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The roles of adult siblings of individuals with a profound intellectual disability

Naomi I. Dorsman[1,2] | Aly Waninge[1,2] | Cees P. van der Schans[1,2,3] |
Jorien Luijkx[4] | Annette A. J. Van der Putten[4]

[1]Research Group on Healthy Ageing, Allied Health Care and Nursing, Hanze University of Applied Sciences Groningen, Groningen, The Netherlands

[2]Department of Health Psychology, University Medical Center Groningen, Groningen, The Netherlands

[3]Department of Rehabilitation Medicine, University Medical Center Groningen, Groningen, The Netherlands

[4]Department of Inclusive and Special Needs Education, University of Groningen, Groningen, The Netherlands

Correspondence
Naomi I. Dorsman, Research Group on Healthy Ageing, Allied Health Care and Nursing, Petrus Driessenstraat 3, 9714 CA, Groningen, the Netherlands.
Email: n.i.dorsman@pl.hanze.nl

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Abstract

Background: Adult siblings are important in the lives of individuals with profound intellectual disabilities, especially as parents age. However, little is known about the roles they assume.

Method: We examined these roles among 58 participants from the Netherlands, who completed an online questionnaire.

Results: Most participants (89.7%) assumed multiple roles, and the majority were content with their roles. Between 7% and 58% indicated that they were the only individuals providing a certain role. Shared roles primarily involved healthcare professionals, other siblings, and parents. Almost half the participants (48.2%) assigned higher scores for the amount of support provided than for the experienced burden.

Conclusions: Adult siblings often assume multiple roles. The shared roles emphasise the importance of collaboration.

KEYWORDS
family, multiple disabilities, profound intellectual disability, siblings, support

1 | INTRODUCTION

In recent decades, the importance of family members' roles relating to individuals with an intellectual disability in general and those with a profound intellectual disability in particular has gained increasing recognition. Studies have found that adults are generally close to and involved with their siblings with an intellectual disability (Bigby et al., 2014; Burke et al., 2015; Rossetti & Hall, 2015) and that time spent together is mutually enjoyable (Rossetti et al., 2020). Over time, siblings assume a special role in their natal families, as they often take over tasks from their ageing or deceased parents (Mailick Seltzer et al., 2005). Despite this transition of roles, siblings' involvement in future planning is generally limited (Heller & Kramer, 2009), and some siblings worry about

their future roles (Davys et al., 2010; Davys et al., 2016; Kruithof et al., 2021).

Adults support their siblings with an intellectual disability by monitoring and influencing formal care; complementing formal care; occupying formal roles and decision making, and securing the future by ensuring that someone would take over their roles should their sibling outlive them (Bigby et al., 2014). These roles relate to care or support. However, a recent study also added the roles of friend and sibling, thus emphasising the mutual aspect of the sibling relationship (Hall & Rossetti, 2017). The role of friend is characterised by social and reciprocal contact, entailing shared and enjoyable activities. The sibling role is characterised by features perceived as typical of a sibling bond. This role is more hierarchical, with siblings providing guidance or acting as surrogate parents (Hall & Rossetti, 2017). Hall and Rossetti (2017)

identified these roles in addition to the support-related roles of caregiver, advocate, legal representative, leisure planner, and informal service coordinator. Some siblings are also involved in communication support, a role that is characterised by mastering communication methods, such as sign language, as well as acting as an interpreter and teaching others to communicate with their siblings (Harland & Cuskelly, 2000). Other roles include supporting their siblings' personal development by teaching them new skills and encouraging them (Harland & Cuskelly, 2000) and providing parents with respite (Burke et al., 2015; Harland & Cuskelly, 2000).

Individuals with a profound intellectual disability have intensive support needs (Schalock et al., 2021). In this study, drawing on Nakken and Vlaskamp (2007) and Van der Putten et al. (2017), we use the term profound intellectual disability when the estimated Intelligence Quotient (IQ) is below 25 points. The exact IQ score is unknown because it is not possible to obtain reliable IQ measures in this range (Van der Putten et al., 2017). These individuals with profound intellectual disabilities express themselves non-verbally, for example, using sounds, facial expressions, or movements. In addition to an intellectual disability, motor or sensory impairments are often present. The severity of the impairments makes these individuals totally dependent on others 24 h a day (Nakken & Vlaskamp, 2007; Van der Putten et al., 2017; Van Timmeren et al., 2017).

These intensive support needs may influence the roles assumed by adult siblings. For example, individuals with intellectual and developmental disabilities are likely to make decisions about their leisure activities, whereas siblings or parents make more formal decisions such as decisions about employment or housing (Burke et al., 2019). However, for individuals with a profound intellectual disability, making decisions independently is more complicated. The need for intensive support can lead to more responsibilities for siblings. Individuals have been found to be more likely to provide care if their sibling has fewer functional abilities and displays more behavioural problems (Lee et al., 2019). Involvement in service planning meetings is also reportedly greater when an individual's sibling has fewer functional abilities (Lee et al., 2020). However, behavioural problems, difficulties engaging in social interaction, and limited communication abilities are common in individuals with a profound intellectual disability and seem to constrain the establishment of close relationships (Rossetti & Hall, 2015). This could reduce sibling involvement, as the quality of the sibling relationship is positively correlated with current sibling caregiving and the number of hours spent in caregiving (Lee et al., 2019).

