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Lived experiences of parents with deafblindness – not ‘a walk in the park’

Agneta Anderzén-Carlsson^{a,b} , Karina Huus^c , Maria Björk^c , Camilla Warnicke^{a,d}  and Moa Wahlqvist^{a,e,f} 

^aUniversity Health Care Research Centre, Faculty of Medicine and Health, Örebro University, Örebro, Sweden; ^bFaculty of Health and Social Sciences, Inland Norway University of Applied Sciences, Elverum, Norway; ^cCHILD research group, Department of Nursing Science, School of Health Sciences, Jönköping University, Jönköping, Sweden; ^dUniversity Health Care Research Centre, School of Behavioural, Social and Legal Sciences, Örebro University, Örebro, Sweden; ^eAudiological Research Centre, Faculty of Medicine and Health, Örebro University, Örebro, Sweden; ^fThe Swedish National Resource Centre for Deafblindness, Lund, Sweden

ABSTRACT

Purpose: To describe how parents with deafblindness experience parenting and family life.

Materials and methods: This a qualitative interview study. Fourteen parents with deafblindness were interviewed. Most were mothers ($n=10$), with ages ranging between 33 and 57 years (mean 46 years). Interviews were transcribed, and the analysis was done using inductive qualitative content analysis.

Results: The analysis resulted in the overarching theme, ‘Living family life as a parent with deafblindness is not a walk in the park, but it is rewarding’, and three subthemes, ‘Being a competent parent despite having deafblindness’, ‘Needing support to fulfil my parental obligations’ and ‘Parenting is a struggle due to my deafblindness’. The results encompass many experiences and feelings and illustrate the complex reality of these parents in their parental role and family life.

Conclusion: The parents expressed their joy in being parents, but these feelings were intertwined with negative aspects of being unable to take on the desired responsibility or not receiving the necessary support. When requested, tailored support should be offered from social services, health care and rehabilitation services in order for parents with deafblindness to take on the parental responsibility they want and to be able to actively participate in family life.

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Deafblindness; disability research; family life; lived experience; needs; parenting

► RELEVANCE FOR REHABILITATION


- The support needs of parents with deafblindness vary, depending on factors such as the effects of their deafblindness, their ability to identify and use strategies in their daily life as a parent, and the age and personality of their child; thus, it is necessary to tailor support to the individual.
- Parents with deafblindness require individualised support in order to be able to master the demands that occur in their lives and to enable them to live up to their standards of being a good parent; the lack of such support could lead to poor health for them and their families.
- In addition to formal support, parents with deafblindness value peer support; therefore, agencies that provide formal support can facilitate such encounters.

Introduction

The focus of this paper is on parenting under-age children and living family life when living with deafblindness – an area that has been sparsely reported in the literature. The right to be a parent on equal terms with others, despite living with a disability, is stated in the UN Convention on the Rights of Persons with Disabilities. The convention addresses the right of parents with a disability to be provided with support to uphold their parental obligations [1]. Nonetheless, research has shown that such parents’ abilities are often questioned. For example, mothers with intellectual disabilities have been questioned regarding being competent parents on the basis of their disability [2,3]. Furthermore, Grue and Lærum [4] found that mothers with physical disabilities experienced the need to present themselves as capable and their children ‘managing normally’ in order to be regarded as ‘mothers’

by the society. Similarly, mothers with multiple sclerosis felt as if they needed to be ideal mothers. These mothers described the need to develop their own strategies for obtaining the necessary information and getting the physical and social support they needed. Moreover, they had to find strategies to save energy in order to be able to keep their babies safe and take care of their children [5]. Deaf parents with hearing children have been studied from a language and cultural perspective which revealed that they met the same challenges in their up-bringing of children as other parents. However, issues related to communication can be more prominent for Deaf parents [6]. Mallory et al. [7] found that Deaf parents more frequently turned to friends and relatives for help with questions on upbringing of their child, than asking for professional support. If the Deaf parents did turn to professional support, such as counselling services or parent support groups, they wanted this service to be provided in sign language [7].

CONTACT Agneta Anderzén-Carlsson  agneta.anderzen-carlsson@oru.se, agneta.anderzen-carlsson@regionorebrolan.se  University Health Care Research Centre, S-house, Örebro University Hospital, SE-70185 Örebro, Sweden.

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Parents with visual impairment or blindness were interviewed about their experiences of raising children and strategies used. The parents expressed positive aspects related to being a parent and having visual impairment, leading to that their children seemed to be more empathic towards others and more accepting of differences. However, they also reported on challenges they had experienced with mobility issues and keeping the child safe, as well as experiences of feeling left out of activities such as sports or when the child was playing in a distance [8].

It is not only the disability itself that affects the parental experience of parents with a disability. The environment and support offered can affect their parenting. Selander [9] found that parents in need of personal assistants sometimes struggled to maintain power and control in their everyday life. Furthermore, Selander and Engwall [10] reported that the parenting strategies of parents living with extensive physical impairments were influenced by when the disability occurred (i.e., before or after being a parent), the gender of the parent and the age of the child. Selander and Engwall [10] also found that a personal assistant could be both an enabler of the parent and a competitor for the child's attention and affection. Still, having a personal assistant was regarded as something that increased the parent's ability to be active in parenting. Berggren and Bergman [11] came to the same conclusion in their interview study – namely, that a personal assistant enables parents with physical and/or cognitive disabilities to fulfil their parental role. However, inflexibility in how this personal assistance was structured negatively affected the parent's opportunities to take on parental responsibility, as well the child's opportunities to take part in activities [11].

Deafblindness is a distinct disability in which an individual experiences combined vision and hearing impairment, where hearing and vision are insufficient to compensate for the loss in the other sense [12]. Thus, according to the Nordic definition, deafblindness limits a person's activities and restricts full participation in society to such a degree that society is required to facilitate special services, environmental alterations and technical solutions [12]. Deafblindness does not imply total blindness or deafness. On the contrary, there is great variation in the degree of visual and hearing impairment, as well as the onset and cause of deafblindness [13]. Deafblindness can be present from birth or acquired later in life [14,15]. The condition is often progressive, and it is common to have problems with adapting to dark or light conditions and experiencing glare or visual field restrictions [16]. Some of the challenges when living with deafblindness relate to difficulties in communication, only being able to receive fragmented information from their environment and restrictions in the activities of daily life [13,17–19]. Individuals with deafblindness often depend on communication and information that is shared in close proximity and by physical contact. Different ways to communicate is used by people with deafblindness, verbal, visual sign language and tactile sign language. Often a mix of modalities are used, depending on the situation [20]. Communication difficulties can occur when proper adaptations in terms of lightning or distance is not met or if interpreters (in sign language or tactile sign language) are not offered to the extent that it is needed [17]. Fragmented information of what can be seen or heard from the surroundings due to vision and hearing impairment can impact on activities in daily living such as the ability to move around safely [18]. Restrictions in daily activities further relates to house cleaning or grocery shopping, as well as the possibility to engage in activities spontaneously [17]. In addition, research shows that health can be compromised when living with deafblindness [21,22]. Health outcomes such as headache, fatigue, depression and suicide ideation has been described, as well as no one to share innermost feelings and thoughts with. Likewise, a strained

economic situation has been described [23–25]. Research has reported unmet needs and lack of formal support from healthcare and social services for individuals with deafblindness [26].

