests more effectively. Participants also highlighted the broader impact of AAC on social participation. Through AAC, their siblings were able to maintain relationships, pursue interests, and engage more actively in family and community life. Nevertheless, aided communication did not eliminate all difficulties. Effective communication required considerable time, patience, and commitment from communication partners. Conversations often proceeded at a slower pace, demanding sustained attention and persistence from family members. The narratives further underscored the role of siblings as communication partners. Owing to years of shared experience, siblings often developed a unique understanding of the communication styles and needs of their brother or sister. However, participants also recognised the limitations of this familiarity, acknowledging that even the closest family members were not always able to interpret messages accurately. These experiences highlighted both the strengths and challenges associated with long-term involvement in AAC-supported communication.

## Sibling Relationships: From Care to Partnership

The emotional experiences described by participants were strongly characterised by ambivalence. Relationships with a sibling with a disability were portrayed as sources of closeness, empathy, loyalty, and personal fulfilment, while simultaneously being associated with tension, fatigue, and feelings of excessive responsibility. Many participants emphasised the exceptional nature of their bond with their sibling. These relationships frequently extended beyond traditional understandings of siblinghood and took the form of partnerships characterised by cooperation, mutual support, and deep emotional commitment. At the same time, participants reported experiences of burden associated with caregiving responsibilities and the need to suppress or postpone their own needs. In some cases, these experiences contributed to family conflicts and efforts to reclaim personal autonomy.

## The Invisible Child? Relationships with Parents and Sources of Support

Relationships with parents constituted another significant dimension of participants' experiences. Many participants described situations in which parental attention was primarily focused on the child with a disability, occasionally leading to feelings that their own needs were overlooked. Despite these experiences, participants often expressed understanding and empathy toward their parents, recognising the challenges associated with raising a child with a disability. Additional sources of support, particularly grandparents and extended family members, played an important role in many families. Such support was perceived as stabilising and helped alleviate some of the emotional and practical burdens experienced by both parents and siblings.

## Responsibility for the Future

The final major theme concerned responsibility for the future of the sibling with a disability. Participants were acutely aware that they might eventually assume primary responsibility for their brother or sister's care. This anticipated responsibility extended beyond current caregiving duties and was often viewed as a long-term moral and familial commitment. At the same time, this responsibility generated uncertainty and concern about the future. Participants reflected on issues such as housing, financial security, long-term care arrangements, and their ability to provide appropriate support. Concerns regarding the future emerged as a persistent source of reflection and emotional burden. Overall, the empirical material portrays the experiences of siblings of AAC users as deeply relational and firmly embedded within the family system. Participants' narratives reveal the coexistence of care, commitment, and meaning alongside burden, restricted autonomy, and uncertainty about the future. AAC emerged as a particularly important factor, not only enabling communication but also shaping family relationships, influencing the distribution of responsibilities, and affecting how siblings experience closeness, support, and caregiving within the family context.

## Discussion

The findings of this study indicate that the experiences of siblings of individuals with disabilities who use Augmentative and Alternative Communication (AAC) are highly complex and multidimensional. Analysis of participants' narratives revealed the coexistence of positive and negative experiences, reflecting what has been described in the literature as the *sibling paradox* in families of individuals with disabilities (Siman-Tov & Sharabi, 2024). Participants reported experiencing closeness, satisfaction, and a sense of meaning derived from their relationship with their sibling, while simultaneously encountering burden, frustration, and limitations on their personal autonomy. Similar observations were reported by Hastings (2003) and Giallo and Gavidia-Payne (2006), who argued that sibling experiences cannot be understood solely in terms of burden or solely in terms of developmental benefits. Rather, these relationships are dynamic and inherently ambivalent, with their significance changing across developmental stages and family circumstances. The findings also support the importance of a systemic perspective in understanding families raising a child with a disability. According to Minuchin's (1974) family systems theory, changes affecting one family member inevitably lead to the reorganisation of the entire family system. Participants' narratives demonstrate that siblings are not passive observers of these processes but active contributors to family adaptation. In many cases, participants assumed responsibilities that extended beyond normative developmental expectations, becoming involved in caregiving and supporting their parents. These experiences can be interpreted through the lens of functional parentification (Jurkovic, 1997). Consistent with the findings of Moyson and Roeyers (2012), early responsibility-taking appeared to foster independence, empathy, and social competence, while simultaneously increasing the risk of emotional overload and the suppression of personal needs.