Sharing roles could reduce the burden experienced. One study reported higher levels of well-being and lower levels of stress in mothers whose other children also provided support to the individual with an intellectual disability (Seltzer et al., 1991). However, another study found that parents of individuals with profound intellectual and multiple disabilities are reluctant to involve their other adult children in caregiving (Kruithof et al., 2021). The question of how adult siblings of individuals with a profound intellectual disability themselves reflect on the amount or burden of the support they provide remains unexplored.

More insight into roles and shared roles of adult siblings may help healthcare professionals and policy makers to foster optimal involvement of the informal social network of a person with a profound intellectual disability. In addition, knowledge about the perceived amount of support can sensitise healthcare professionals to situations wherein adult siblings may experience their roles as overwhelming. In this study, we aimed to expand knowledge about siblings' roles by focusing specifically on individuals with a profound intellectual disability. We investigated how adult siblings reflect on their roles, how roles are shared within their social networks, and how siblings experience the amount and burden of the support they provide. Data were gathered between November 2020 and May 2021, when preventive measures against the COVID-19 pandemic were in place in the Netherlands. These circumstances were taken into account by including COVID-19 as a research topic.

We sought to answer the following research questions:

1. Which roles do adult siblings assume in the lives of individuals with a profound intellectual disability?
2. How do adult siblings reflect on the sibling relationship, their contentment with their roles, and the effect of the COVID-19 pandemic?
3. To what extent are their roles shared with others?
4. How do adult siblings perceive the amount and burden of the support they provide?

2 | METHODS

2.1 | Participants and recruitment

This study is part of a larger project about adult siblings of individuals with a profound intellectual disability in the Netherlands. Ethical approval was obtained from the Hanze University of Applied Sciences Groningen's Ethical Review Board (approval number: heac.2020.018). There was no financial incentive offered to participate in the study.

Participants completed an online survey focusing on their roles and experiences. The study's inclusion criterion was having a sibling aged above 30 years with a profound intellectual disability. To help individuals determine whether they were eligible to participate, a description of a profound intellectual disability, as presented in the introduction section, was provided at the beginning of the survey.

Information about the study was disseminated through eight organisations in the Netherlands that support individuals with intellectual disabilities. including those with a profound intellectual disability. These organisations provide ambulatory support, day care and care with residence, for example, in group homes. We also disseminated information through interest groups and on social media, and participants could share the survey within their own social networks.

After signing up, participants received an email with information and a clear explanation of their rights, including the right to withdraw from the study, along with an informed consent form. Thereafter, they received a link to the online survey. Participants provided informed

TABLE 1 Demographic data on participants and their siblings.

n = 58, Variable	Participants		Siblings	
	n	%	n	%
Country of birth				
The Netherlands	55	94.8		
Other	3	5.2		
Highest education level				
Primary	1	1.7		
Secondary	2	3.4		
Post-secondary vocational	20	34.5		
Higher vocational	24	41.4		
University	11	19		
Number of siblings in the family in addition to the respondent and the individual with a profound intellectual disability				
No other sibling	16	27.6		
1 other sibling	20	34.5		
2 other siblings	8	13.8		
3 or more other siblings	12	20.7		
No answer	2	3.4		
Health problems				
Incontinence			38	65.5
Epilepsy			32	55.2
Visual impairment			29	50
Contractures			26	44.8
Constipation			25	43.1
Behavioural problems			18	31
Spasticity			14	24.1
Reflux			13	22.4
Other			16	27.6

consent by ticking a box. Survey data were aggregated between November 2020 and May 2021 using Qualtrics, a secure survey platform.

Of the 79 participants who signed up, 61 met the inclusion criterion. Three survey forms were excluded because they only contained background information. The remaining 58 forms were included in the analysis. The mean age of the 58 participants was 50.1 years (SD = 12.0 years), and 79.3% were female. A total of 25.9% of the participants indicated that their parents were strongly involved in supporting their siblings, 32.8% indicated that their parents were still involved but had transferred some of their tasks to others, and 41.4% indicated that their parents were no longer involved in supporting their siblings. Of the participants whose parents were no longer involved, two had no other siblings and could, therefore, be seen as the only individuals within the direct family who could provide support. Additional caregiving responsibilities, including caring for their own young children, parents, or parents-in-law, were reported by 60.3% of the participants.

The mean age of the siblings with a profound intellectual disability was 49.6 years (SD = 10.8 years), 65.5% were female. A total of 20.7% of the siblings with a profound intellectual disability were aged between 0 and 5 years when they moved into a care facility or group home, 51.7% were aged between 6 and 18 years, 24.1% were above 18 years, and 3.4% were still living at home. Table 1 provides further demographic information on the participants and their siblings.