The sparse literature on family life when a parent is living with deafblindness has mostly focused on the partner's and children's perspective. In a study by Björk, Wahlqvist, Huus and Anderzén-Carlsson [27], the experiences of partners sharing a household with a parent with deafblindness were explored. The results showed that family life was affected in almost every activity and that communication was a challenge due to not sharing the same language (i.e., sign language vs. spoken language). The partners also described putting themselves in second place on behalf of the parent with deafblindness, in order to facilitate family life. When interviewed on their experiences, children of parents with deafblindness described their family life as being similar to that of their peers but still a bit different when it came to considerations on behalf of the parent with deafblindness. For example, like other children they went shopping with their parents, they watched television and played with their friends. On the other hand, they adjusted to the parent's needs, helped their parent and protected them from harm in a way that their friends might not do [28]. Health-related quality of life, sense of coherence and family climate were explored in a study that covered all the family members in families including a parent with deafblindness [29]. The results revealed that family life was affected by the deafblindness, and that there was a risk that the health-related quality of life would be hampered. These families were reported to have a low sense of coherence, although the family climate was described as being characterised by closeness. Similar results were presented in an article by Damen, van Zadelhoff and Tijsseling [30], who described the experiences of families in which a parent had progressive deafblindness due to Usher Syndrome Type 2 (Usher Syndrome is the most common genetic diagnosis under the umbrella concept of deafblindness). The researchers found that parents with deafblindness experienced feelings of loneliness, as well as other psychological consequences of deafblindness. They also reported the possibility of inequality in the relationship between parents. The families in the above-mentioned studies were described as requiring support from society, which was often lacking [27–30]. Evans and Baillie [31] described experiences of family life and parenting in such families. Their results revealed that the mothers with deafblindness experienced questioning from professionals regarding their competence as parents, due to their deafblindness. However, these parental experiences were revealed by older adults looking back at the time when their children were young.

Given the limited research of first-hand experiences of being a parent and living family life when having deafblindness, additional research is called for, in order to identify potential needs that should be accommodated to enable the parent and family to live life on equal terms with others. Thus, the aim of this study is to describe how parents with deafblindness experience parenting and family life.

Methods

Design

The study is a qualitative interview study as this is considered to be suitable when investigating what it feels like to be a member of a family [32]. This study is the last in a series of studies [27–29] within a larger research project focusing on the health and lived experiences of families that include a parent with deafblindness. This study is presented in line with the COREQ checklist for reporting qualitative findings [33], see [Appendix 1](#).

Participants and setting

A convenience sampling technique was used to identify participants for this research [34]. The inclusion criteria were: having deafblindness, being the parent of a child aged 6–18 years (as their children were invited to participate in interviews for a separate study and as we wanted to collect ongoing experiences of parenting a child living at home), and living with the child at least 50% of the time. In addition, the participant had to be able to communicate with the researchers using spoken Swedish or Swedish sign language, either directly or through professional interpreters from Swedish sign language to spoken Swedish.

The board members of the family section of the Swedish Non-governmental Association of the Swedish Deafblind disseminated information about the study verbally, *via* sign language and over Facebook. To disseminate information through social media has previously been proven to be successful with regards to people with deafblindness, see for instance Jaiswal et al. [35]. Interested parents contacted the researchers and received written information. After being given some time to reflect on their participation and the opportunity to ask further questions, the participants signed a form to give their informed consent. The procedure to facilitate informed consent needs to be flexible [36] and adapted to the individual needs of the individuals' with deafblindness [37]. Extra time, and accessible formats to meet the specific needs of the target group has been empathised [35]. These recommendations were adhered to.

The current study included 14 parents, most of whom were mothers ($n=10$). The participants' ages ranged from 33 to 57 years (mean 46 years). The majority of the participants used visual or tactile sign language as their preferred communication mode; however, five of the participants used oral language, and some used both oral language and sign language. Six parents were working, and two held an internship. Five reported being on sick leave or disability pension, and two reported being currently unemployed.

Data collection

The participants chose the time and place for the interview, a procedure described as important to facilitate for individuals with deafblindness to participate in research [35, 38]. They were interviewed individually by researchers experienced in interviewing (AAC, MW and KH). Most of the interviews were conducted in sign language, with two being conducted using tactile sign language. Professional interpreters were used in two interviews. As the last author (MW) is fluent in sign language, the participants who preferred this mode of communication could choose to use a professional interpreter or communicate directly with this researcher [c.f. 35,37–39]. All interviews were conducted using a semi-structured interview guide (Appendix 2). The interview begun with the open question 'Please tell me what it is like to be a parent with deafblindness'. Further questions revealed how the participant found that their deafblindness influenced various areas of family life. Follow-up questions such as 'Please tell me more' and 'What do you mean?' were used as probes. The interviews lasted for 21–83 min (mean: 49 min). All verbal interviews were audio-recorded and transcribed verbatim. The interviews conducted in signed language were video-recorded. The last author transcribed these interviews into written Swedish, while focusing on the meaning of the expressed experiences instead of a verbatim transcription. The reason for this decision was that Swedish sign language does not have the same grammar as the Swedish language, nor does it have its own written language. Thus, it

seemed more important to capture the meaning of the utterances. It was also regarded as easier to analyse the text using the style and grammar of Swedish language for all transcripts. To validate the transcriptions from the video recordings, another researcher who is a certified interpreter between Swedish and Swedish sign language (CW) checked the interviews and compared them with the transcriptions. Any discrepancies were discussed by the two researchers skilled in sign language until consensus was reached. The procedure to video-record and transcribe interviews conducted in sign-language have been described by Arndt [39]. As many of the participants struggle with reading or listening, we decided not to ask them to confirm the accuracy of the transcriptions.