One of the most significant findings of the present study is the identification of AAC as a key factor shaping family relationships. In contrast to many previous studies that have focused primarily on AAC users or their parents, the present findings highlight the perspective of siblings as communication partners. Participants' accounts suggest that communication was not merely a technical process of information exchange but an essential component of relationship-building, emotional closeness, and mutual understanding. These findings are consistent with the relational model of AAC proposed by Light and McNaughton (2014), which emphasises that successful communication depends not only on the competencies of the AAC user but also on the involvement of communication partners. Participants described numerous situations in which they supported their sibling's communication development, assisted with the implementation of AAC systems, and adapted their own communication styles to their sibling's abilities. In many cases, siblings became the individuals who best understood the communication needs and preferences of their brother or sister. At the same time, the findings demonstrate that AAC places additional demands on communication partners. Participants repeatedly emphasised the need for patience, the allocation of additional time for interaction, and the adaptation of conversational pace to their sibling's communicative abilities. These challenges were particularly evident when more complex AAC systems, such as alphabet boards, communication books, and eye-tracking technologies, were used. Such findings correspond with previous research indicating that communication outcomes depend on the competencies and commitment of the entire social environment surrounding the AAC user (Kent-Walsh & McNaughton, 2009). The analysis further suggests that AAC serves functions extending beyond communication support alone. Participants described communication tools as sources of agency, autonomy, and social participation for their siblings with disabilities. AAC enabled not only the expression of basic needs but also the development of interpersonal relationships, engagement in education, participation in social activities, and the pursuit of personal interests. These findings are consistent with perspectives that view communication as a fundamental prerequisite for self-determination and full social participation among individuals with disabilities (Light & McNaughton, 2014). Nevertheless, AAC did not eliminate all challenges experienced by siblings. Participants described situations involving frustration arising from misunderstandings, technological limitations, or the need to act as communication mediators. Siblings frequently assumed responsibility for facilitating communication and interpreting the needs of the individual with a disability for other family members or members of the wider social environment. This finding suggests that AAC should not be understood solely as an assistive technology but also as a factor shaping relationships, responsibilities, and role distribution within the family system. Another important theme emerging from the study concerns relationships with parents. Participants demonstrated considerable awareness of the burdens experienced by their parents and often interpreted parental behaviours in the context of the challenges associated with raising a child with a disability. At the same time, some participants reported feelings of invisibility, neglect of their own needs, or excessive responsibility. These findings align with previous research suggesting that unequal distributions of parental attention and family resources may contribute to feelings of marginalisation among siblings (Hastings, 2003; Giallo & Gavidia-Payne, 2006). Conversely, the presence of additional sources of support, such as grandparents or other relatives, appeared to play a protective and stabilising role. The findings also underscore the importance of social support in shaping siblings' experiences. Consistent with the conclusions of

Hacker et al. (2023), Levante et al. (2024), and Wolff et al. (2023), access to emotional and informational support appears to promote more adaptive functioning among siblings of individuals with disabilities. In the present study, the absence of such support was associated with feelings of loneliness and the need to manage difficult emotions and responsibilities independently. Particularly significant was the theme of prospective responsibility regarding the future of a sibling with a disability. Participants frequently perceived themselves as future caregivers for their brother or sister. This responsibility was described not only in practical terms but also as an existential and moral commitment. These findings are consistent with previous studies indicating that concerns about the future constitute one of the most common sources of stress and burden among siblings of individuals with disabilities (Hacker et al., 2023; Levante et al., 2024). At the same time, some participants viewed this responsibility as a natural and expected aspect of family relationships, further illustrating its inherently ambivalent character. In summary, the findings demonstrate that the experiences of siblings of AAC users constitute a complex phenomenon situated at the intersection of family relationships, communication processes, and developmental tasks. Particularly important is the recognition of siblings as communication partners of individuals who use AAC. This perspective enables AAC to be understood not merely as a technological tool but as a factor that actively shapes family relationships, influences the distribution of responsibilities, and contributes to the everyday experiences of all members of the family system. The findings highlight the need to include siblings in support initiatives for families of AAC users, both within educational and therapeutic practice and in future research.

## Conclusions

The findings of this study demonstrate that the experiences of siblings of individuals with disabilities who use Augmentative and Alternative Communication (AAC) are complex, multidimensional, and inherently ambivalent. Analysis of participants' narratives indicates that relationships with a brother or sister with a disability constitute both a source of closeness, empathy, and personal growth, and a source of emotional burden, increased responsibilities, and tensions associated with limitations on personal autonomy. Siblings therefore function within a space of ongoing negotiation between care and responsibility for another person and the pursuit of their own needs, aspirations, and life goals. One of the most important conclusions emerging from the study concerns the distinctive role of AAC in shaping siblings' experiences. AAC serves not only as a tool enabling communication for individuals with disabilities but also as a significant factor organising everyday family relationships. The findings indicate that siblings frequently assume the role of communication partners, actively participating in communication processes, supporting the use of AAC systems, and assisting in the interpretation of messages produced by their brother or sister. Such involvement promotes closeness and mutual understanding while simultaneously requiring patience, time, and considerable emotional resources. The findings further demonstrate that AAC enhances opportunities for self-determination, agency, and social participation among individuals with disabilities. Through AAC, individuals are able not only to express basic needs but also to communicate emotions, develop interests, establish interpersonal relationships, and participate actively in social life. At the same time, the effectiveness of AAC-supported communication remains closely dependent on the willingness, skills, and engagement of individuals within the immediate social environment, including siblings. The study also highlights the important, though often overlooked, role played by siblings within the family system. This role can be adaptive and may contribute to the development of social competence, responsibility, and emotional maturity. However, it is also associated with risks related to emotional overload, parentification, and experiences of accelerated maturation. These findings underscore the need for greater recognition of siblings within support services designed for families of individuals with disabilities. The results additionally emphasise the importance of social support in promoting sibling well-being. The presence of supportive family members, professionals, and institutions may serve a protective function by reducing feelings of loneliness and burden. Conversely, insufficient support may increase the likelihood of cumulative stress and long-term consequences for siblings' psychosocial functioning. From the perspective of educational and therapeutic practice, the findings suggest the need to view the family as an integrated system of support. Particular attention should be paid to recognising siblings not only as individuals who assist with caregiving and communication but also as independent recipients of support services. Involving siblings in AAC-related educational activities, providing opportunities for emotional expression, and ensuring access to psychological support may contribute both to improved sibling well-being and to enhanced communication outcomes and family functioning. The present study contributes to the growing body of knowledge concerning the experiences of siblings of AAC users. Due to the qualitative nature of the research and the relatively small number of participants, the findings cannot be generalised to the wider population. Future research should include larger and more diverse samples, as well as longitudinal studies that examine changes in sibling experiences across different stages of life. Particularly valuable directions for future research include further exploration of the role of AAC in shaping family relationships and the identification of support strategies that effectively address the needs of siblings of individuals who use AAC.

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