2.2 | Data collection

We investigated the roles assumed by adult siblings with reference to those identified by Hall and Rossetti (2017), who performed a thematic analysis of open-ended responses to a survey. They identified the following roles: *caregiver, friend, advocate, legal representative, sibling, leisure planner, informal service coordinator,* and *no role.* We added *communication support, personal development support* (Harland & Cuskelly, 2000), and *providing respite for parents* (Burke et al., 2015; Harland & Cuskelly, 2000). For the additional role of *providing respite for parents*, we categorised activities such as looking after their siblings while parents ran errands as part of that role rather than as part of the *caregiver* role described by Hall and Rossetti (2017). In addition, we

TABLE 2 Overview of the roles and the examples provided in the survey.

Role	Example
No role	-
Caregiver	You help with dressing, showering, and teeth brushing; feeding and giving drinks to your sibling; and you provide new and clean clothes.
Friend	You maintain regular contact, visit your sibling, or send them a card. You have fun together, and you have coffee together.
Advocate	If you notice that your brother or sister is not feeling well, you discuss your concerns with the care staff. You are present at meetings held to discuss your sibling. If your sibling has a specific wish, you make arrangements to ensure that it is fulfilled.
Legal representative/ administrator/ mentor	You take care of the financial responsibilities. You are the contact person for emergencies. You are jointly responsible for the care that is provided.
Sibling	You share special jokes with your sibling or like to tease them. You are like a second parent. You bring them the treats that your parents always gave you both when you were children.
Leisure planner	You come up with fun outings or a fun activity to do together at home. You arrange for a volunteer to assist with swimming because your sibling loves swimming. You take your sibling to family gatherings.
Informal service coordinator	You ensure that your sibling receives good care now and in the future. You explain their wishes and needs to new care staff.
Communication support	You are usually well aware of how your sibling is feeling and the signals that they are sending out. You pass this information on to the care staff.
Personal development support	Together with the staff of the care facility, you consider appropriate new challenges for your sibling.
Providing Respite for Parents	You look after your sibling when your parents go on an outing. You are the contact person for the institution when your parents go on holiday.
Other	

changed the role of *legal representative* to *legal representative/administrator/mentor*, which includes some of the activities that Hall and Rossetti (2017) assigned to the *informal service coordinator* role. We had help from an adult whose sibling has an intellectual disability, to define examples of each of the roles that matched the situation in the Netherlands, thereby facilitating the participants' recognition of the roles. These examples were included in the survey (Table 2). Participants were asked which roles they assumed and could choose multiple roles.

Next, we analysed the participants' reflections in response to the following questions about their roles:

- How would you describe your relationship/involvement or connection with your sibling?
- Are you happy with the roles you take on, or would you like something to be different?
- Are the COVID-19 prevention measures affecting the roles you take on? If so, how?

Participants were then asked if they shared each of the roles listed in Table 2 with others. They could specify whether they were the sole persons assuming this role or whether they shared the role with their parents, other siblings, other non-sibling family members, healthcare professionals, volunteers, or others.

Lastly, we investigated how adult siblings perceive the amount and burden of the support they provided. Responses to the following two questions were analysed:

- To what extent do you support your sibling? A numeric 10-point scale was provided, with responses ranging from 'not' to 'very intensive' support.
- How do you perceive the support you provide? We provided a numeric 10-point scale, with responses ranging from 'light' to 'heavy' burden.

2.3 | Analysis

We applied descriptive statistics to analyse the roles assumed by participants. We first calculated the mean and SD values for the number of roles that participants took on, followed by the frequencies at which the 12 roles were assumed. Next, we calculated separate frequencies for the participants who assumed the *sibling* role and those who did not. Frequencies were also calculated to determine the percentage of participants who shared roles with others.

We performed thematic analysis (Braun & Clarke, 2006) on responses to the open-ended questions about participants' relationships with their siblings with a profound intellectual disability, their contentment with the assumed roles, and the impacts of COVID-19. For each question, a separate coding scheme was developed using an inductive approach. The analytical steps were as follows:

1. All responses to the open-ended questions were read to gain a first impression of the data.
2. All responses were coded sentence by sentence, and each new topic was assigned a new code. If subsequent sentences were about the same topic or conveyed the same idea, they were assigned one code. If more topics were present within the same sentence, multiple codes were assigned.
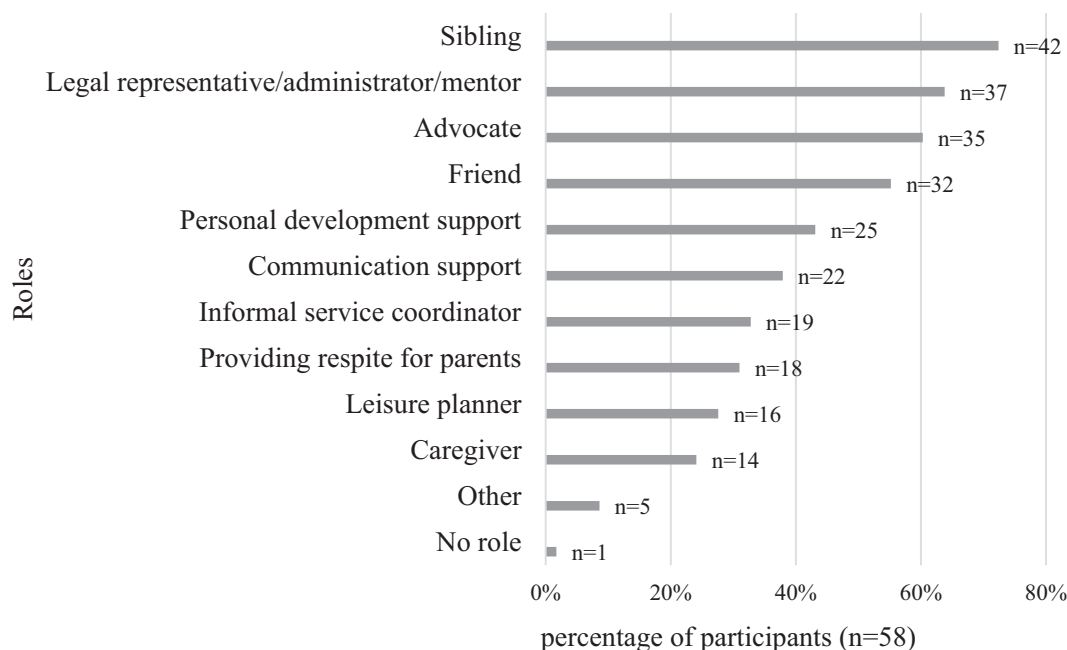
FIGURE 1 Percentage of participants assuming different roles.

3. Similar codes were subsequently merged, and a coding scheme was developed.

4. The final coding scheme was used to re-code all the answers.

5. After the first author had coded the data, AW and JL checked the data and assigned codes. Both co-authors agreed with the coding frame and the way of assigning codes to the data. There was a brief discussion about codes that were only assigned once or twice. A consensus was reached on including topics raised by two or more participants, thereby incorporating less common views into the analysis.

We used descriptive statistics to analyse scaled responses to the questions on the amount and burden of the provided support. Three participants did not answer one of these questions. Therefore, 55 participants' responses were included in this specific analysis. The mean and SD values were calculated and the relationship between the perceived amount and experienced burden of the provided support were analysed visually using a scatterplot. Thereafter, responses relating to each of the different roles were analysed separately by dividing the participants in two groups for each role: those who assumed a specific role and those who did not. For each group, we calculated the mean values for the perceived amount of support and the experienced burden of the support. As most participants took on multiple roles, the groups overlapped.

3 | RESULTS

3.1 | The roles assumed by adult siblings

Most participants (89.7%) took on multiple roles, with a minority (8.6%) assuming one role. We obtained a mean of 4.6 roles per person (SD = 2.6). Figure 1 depicts an overview of the percentage of participants assuming different roles.

Our comparison of participants who did and did not assume a *sibling* role revealed differences between both groups. All roles apart from those of *legal representative/administrator/mentor* and *other* were assumed by a higher percentage of siblings reporting a *sibling* role. A total of 75% of participants who did not assume a *sibling* role took on the role of *legal representative/administrator/mentor*, compared with 59.5% of participants who also fulfilled a *sibling* role.

3.2 | Reflections on the roles assumed

3.2.1 | The sibling relationship

Most participants (74%) described their relationships with their siblings with a profound intellectual disability in positive terms, as loving and warm or stating that they had a good relationship or felt deeply connected.

> Lovely, warm, cuddly, loving.
>
> (Participant 22)

> She is often in my thoughts. Visits do not happen very often but they are precious.
>
> (Participant 26)

A minority (9%) did not have a close bond or were uncertain about whether they had a bond. Some participants mentioned the following characteristics of their bonds with their siblings: being like a second parent, a non-reciprocal relationship, and a changing

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relationship (becoming closer or less close). Profound disabilities, outbursts of anger, declining health due to illness, and not growing up together were mentioned as factors that influenced the sibling bond.

> Distant: My sister left home when I was aged one. As a result, I was barely able to bond with her and when I am with her, I feel uncomfortable. Since my mother's death, I've been the legal representative. So, I mostly arrange all the affairs.
>
> (Participant 15)

Some participants described bonds with their siblings based on the responses they received from them, for example, expressions of love or happiness.

> Close-knit: She recognizes me and becomes visibly and audibly happy about my presence.
>
> (Participant 10)

Two participants mentioned that their siblings recognised them, and two others stated that although their siblings recognised them, they did not show that they missed them. Participants also frequently described their relationships as entailing engagement in activities, notably visiting their siblings or doing things together.