Data analysis

Data were analysed *via* an inductive content analysis using the steps described by Graneheim and Lundman [40]. The accuracy of the audio-recorded transcripts was verified by concurrently reading and listening to the recorded interview. The authors AAC, MW and CW conducted the analysis. The researchers individually read through the transcripts several times to get a sense of the whole. Thereafter, the text was inserted into the software Nvivo for further analysis. First, meaning units related to the aim of the study were identified. Second, these meaning units were labelled with a code aligned with the text. After approximately 300 codes had been identified, they were checked for redundancy; in this step, some of the codes were merged. Next, in the categorisation phase, codes with a similar content were collapsed into more general categories, while depicting a manifest level of content. The categories were labelled with a name that expressed the content in a first-person style, to give voice to the participants' experiences. The categories were then sorted into sub-themes to illustrate the data on an interpretative level. Finally, in the last stage, an overarching main theme was identified, based on all the categories and themes, to illustrate the core experience of being a parent with deafblindness. Researcher reflexivity [41] was practiced during the entire analysis process, as the authors continuously discussed their pre-understanding, their experiences from the interview situations and what details in the data that could be regarded as general and what was specific to parenting when having deafblindness.

The final analysis was discussed among the whole research group until consensus [40] regarding the categories, sub-themes and an overarching main theme was reached. The authors have different professional backgrounds; three are paediatric nurses, one is a social worker, and one is a certified interpreter between Swedish and Swedish sign language and interpreter trainer, all which contributes to the addition of different perspectives. The intention was to share preliminary results to the board members of the family section of the Association of the Swedish Deafblind, as a way of member checking, but it proved hard to realise. Thus, no member-checking was performed. As the analysis was conducted in Swedish, selected quotes were later translated into English by the team for the purpose of publication.

Ethical considerations

This study was approved by the Regional Ethics Committee of Uppsala, Sweden (DNR 2016/124). As parents with deafblindness comprise a small group, it was important to pay specific attention to ensuring confidentiality when reporting the results. Despite the difficulty in maintaining confidentiality, there is value in giving

this particular target group a voice, as these people might have specific difficulties and needs that should be known and understood. Special consideration was taken to adapt the written information (i.e., using a larger font, printing on pale yellow paper or printing in Braille). When a researcher skilled in sign language was not available, the oral information was translated into sign language by professional interpreters, to ensure that information was truly accessible [35,37].

Results

The overarching theme of the analysis, *Living family life as a parent with deafblindness is not a walk in the park, but it is rewarding*, is an interpretation of the latent content of the data. It was also inspired by one of the mother's reflections on the initial interview question: 'So, [having deafblindness], well that's not always easy, ehh, and being a parent, that fills me with joy, but of course it was more complicated when combined with deafblindness'.

The findings are presented under the three subthemes, *Being a competent parent despite having deafblindness*, *Support is needed for me to fulfil my parental obligations* and *Parenting is a struggle due to my deafblindness*. Taken together, these subthemes illustrate a complex reality with many mixed experiences and feelings. An overview of the results is presented in Table 1.

Being a competent parent despite having deafblindness

This subtheme covers the mainly positive sides of being a parent and experiencing family life with children. Being a parent filled the participants with joy. They regarded themselves as competent and found that their unique condition had positive implications for their child. Part of the experience of being a competent parent was the ability to find individual solutions to taking on parental responsibility in various situations, which was complex due to the deafblindness.

I Feel joy, but I also worry

The parents described how their children added a new dimension to their life. Some even said that being a parent made life worth living and, because of their children, some of the problems related to the parents' deafblindness were felt less strongly. They were proud of their children and expressed gratitude to their partner who loved them despite their deafblindness. The parents stated that their deafblindness did not stop them from being a good and competent parent. They had witnessed how others with a similar condition managed; thus, it seemed natural for them to be able to manage too.

However, these feelings of joy and fulfilment were intertwined with the feeling of fear. The parents realised that, although they were a competent parent, the deafblindness posed some specific challenges in parenting that needed to be dealt with. Everyday life could be difficult to handle; for example, the parents were

afraid of being unable to protect their child from harm. They described fearful situations related to losing track of where their child was. Their limited vision field caused the parents to look over or past the child, without being able to use their hearing to localise the child. In such situations, mild worry could rapidly escalate to anxiety and despair, which in turn made it even more difficult to look for the child. A parent with younger children said:

If I look away for just a second, things can happen in my near surroundings, which I don't register. It is hard trying to see, and use my eyes to look, to find out where my children have gone. If they start to disappear, the worry gets worse and worse. If I were able to hear, I could register where they've gone. That would be a different situation.

Parents with young children, and those who recalled when their children were young, described worrying about not realising it if the child woke up during the night. They also worried about risks for the child in the home environment, such as reachable sharp kitchen knives, a hot kitchen stove or stairs. The parents worried about whether the children had clean clothes or were properly dressed. When their child grew older and started to spend more time with friends and go to parties, the parents worried about what their child did and with whom they spent their time. As the parents could not drive a car, they could not go look for their child. Thus, it could be emotionally difficult to let go of their child and allow the child to do things on her or his own.

It was often difficult for the parents to help with homework. There were various reasons for this, such as not being able to see the text on paper or lacking grammatical skill in the Swedish language, when Swedish sign language was the parent's first language. Similarly, if the parent was born deaf, it was difficult to assist with homework dealing with pronunciation in Swedish or English. It was easier to help with homework when it was computer based. The parents' inability to help caused them to worry that their child would not manage at school due to the parents' deafblindness.

I am able to find individual solutions in my parenting

The parents described how, in order to be a competent parent, they always had to be prepared to find individual solutions and to adapt to the development of their child and the progression of their deafblindness. Some noted that it was easier for them to manage under certain circumstances, such as at home in their well-known environment and at their own pace. The parents emphasised that they always acted in line with the best interests of their child, despite their own needs. They had learned to be open about having deafblindness and described turning to the health care sector and social services to ask for support. They informed their child's school about the deafblindness and were always open with their condition in relation to the child. They learned parenting skills and made use of practical tips from other parents with deafblindness; in addition, they used the strategy of

Table 1. An overview of the theme, three subthemes and categories.

Theme	Living family life as a parent with deafblindness is not a walk in the park, but it is rewarding		
Sub themes	<i>Being a competent parent despite having deafblindness</i>	<i>Support is needed to fulfil my parental obligations</i>	<i>Parenting is a struggle due to my deafblindness</i>
Categories	I feel joy, but I also worry I am able to find individual solutions in my parenting My condition has contributed to a special childhood	I need help and adaptations We share the responsibility for our children and home My child shows extra consideration	I experience energy loss I have difficulty living up to the standard of being the parent I want to be My child risks being negatively affected by inadequate support I feel heartbroken

relying on interpreters, personal assistants and others to assist them in performing things that were difficult to do.

When their children were young the parents wanted to be engaged in their child's life and facilitate the child's play and development. One parent recalled how she and her child had established their own routines together for bedtime when the child was younger:

She's asked me to sing for her at bedtime instead of reading her a story, because I cannot read a storybook. Well, of course, I can if we use Braille, but that takes time, and it's not the same, so she thinks it's cosier when I sing.

The parents sometimes used various pieces of equipment that could enable them to keep track of their child, such as baby alarms that could by touch alert them when the child woke up. One solution to keep the child safe was to limit the child's space. It was necessary to have the child close by and to restrict them from leaving what was regarded as a safe zone. Thus, it was preferable for infants and toddlers to play in a crib when indoors and to stay in the pram when out for walks. When they were not in a pram, toddlers were asked to hold their parent's hand and were explicitly told to stay close by. Some parents used a walking line or a long leash intended for dogs to keep track of their child during outdoor activities. Others described using the strategy of only taking the child out into a fenced garden or a designated playground close to their house. One parent, whose children were still young said:

I usually take the children to the playground just outside our house. There is a small playground there where they can play, surrounded by the block of houses, instead of us going outside of the houses. However, now the children are getting a bit fed up with staying there, they want to move on outside of the buildings.

Using a baby carrier instead of a pram made parents more aware of their infant's signals, which made them feel safer. Those who used a pram always pulled it behind them so that any approaching object they could not see would not hit the pram first. This way of walking also facilitated the use of a white cane.

When the children grew older, they were often given a mobile phone at quite an early age, so that they could easily communicate with their parent verbally or *via* text messages. However, other parents perceived their child as being spoiled because the child was given a mobile phone earlier than other children were. When the child was a teenager, the difficulties in keeping track of the child could be solved by establishing contact with the parents of the child's friends. The parents with deafblindness did not hesitate to contact other parents when they were unable to contact their child. Another strategy practiced by parents with older children was to have an open and honest relationship, encouraging the child to always tell the truth, even when it was ugly. This approach made it easier to allow the child to explore life while retaining some degree of control.

When their vision and hearing decreased, some parents said that they compensated for it by using other senses. For example, they used their intuition, tactile sense or smell (e.g. to decide when it was time to change a diaper). They also described sensing the emotional state of people in the environment *via* body odour or body contact. By asking their child to hold hands when arriving home from school, the parents were able to check the well-being of their child by sensing.

Being unable to drive affected many areas of life. Instead of driving their child to activities, the parents described how they used their imagination to make a boring walk to school more fun and how they walked to a nearby lake for a swim on a warm

summer day, instead of going to a community swimming pool farther away. They also used their subsidised transportation service to bring the child to leisure activities or arranged with other parents to drive the child.

The parents found ways to communicate with the teachers at school or kindergarten, often by writing; they managed to figure out what information from school they needed to be aware of and what could be ignored.

My condition has contributed to a special childhood

The parents stated that their deafblindness had contributed to an enriched childhood for their children. The positive effects of the parental need for physical contact contributed to a unique bond between parent and child. It was regarded as a privilege that the parent – due to sick leave or because of having a disability pension – spent a great deal of time at home, which facilitated emotional closeness with the child.

The parents believed that their deafblindness had contributed to their child's learning in regard to taking on responsibilities at home. However, the tasks they mentioned were viewed as being similar to what other children learn to do, such as making the bed, putting dirty clothes in the laundry or doing light cleaning in their bedroom. Thus, the parents regarded it as part of natural development, not an extra burden being put on the child. They argued that they wanted their child to feel free to spend time with friends and not to feel forced to help the parent. However, they also acknowledged that – without their deafblindness – they might have paved the ground more for their child.

The parents gave many examples of their children's unique knowledge and skills regarding deafblindness. They claimed that their child 'knew' from an early age about the parent's deafblindness and adapted her or his behaviour accordingly. One mother recalled:

We had one of these, we were offered [a baby watch] from the audiological department, it had a microphone in her bed. And when she cried, for a second, my receiver started blinking. But she sort of only 'aaa aaa aaa' [quiet crying], so the device didn't really set the alarm off, so she started to scratch the microphone instead, and after a while she only did the scratching, instead of crying. People visiting us were amazed, when she woke and did not cry. Babies usually cry, but she only scratched the microphone. That's cool, babies adapting themselves, they don't know how things normally are. Instead, they act in a way that works.

There were similar accounts when it came to the child adapting to the parent's vision impairment, such as when a child younger than a year old directed the spoon when being fed, or when children learned to turn the light on so their parent could see them, before starting to sign to the parent at night. Some toddlers had learned to notice when their parent did not quite understand what the child told them *via* visual sign language, and spontaneously began to use tactile sign language. Furthermore, the parents described how some toddlers had learned to stay by their parent's side when outdoors and to clap on their parent's leg to signal that the child was standing next to the parent.

The parents argued that their children had gained unique knowledge about deafblindness just by living with their parents, as well as by having the opportunity to meet with other deafblind people. They believed that their unique condition had made their children more independent and stronger, as the children had taken on additional responsibility from an early age. An additional benefit from growing up with a parent with deafblindness was the opportunity to learn a second language: sign language.

Support is needed for me to fulfil my parental obligations

This subtheme focuses on the experience of needing help and assistance in some situations; it includes the spouses' adaptations to each other's strengths, weaknesses and interests, and reflects the parent's understanding of the child's caring and consideration for the parent.

I need help and adaptations

The parents needed help to manage their everyday life, including their parental responsibilities. Some wanted help with cleaning the house, which had become more difficult due to the progression of their vision loss. Being unable to contribute to the household as they had done before was described as putting an extra burden on their partner. With a personal assistant, the parent could be independent from the partner and feel involved in the care of the child: 'Well, instead of the partner being responsible for some areas, which is often the case, when having a personal assistant, they can help, so that I myself can take on the same responsibility. That means I'm not excluded'.

The parents emphasised the need for someone to assist them during outdoor activities. Without such support, they could not take their child outdoors themselves. Some described how their personal assistant – who should not help the child, according to regulations – actually did help to keep an eye on the child when outdoors. Others described having had valuable help from a personal assistant when shopping for clothes for the child. The personal assistant acted as the eyes of the parent and could tell whether the clothes looked appropriate or not, which enabled the parent to make an independent decision regarding whether to buy the clothes.