> I have a good bond with my sister and visit her regularly. Apart from during the coronavirus pandemic, another sister and I take her into town to buy clothes and have lunch. Once a year, we go on a midweek break with her.
>
> (Participant 42)

Some participants mentioned that they felt that they should visit their siblings more often. When describing the relationship, participants referred to different aspects of the roles they assumed, such as being a mentor, voicing their siblings' needs, and monitoring their siblings' well-being. A few participants mentioned that their parents did the most for their siblings.

3.2.2 | Contentment with the assumed roles

When asked whether they were content with the roles they assumed and whether they would like things to change, some participants indicated that they wished to spend more time together or do more for their siblings with a profound intellectual disability. Others desired greater sharing of their roles. Two participants noted that they were content with the current situation, although they would rather have had healthy siblings. However, the majority of participants (75%), indicated that they were content with their roles, whether extensive or limited:

> I am very satisfied with the roles I fulfil. I wouldn't want it any different. I also wouldn't know what to do without her; she is everything to me.
>
> (Participant 39)

> Yes, I am satisfied and do not wish for more. I am no longer expecting a connection to surface. In addition, the distance (…) is also a hindrance (the return journey takes around 6 hours). And I have a busy life myself.
>
> (Participant 15)

3.2.3 | The effects of the COVID-19 pandemic

During the period when COVID-19-related measures were in place, two participants brought their siblings home to care for them. Others observed that measures relating to COVID-19 did not affect their roles. However, the majority of the participants had less contact or temporarily lost contact with their siblings with a profound intellectual disability. Participants noted that certain mutual activities were no longer possible or that visits were less enjoyable. Not being able to have physical contact could be difficult because for some participants, this was an essential part of being together with their siblings with a profound intellectual disability.

> No massages, no intimate moments in her room, no listening to music together in her room. A real shame, and damaging for our relationship.
>
> (Participant 4)

Participants were afraid of infecting their siblings or others in the group home, and having to plan the visits led to less spontaneous contact. Some participants monitored their siblings' situations more closely or used alternative forms of communication with their siblings or support staff, which were sometimes successful as illustrated by one participant:

> At that time, I couldn't visit as often, but we tried out video calling, which was also enjoyable, so I was able to sing to her before sleep once while I also put my own children to bed, which was very cosy. My sister was quite surprised but she did enjoy it.
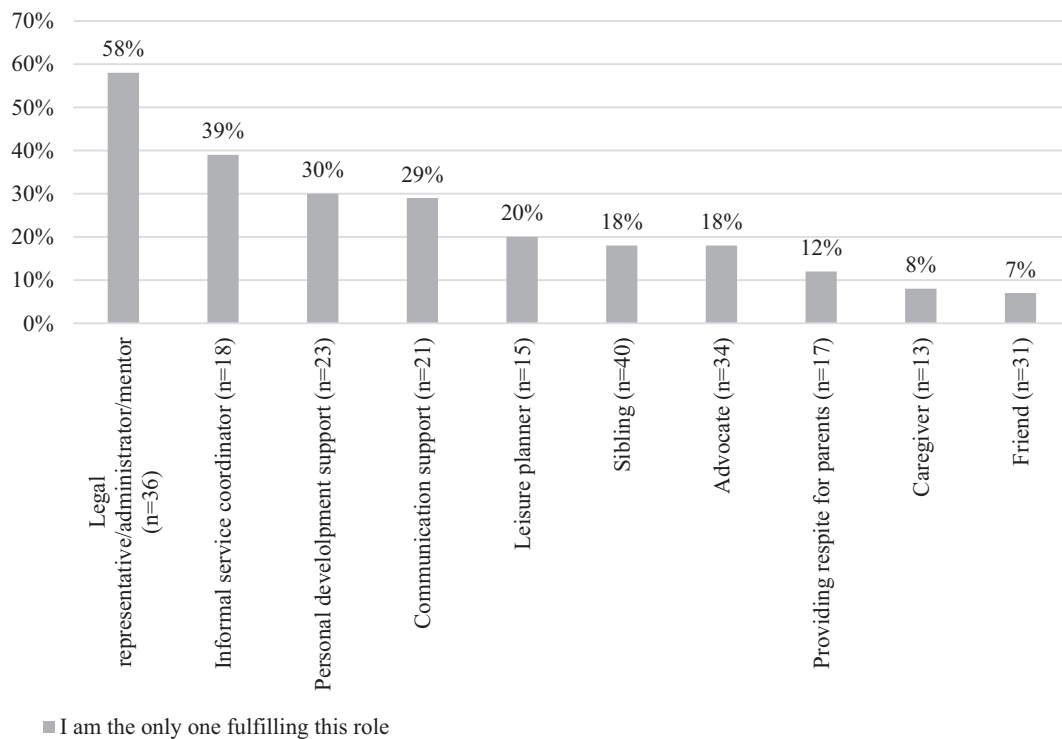>
> (Participant 30)

3.3 | The extent to which roles are shared

3.3.1 | Being the only person assuming a certain role

The percentage of participants reporting that they were the only persons fulfilling a particular role ranged between 7% and 58% for the different roles (Figure 2).