Personal assistants also acted as the parent's eyes and ears in everyday life at home and could drive the parent and child to joint activities. A few of the parents had been offered specific support from social services in assisting with parenting tasks the parents could not do themselves, such as brushing the child's teeth, helping the child use the toilet or feeding the child; however, more often, social service support was appointed only for parent's personal needs.

It was important that the parent and child liked the person who was appointed as a personal assistant, as they spent a great deal of time together. Continuity was also of importance. Despite the benefits of personal assistance, it brought the risk of decreased parental power and responsibility for the parent, which ideally was dealt with by having explicit rules regarding how the support from assistants should be carried out. Another negative side of assistance at home for many hours per day was that it threatened the personal integrity of the various family members. Although the parents with deafblindness cared less about this, they were under the impression that it affected their partner's life in a negative way.

The social insurance system made it possible for both parents to stay home when a baby was born, if the parent with deafblindness was on sick leave, because then the partner could take parental leave. This arrangement gave the family a smoother start to parenthood and allowed the parents to figure out how to best take care of their child. Another factor that facilitated parenting was when the child health care nurse visited at home, instead of the parent having to visit the clinic.

Sign language interpreting was of importance, such as during meetings at school and when joining shared activities with the child. Furthermore, the local deafblind team offered information about deafblindness at the children's schools and helped to claim

the right to learn Swedish sign language. The parents wanted to keep up with their child's school achievements, and teachers could be supportive in this regard. The parents appreciated when the teachers booked an interpreter for meetings without them having to mention it. At some schools, there were teachers who could use Swedish sign language, which made contact and information much smoother. Without support, some parents managed to communicate with teachers in one-to-one situations, but they had difficulties at meetings for all parents and therefore chose not to attend such meetings. It was also viewed as supportive when the parents felt able to ask teachers to let them know if their children were improperly dressed or ask the teachers to put in extra effort in areas where the parents had difficulties, such as praising the children for creative work, which the parents were unable to see.

Support from the parent's social network was important; the parents mentioned that their extended family or friends offered support with shopping, picking up children from school or taking them to leisure activities or health care visits. This was especially appreciated during the dark period of the day or year, when it was more difficult for the parents to see and move around safely. The parents also saved energy when they were offered help with household chores or playing with the child. Some parents described having stayed with their parents or parents-in-law for a limited time for family support. Others said that their child could stay with the grandparents sometimes, so that the parent and partner could have some time on their own. Relatives with hearing could also play a role in a hearing child's verbal language development. However, it was appreciated when relatives just visited the family, rather than always having to assist.

A physical environment that was facilitative in various regards made it easier for the parents in their family life. They talked about choosing to live in a less busy area with fewer roads to cross on their way to the child's school, which made it easier for them to take the child there without support. Others chose to live in a more central part of town, in order to have all the necessary services within a reasonable distance and to be able to rely on public transportation. One parent with younger children said:

If we were to move to another, calmer area, the problem would be access to public transportation, and I don't dare to walk on my own in the dark. I don't feel safe calling for subsidized transportation, you never know if they will show up or not and how long I'll have to wait. So, I think it's better to live downtown. I feel safe when I have easy access to everything I need. I don't experience any barriers, and I can be independent. I don't have to ask my husband to drive me if I'm going somewhere.

Some parents also talked about the benefits of living in a town where they were not the only one with deafblindness and where they did not feel exposed.

We share responsibility for our children and home

The parents described the mutual adaptations that were developed between spouses, where personal interests, strengths or limitations determined who did specific tasks. Some had defined responsibilities, while others had less defined areas of responsibility. One parent of older children said: 'We share our household chores. If one is cooking, the other one takes the washing up. So, I think we cooperate and share the responsibilities. We don't have typical mother and father roles. Instead, we have our own internal rules'.

Often the partner took on the responsibility for outdoor activities and for games that were difficult for the parent with

deafblindness to engage in. When the child wanted to play such games, they could refer the child to the other parent or suggest other activities they were able to do with the child. The partner was often the one who did the shopping, but there were accounts of the spouses doing this together, where the parent with deafblindness kept the shopping list in mind and arranged for the other family members to pick up the groceries needed.

Although the responsibility for the children and home was generally shared, there were accounts of the parent with deafblindness having the main responsibility; this occurred when the parent was a single parent, when the partner worked away from home during the week, or when the partner suffered from health issues or was uninterested in family life. One parent described doing household chores with the help of a personal assistant, to relieve the partner from responsibility.

Because of the progression of the deafblindness, responsibilities sometimes had to be reconsidered, which could require the partner to take on greater responsibility. Thus, in some families, the partner was responsible for all household chores, because the parent with deafblindness was too exhausted to participate in family life.

My child shows extra consideration

According to the parents, their deafblindness was natural to their children, who were used to their parents' difficulties in everyday life. Generally, the parents found that their children were kind and caring and showed consideration, which the parents experienced as supportive and as making some aspects of family life easier. For example, the children spontaneously removed items from the floor and closed open doors, so that the parent would not walk into them. Similarly, they voluntarily assisted when their parent was in need of help, although the parents emphasised that this was by choice. When the children saw the parent dropping a small item on the floor, for example, they helped to search for it, and if the parent dropped something that broke, the children helped to take care of the mess. They assisted the parent when out walking by describing approaching objects or uneven ground and by guiding the parent in the same way as an educated guide would do. The children could assist with shopping, with computer issues or even with driving the car, in the case of older children. The children also took on more responsibility for their own leisure activities, as compared with their friends. Some children were described as checking the accuracy of professional interpretations; at times, the child acted as an interpreter, although this was generally not preferred by the parent. One single parent said:

And they can help with some interpretation. If we are out shopping for groceries, and someone asks me something, or if I have to ask something, then they always tell me that someone is approaching me ... Previously, I used to make notes to communicate, or point or use gestures. So, that's positive, I think [that the children help]. But it's only minor interpretation tasks, they don't act as professional interpreters, it's more if something happens, then they can ask on my behalf.

The children actively made an effort to include the parent, such as by teaching their friends to say 'Hello' using sign language so the friends could greet the parents when playing at their home. The children also encouraged their parent and explicitly praised their competence, reminding them of what they had achieved in life. The children could be extra vigilant regarding what the parent was doing and extra kind and caring when they knew that life was tough. Some parents reported that their children did not want to put an extra burden on them by bothering the parents with their problems, which was something the parents disliked.

Parenting is a struggle due to my deafblindness

Despite the positive experiences of being a parent and living family life, the parents did not always feel supported in their lives, and being a parent was not always easy. At times, the parents felt exhausted, helpless and in despair, believing that their child had suffered as a result of their deafblindness.

I experience energy loss

Having deafblindness was experienced as energy draining; moreover, despite the parents' happiness of being part of a family with children, their deafblindness could cause exhaustion and the need for extra rest. Some noted that it was easier for them to participate in family activities when they had enough energy and they mentioned that, because of stress, they needed to plan their days ahead in order to get the rest they needed.

Becoming a parent was a life-changing event, and some of the parents found that it was even more intense when a second child was born. Due to the deafblindness, it took a lot of energy to manage things like shopping or doing the laundry, and it was even more complicated to keep an eye on what the child was up to at the same time. Parenting was associated with a more intense everyday life, which could make the parents even more exhausted and withdrawn. One parent, who nowadays did not work said:

Before, when I was in my twenties or when growing up, I was often tired but also stubborn and curious about the world, wanting to try things out. I struggled on, even though I was tired at times. In school and in life, I struggled to participate and be included. I did so through high school and when starting to work. When I started to have a family, I stopped being curious about the world. I could not manage to continue my struggle anymore. I had to let go. Previously, I was often stressed, and I could manage stress, but nowadays I cannot manage stress anymore. I've lost a lot.

On top of their daily battle to manage everyday life, the parents with deafblindness experienced a constant fight with different authorities to claim the help they needed. This put an extra burden on them. When they were exhausted, the limits to what the parents could manage in everyday life became tighter. At such times, they had difficulty dealing with noise or activity from the children or any other distractions. This irritated the children, which in turn caused sorrow and guilt. One mother recalled:

It is sad, it is. I wish I was like every other parent, the normal ones. But, on the other hand, everyone is more or less tired in the evenings. Many parents have children who are more or less loudmouthed. However, it's an extra burden to me because, when my energy is drained, it is totally drained. Then I cannot manage anymore. I am so exhausted, and then I cannot manage to keep my voice calm.

When they were exhausted, the parents were unable to function as parents and participate in family activities, which made them sad. One middle aged father said:

Everyday life is difficult. It all depends on my health status that day. If I'm not feeling well, and the children want to participate [in cooking], then I can't manage. Then my wife has to manage on her own, and I'm left out. I'm always excluded in everyday life; in fact, I'm very much left out.

Time and a private zone was needed to get some rest. Rest was sometimes also needed before attending an activity. In addition, the parents emphasised their need for a private zone to do things other than resting. For example, they expressed their need to go for a walk or swim, or perhaps visit a theatre to regain

some energy. Another means of self-care was mindfulness. One work active parent said:

I practice mindfulness and actively try to identify ways to promote my well-being. The other day, the deafblind team talked about mindfulness, and that's exactly what I'm practicing to take care of myself. That's why I've managed. Without it, I would not still be around.

I have difficulty living up to the standard of being the parent I want to be

One of the burdens the parents carried was that the consequences of their deafblindness – or their lack of support with it – caused difficulty in living up to their standard of parental responsibility and playing their role in the family. This could lead to feelings of failure. For example, the constant need for planning was a hindrance to playing their parental role. Some revealed that, earlier in life, when the deafblindness was not as profound, they had enjoyed performing activities spontaneously, but this was not possible anymore. In order to accompany their children to leisure activities or appointments with doctors, hairdressers and so forth, they had to pre-order subsidised transportation services days or weeks ahead. Others had to plan to go shopping on the day(s) when they were provided with a personal assistant. Furthermore, they needed to know about meetings with the school or other authorities in advance in order to book a professional interpreter. Short notice of a meeting could make it impossible to attend, which was not in line with what was expected of them as a parent. There were also accounts of older children taking the initiative to do activities on their own instead of waiting for their parent, who needed transportation or an interpreter. This made the parents feel like they were abdicating their parental responsibility. One parent of older children explained:

I'll tell you an example: If I am to accompany my child to buy new glasses, then I have to book an interpreter in advance. We cannot just go ahead. Instead, we have to plan this two weeks ahead, to get an interpreter. In such cases, my child gets irritated and goes there on their own. So, often, I have to let go of my parental role, as the children do quite a lot on their own.

The parents regarded it as being an inherent part of their parental role to listen to what their children had to say. Thus, they sometimes felt helpless when they were unable to comprehend what their child wanted to communicate. In addition, the parents expressed frustration at being unable to overhear their children's verbal communication.

Another barrier in everyday life was darkness. During the dark hours of the day or year (as the winter season in Sweden is long, with many dark hours), the parents had trouble orienting themselves or moving around safely. Thus, it was hard for them to take on ordinary parental duties, such as going shopping or taking their child to and from school, to the doctor, or out to play. This made them sad and frustrated. One parent who worked full-time said:

Sometimes I'm so fed up with it all. The children like to play [outdoors] and it gets darker and darker. When I say, 'please, we have to go home now', they refuse. Then I get frustrated and lose my patience; the children are enjoying themselves, and I have to stand in the dark [...] Sometimes I have to say, 'No, I can't deal with staying here anymore'.

The parents' limitations in understanding what was taking place in their immediate surroundings were also experienced as troublesome. These limitations could hamper their ability to take on full parental responsibility. For example, if their children got into an argument and blamed each other, it could be difficult for the

parents to sort out the issue, as they did not know what had actually happened and which of the children's stories was true. The parents were also frustrated when their children acted out in a way they knew their parent might not notice, such as sneaking sweets from the cupboard or playing loud music late at night, which might disturb the neighbours.

Another parental responsibility that was complicated by deafblindness involved receiving information from the school on a day-to-day basis, especially when the teachers were unwilling to offer adapted information. As one parent of two children put it, 'There were many substitutes [substitute teachers at school], only staying for a short period of time. However, we tried to show them the contact book, but they didn't use it. It was there, but they didn't have the time to write in it'. For some parents, it was difficult to communicate *via* text messages, which made them withdraw from contact with the parents of their children's friends, even though they acknowledged the benefit of keeping in contact.

The parents' difficulty living up to their desired parental standard was complicated by insufficient and untailored support. One parent recalled when the children were school aged:

Interviewer: What support were you lacking?

Interviewee: Well, some kind of help at home, someone who could complement my vision and hearing, helping my children with activities in everyday life, such as going to the swimming pool in the summer, help with homework when they got a bit older. Such activities and, when they were toddlers, help with bathing and other daily routines...