FIGURE 2 Percentage of participants indicating that they were the only persons assuming a particular role in their siblings' lives. For each role, *n* indicates the total number of participants who assumed that role.

TABLE 3 Roles shared with others.

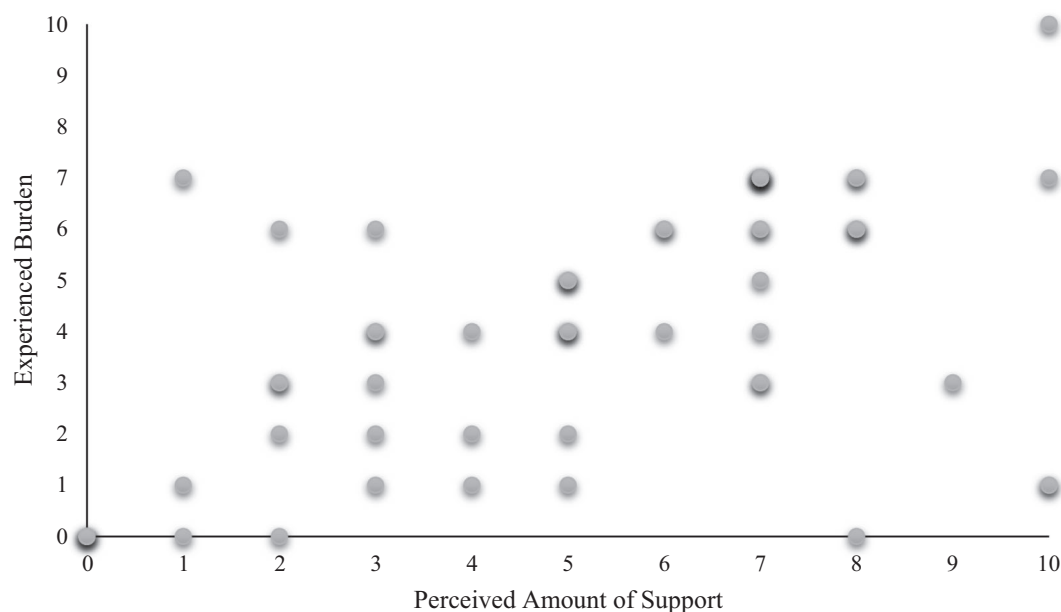| Role (n[a])	Healthcare professionals, %	Siblings, %	Parents, %	Volunteers, %	Other family members, %	Others, %
Sibling (40)	20	**55**	18	13	13	10
Legal representative/administrator/ mentor (36)	3	17	25	-	-	3
Advocate (34)	**41**	**35**	29	3	-	18
Friend (31)	**39**	**42**	**36**	**36**	10	23
Personal development support (23)	**39**	17	26	9	4	4
Communication support (21)	**38**	**33**	**33**	10	14	10
Informal service coordinator (18)	17	22	**33**	11	6	6
Providing respite for parents (17)	29	**47**	18	12	18	12
Leisure planner (15)	**53**	27	**33**	**40**	7	7
Caregiver (13)	**46**	**46**	**46**	-	-	23

[a]Only respondents who answered the question about shared roles were included. As multiple answers were possible, percentages did not add up to 100%. Bold font is used to highlight percentages >30.