The parents wanted to be prepared and to take care of their infant in the best possible way. However, they found that – although the child health care clinics were knowledgeable in childcare – the clinics could not offer deafblind-specific parental support, nor would the deafblind team offer professional support focusing on the parental role or parenting with deafblindness. One father shared this experience:

When my wife was pregnant, which was a happy period, I tried to find someone to discuss with [...] I made contact with the deafblind team and said I wanted to meet and talk to someone. The answer was that there was nobody to talk to. It was not their responsibility to offer such support. Family issues were not prioritized, they said.

My child risks being negatively affected by inadequate support

The parents claimed that their deafblindness and the strategies they used to carry out their parental responsibility could affect their children negatively, unless they or their child received adequate support. For example, the parents wanted support from the deafblind team in talking to their children about their situation as the children of a parent with deafblindness; they also wanted support that would allow their children to share their experiences with others in a similar situation. The parents wanted to counteract the risk that their children would suffer from the consequences of the parents' deafblindness; however, when they asked for support from the deafblind team, the parents were informed that this was not included in the deafblind team's responsibility. This bothered the parents.

Furthermore, even when the parents applied for support in everyday life to take on their parental responsibilities, such support was often denied, which added to the parental burden. Based on current Swedish laws and regulations, the parents were informed that support was only permitted for their personal needs and was not provided to help take care of or support their children. According to the parents' narratives, some of their children

had gotten into trouble as a result of such decisions, and it was not until then that they received support. One parent, with older children said:

There is a law that states that, if your child has a diagnosis ... For example, when they [the children] finally got diagnosed, it was no problem [to get support]. I believe they [the children] could have been offered support at an earlier stage, even before they were diagnosed, if the social services had just been a bit more open minded ... I don't think one should need a diagnosis to have the right to support with homework or some extra help at home.

Some of the children suffered from delayed language development, which the parents believed was due to them being unable to practice verbal language with their children. Another aspect of the children being disadvantaged because of the parents' deafblindness was when the children required health care. The parents found it complicated to visit the hospital with sick children, as the professionals there were often unused to booking an interpreter in advance. Furthermore, when a child was in need of acute care, there might not be time to contact an interpreter. Instead, the parents had to communicate about the child's health and symptoms in writing, which was not optimal and could be a disadvantage for the child.

I feel heartbroken

There were many reasons for the parents to feel heartbroken. They revealed that they sometimes felt excluded in their family, which made them feel vulnerable and sad. This could be the case when the other parent (without deafblindness) was favoured by the children, as it was easier to communicate with that parent or because the other parent could participate in the children's activities in a way the parent with deafblindness was unable to. The parents said that they missed out in sharing some experiences, such as music, stars in a dark sky or a drawing made by the child; as one parent of two children said, 'That's what I've mourned the most; not being able to see all the drawings she's made'.

Others were frustrated and sad at being unable to manage activities on their own with the children or with the help of a personal assistant. A parent with young children stated: 'No, I cannot do that on my own. I always have to do that together with my husband. We are never separated; we have to spend all our time together, as I'm not provided with enough hours with personal assistants'. When the parents with deafblindness felt frustrated with their own shortcomings or in despair, it could affect the entire family.

Furthermore, the parents described sometimes feeling like they were a burden on the rest of their family, because their partner had to adapt his or her life and take on greater responsibility at home. The parents felt that they were a burden when they disappointed their family members by being unable to participate in activities suggested by the other family members. There were also accounts of feeling less worthy as a parent and partner; one parent who did not work full-time commented: '... when we spend time together, my partner and I, I always feel half, like I'm always deficient and never good enough ...'.

The parents also described feeling hurt when their child felt ashamed of being seen with them. One parent recalled: 'Well, when she was about to start school, at that time, she did not even want me to enter the schoolyard, and that really hurt me'. In line with this, the parents described being sad when their children – sometimes together with friends – made jokes behind their back, testing the awareness of the parent with deafblindness.

Some parents reported that people in society, such as teachers and health care workers, had judged them as parents in a negative and prejudiced way. They feared that social services would investigate their parental skills, just because of their deafblindness. There were also accounts of the family being isolated because of the parent's deafblindness, as it had become more difficult to meet up with old friends or neighbours who were sighted and hearing. Similarly, it was difficult to relate to other parents. At times, the parents felt so exposed and vulnerable due to their deafblindness and difficulties in family life that they did not know how to survive. Some had reached out for professional support. One parent, whose children were a bit older said: 'When I met with my GP to get the medical certificate, I told him that I, ... that I find it hard to ... well, that it would be a relief not to live anymore ... that that was the way I felt ...'.

Discussion

The results highlight both the joy and the difficulties parents with deafblindness experience in being a parent and living family life. When they were able to find and use individual solutions to address deafblind-specific difficulties or when they received adequate support, the parents enjoyed parenthood and family life. They felt competent and believed that they positively contributed to a unique childhood for their child. However, parenting and family life could be difficult and could cause sorrow, due to the effects of deafblindness and a lack of adequate support.

Although the literature on this topic is sparse, similarities between our findings and previous research exist. For example, Damen et al. [30] also reported that parents with deafblindness were satisfied with raising their children, yet experienced loneliness at some point. Similar to our study, they found that the parents shared household chores with their partners. However, Damen et al.'s [30] study reported that the parent with deafblindness did most of the parenting, while the partner earned money, which was not as significant in our study. This difference may be due to the different social security systems in the Netherlands and Sweden. Both studies found that the parents with deafblindness used various strategies to cope with their situation and sought help when needed. Likewise, both studies found that the parents were eager to prevent their condition from affecting their children; nevertheless, the deafblindness did make a difference in the children's lives, such as when the children adapted to the needs of the parents or tended to take on responsibility for themselves. Interestingly, our study's findings about support differ from those of Damen et al. [30], in that our participants were much more vocal about their need for and experiences of support with practical tasks in daily life in order to live up to their desired parental standard. Here, our findings are more in line with those of Payne and McPherson [5], who reported that mothers with MS described their need to find physical and social support.

Personal assistants were frequently mentioned in our study; these were mainly regarded as facilitating for the parents. Assistants could act as the parents' eyes and ears in various situations, such as when safeguarding young children. Previously, Berggren and Bergman [11] and Selander and Engwall [10] similarly concluded that personal assistants facilitate parents with disabilities in fulfilling their parental role. In line with a study by Selander [9], who interviewed parents with a physical disability, the findings from our study add to the knowledge that parents with a disability such as deafblindness may struggle to maintain power and control in their everyday life when receiving support from a personal assistant. Our findings indicate that it is important

to find an assistant who can get along well with all the family members, as inflexibility in how personal assistance is structured can negatively affect the parent's opportunity to take on responsibility, as well the child's opportunity to take part in activities [11].