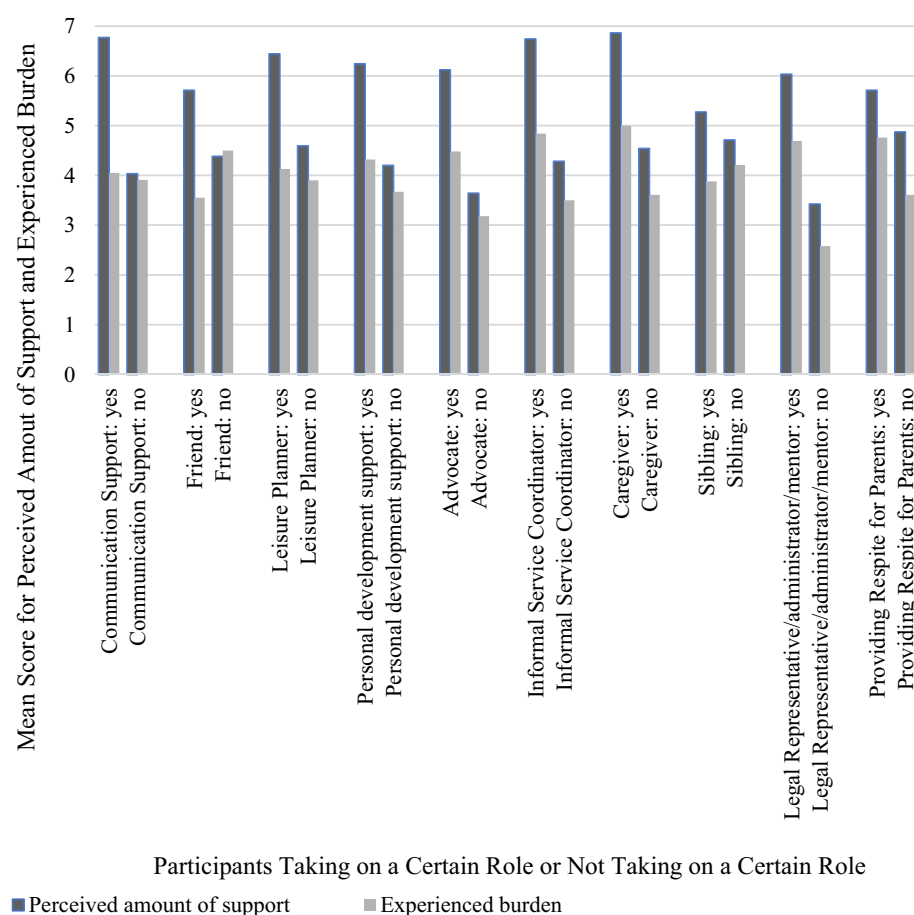## 3.3.2 | Sharing roles with others

Roles were reportedly shared most frequently with healthcare professionals, other siblings and parents, and, to a lesser extent, with volunteers, other family members, and others such as neighbours or friends (Table 3).

3.4 | The amount and burden of the provided support

Figure 3 shows the extent to which participants indicated that they supported their siblings ($M = 5.1$; $SD = 2.9$) and whether providing this support was experienced as light or as a heavy burden ($M = 4.0$; $SD = 2.6$).

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FIGURE 3 Scatterplot of the perceived amount of support and the experienced burden.

FIGURE 4 Mean scores for the perceived amount of support provided and the burden experienced when assuming different roles.

Considering both questions, 48% ($n = 28$) assigned a higher score to the perceived amount of support jarvided compared with the experienced burden of providing this support. A total of 12% ($n = 7$) assigned higher scores to the burden than to the amount of support provided.

In general, those who assumed a certain role assigned higher scores for the amount of support provided and the experienced burden compared with those who did not (Figure 4). By contrast, participants assuming the *sibling* and *friend* roles generally perceived that

they provided more support but experienced a lighter burden compared with participants who did not take on these roles.

For the most part, differences between the scores for the amount of support provided and experienced burden were more significant for the group assuming a certain role compared with the group that did not assume this role. This was most evident for the *communication support* and *friend* roles.

4 | DISCUSSION

This study explored the roles assumed by 58 adult siblings of individuals with a profound intellectual disability, how they reflected on these roles, to what extent siblings shared their roles with others, and how they perceived the amount and burden of the support they provided.

Our finding that most participants assumed multiple roles supports those of previous studies on the siblings of individuals with an intellectual disability (Burke et al., 2015; Hall & Rossetti, 2017; Harland & Cuskelly, 2000). In the current study, the *sibling* role was the role most assumed, however, strikingly, not all participants identified with this role. This finding may be attributed to emotional closeness associated with the *sibling* role (Rossetti et al., 2018). While most of the participants described their relationships with their siblings with a profound intellectual disability in positive terms, some participants were unsure about the bond with their siblings or indicated that they did not have a close bond. In addition our findings showed that a higher percentage of participants who did not assume the sibling role took on the role of *legal representative/administrator/mentor*. The responsibilities that come with this role may make individuals feel less like a *sibling*.

A majority of the participants were content with their roles. However, our findings indicated that decreased contact resulting from measures implemented against COVID-19 impacted the sibling relationship. A recent study found that the disruption of their siblings routines and activities due to COVID-19 was the main concern of adult siblings of individuals with an intellectual disability (Redquest, Tint, Ries, & Lunsky, 2020). In the current study, participants raised concerns relating to maintaining the sibling relationship, such as fewer shared activities and lack of physical contact. The latter can be particularly difficult because for some participants, it is an essential component of being together with their siblings with profound intellectual disabilities.

Participants frequently reported that they were the only persons taking on a certain role, especially that of *legal representative/administrator/mentor* and *informal service coordinator*. Notably, approximately one-third of the participants who assumed the *personal development support* and *communication support* roles also indicated that they were the only persons doing so. One reason for non-sharing of roles may have to do with the limited informal social networks of individuals with profound intellectual and multiple disabilities (Kamstra et al., 2014). There may only be a few individuals with whom roles can be shared. Indeed, we found that roles were most commonly shared with

healthcare professionals, parents, and other siblings and were shared only infrequently with others. Taking on multiple roles and not being able to share them can impact an individual's quality of life and make their position vulnerable. It is unknown whether others will be able to take over the siblings' roles if they are unable to maintain them. This also implies the vulnerability of the person with a profound intellectual disability, who benefits from their sibling's practical and substantive involvement.