When comparing our results with the results from studies focusing on parenting when having a single sensory impairment, there are some similarities, such as the value of informal support from friends and family. Furthermore, with regards to individuals using sign language, services are preferable to be offered in sign language [7]. Like in our results, parents with blindness expressed a positive view of parenting, and believed that their condition added to the development of empathy in their children [8]. However, similar to our results Rosenblum et al. [8] also found that parents experienced some challenges with mobility issues and with safeguarding of the child. They also reported that at times the parent could feel being left out of certain activities, such as sports.

Our findings differ from previous research [2–5] in that the parents in our study only very sparsely reported experiencing prejudice from others and having their parental ability questioned. This is a positive finding. On the other hand, the parents described needing more practical support in taking care of their children – a need that was not always met and that made them feel that their child was disadvantaged, or their child's health was at risk. On a community level, it could be beneficial to acknowledge the needs of parents with deafblindness, to improve the well-being of both parents and children.

People with deafblindness should have the right to define their own needs [42]. However, our findings and those in the literature indicate that this might not always be the case, as individuals with deafblindness do not always have access to appropriate formal support, such as support from health care or rehabilitation teams that specialise in deafblindness [16]. In addition, support from the social service system may be inadequate. From a Nordic perspective, it has been argued that it is the organisation of a society – not the deafblindness *per se* – that poses barriers to full participation in society, and that it is the responsibility of rehabilitation services to facilitate people with deafblindness in participating in society on equal terms [43]. Following this argumentation, our findings indicate that the organisation of support and rehabilitation can pose barriers to taking on full parental responsibility, instead of facilitating the parental role. This is not congruent with the UN Convention on the Rights of Persons with Disabilities [1], which states that a person has the right to be a parent on equal terms despite living with a disability. Furthermore, this matter affects not only parents with deafblindness but also their children. Concerned authorities should include the children's perspective as well, as all children should have the same right to healthy growth and development as their peers [44]. This study has demonstrated that the goals in the convention on the Rights of the Child [44] or the parental rights according to the UN Convention on the Rights of Persons with Disabilities [1] are not always achieved.

Based on our results, and the rights of parents and children, it is reasonable to say that parents with deafblindness might need support during various periods of the child's upbringing. Some of this support takes place within the family or is offered by friends, almost automatically. However, access to informal support can vary, and thus some parents might need more formal support than others. The WFDB states in their second world report that deafblind-specific services are a precondition for inclusion, and that such services can include rehabilitation, assistive devices and technologies, interpreter-guides/interpreters, as well as other forms of live assistance [45]. In Sweden some supports are offered by

the municipality, such as companion service according to The Swedish Act (1993:387) concerning support and service for persons with certain functional impairments (LSS). In this article, this service has been included in the broader term; "personal assistance". To have access to this service, the individual has to make an application, which is a two-step procedure (SFS 2022:1253). Lately, the rejection rate of companion service has increased for people with deafblindness in Sweden [46], which could pose a problem for parents who are in need of support. Formal support can also be offered by rehabilitations services such as local deafblind teams. In Sweden, they for example offer psychological support or counselling, which can include help to apply for personal assistance, subsidised transportation services, guide dogs or financial assistance, all which were mentioned supportive by the participants in our study. Individuals with deafblindness can also be offered mobility training and help to develop sign language or to read braille. Some teams also offer support and guidance to family members. The content of the Swedish deafblind teams' work is congruent with the description of how the WHO view rehabilitation; working with the person with a condition and their families to address underlying health conditions, modifying their environment, using assistive devices, educating to strengthen self-management and adapt tasks to be performed more safely and independently [47]. According to the WHO, rehabilitation can help people to be as independent as possible in important areas of everyday life, including taking care of a family. Rehabilitation is an important aspect of universal health coverage and a key strategy to reach the third Sustainable Development Goal; "ensure healthy lives and promote well-being for all at all ages" [47]. In addition to formal support, it is important to remember the significant contribution of Non-governmental Associations. They have dual roles; they support individuals in different ways and act to inform about the rights and needs of the target group. With more information about deafblindness in society, knowledge among stakeholders and individual citizens can increase, which in turn might increase inclusion for parents with deafblindness, for example making it easier for them to follow their child's developments in school or join in with their children's leisure activities.

Further research is needed to develop and implement supportive interventions for people with deafblindness in both general and specific situations, such as when being a parent. In addition, legislation on supportive services must be developed and interpreted with the aim of supporting peoples' lives, rather than being used as an excuse for why services cannot be offered that align with actual needs, both in general and for parents with deafblindness.

Strengths and limitations

The major strength of this study is that it adds to the sparse literature on the experiences of family life in families including a parent with deafblindness. This knowledge is important in order to create more awareness of these families' situation and to develop and tailor support for the individuals within these families, as well as for the family as a whole. The credibility of the findings is strengthened by the interdisciplinary research collaboration. The use of quotations from almost all participants adds to the confirmability. The lack of a more thorough demographic presentation of the participants secures the confidentiality but can be regarded as a limitation in terms of judging the transferability of the findings. The fact that there are some similarities between our results and those of the study by Damen et al. [30] in a Dutch context is however useful for judging the transferability. It is possible that the practical arrangements related to the

interviews in sign-language, where some were conducted with interpreters and some *via* direct communication could have impacted the data. However, for ethical reasons we prioritised for the participants to choose if they preferred to use an interpreter or not. To counteract any misunderstanding, two researchers fluent in sign-language independently viewed the video-recorded interviews to assure the agreement of what was signed by the individuals involved in the interviews.

Conclusion

The interviewed parents with deafblindness expressed their enjoyment of parenthood, even though these feelings were intertwined with more negative feelings of being unable to take on the desired responsibility or lacking necessary support. Parents revealed that they needed tailored support from social services, health care and rehabilitation services, in order to take on their desired parental responsibility and be able to be active participants in family life. There is a lack of parental education programs for parents with deafblindness, and such programs need to be developed. Further research is also needed to gain more knowledge about family life and parenting for parents with deafblindness. This includes longitudinal studies covering a life-span perspective.

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ORCID

Agneta Anderzén-Carlsson  <http://orcid.org/0000-0001-7352-8234>
 Karina Huus  <http://orcid.org/0000-0003-4599-155X>
 Maria Björk  <http://orcid.org/0000-0001-6419-2417>
 Camilla Warnicke  <http://orcid.org/0000-0002-6378-4151>
 Moa Wahlqvist  <http://orcid.org/0000-0002-6965-6820>

Data availability statement

The participants of this study did not give written consent for their data to be shared publicly, so due to the sensitive nature of the research supporting data are not available.

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