Contrary to what we expected, the *sibling* role was not understood as a role solely fulfilled by siblings. Several participants indicated that they shared this role with healthcare professionals, parents, volunteers, family members, and others. When responding to this question, the participants may have had the specific activities in mind that were provided as examples of the sibling role, and they may have consequently reflected on whether others performed these activities.

Our findings on the perceived amount of support provided were comparable to those of previous studies involving the siblings of individuals with less severe disabilities (Redquest, Tint, Ries, Goll, et al., 2020). Intensive support needs do not seem to elicit perceptions of a higher degree of support provided. Interestingly, we found that almost half of the participants assigned a lower score for the experienced burden than for the amount of support they offered. However, 12% of the participants assigned a higher score for the burden than for the amount of support provided, indicating that for some siblings, providing support is experienced as a relatively heavy task.

For most roles, the difference between scores for the amount of support provided and the experienced burden was greater for those fulfilling a certain role compared with those who did not. Individuals may take on roles that do not overly increase their burden. It is also possible that individuals who take on roles are more resilient. Consequently, providing more support results in only a slight increase in the burden. In addition, the type of role seems to be related to the experienced burden. Participants fulfilling the roles of *sibling* and *friend* reported a lighter burden than those who did not assume these roles, while also assigning a higher score to the amount of support they provided. The feeling of friendship and emotional connection or closeness entailed in these roles may be protective factors that can diminish the experienced burden.

4.1 | Limitations of the study

This study had some limitations. By distributing the survey via interest groups and healthcare organisations, we may have targeted a selective group of highly involved siblings. In addition, only a few participants from minority groups were involved. Moreover, most of the participants were female, which could have further biased the results, as one study found that sisters of individuals with an intellectual disability are more involved in supporting them than brothers (Orsmond & Mailick Seltzer, 2000). Therefore, our findings cannot be generalised to the entire group of adult siblings of individuals with a profound intellectual disability. A second caution relates to the sizes of our subsamples. By separately analysing shared roles and the

perceived amount and burden of the provided support for each role, the number of participants within each subgroup was limited, especially for the least fulfilled roles. It is also noteworthy that while examples were provided for each role, clear definitions were lacking. For example, individual interpretations of a *sibling* role may differ.

4.2 | Implications for future research

Shared roles necessitate positive collaboration between siblings, parents, and healthcare professionals. A strained relationship may impact sibling involvement, reducing the possibility of sharing information about the person with a profound intellectual disability, and thus negatively impacting this individual's quality of life. Therefore, improving collaboration between adult siblings and healthcare professionals is an important topic for future research. This research could include caregivers' perspectives and seek to identify elements of positive collaboration that can be expanded. In our study, we asked participants about their current situation. A life course perspective could also be of value (Coyle et al., 2014; Dew et al., 2008) for expanding our understanding of adult siblings' experiences during different phases of life.

4.3 | Implications for practice

The topic of collaboration between siblings and healthcare professionals merits special attention in practice. It is crucial to ensure that important information is transferred to newly attending healthcare professionals, particularly in situations entailing regular staff turnover. This information covers siblings' relationships, roles, and wishes. Sibling involvement, for example, could be included as a recurring topic of discussion in service planning meetings.

Because roles are frequently shared between siblings and parents, collaboration between family members is another area that requires attention. Studies on future planning have found that often, expectations about future roles and responsibilities were not explicitly discussed (Coyle et al., 2014; Kruithof et al., 2021; Leane, 2020), although the expectations of siblings and parents seemed to be aligned (Kruithof et al., 2021). However, when parents communicated their expectations more explicitly, siblings felt they were better prepared to take over the role of caregiver (Coyle et al., 2014). Healthcare professionals can play a facilitating role by including siblings in service planning meetings at an early stage. By bringing up the topic of shared roles and future planning, they could encourage all family members to reflect explicitly on their roles, involvement, needs, and wishes. Finally, healthcare professionals can assume a coordinating role relating to the involvement of different members of the social network.

Our study has shown the value of the involvement of adults in the lives of their siblings with profound intellectual and multiple disabilities. Siblings often take on multiple roles, offering substantive practical and emotional support. Roles are frequently shared between adult siblings, parents, and healthcare professionals. This emphasises the importance of positive collaboration. When siblings are the only persons assuming a certain role, this may lead to a vulnerable situation, as it can impact the supporting siblings' quality of life, and it is unclear whether others will be able to take over their roles if they are unable to maintain them. Because the amount of support provided is not always in accordance with the experienced burden of providing this support, it is important to ask siblings about their individual experiences.

CONFLICT OF INTEREST STATEMENT

We have no conflicts of interest to disclose.

DATA AVAILABILITY STATEMENT

Research data are not shared due to privacy or ethical restrictions.

ORCID

Aly Waninge https://orcid.org/0000-0002-2316-2577

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