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Is the Right to Access to the Services and Supports Ensured for the Deaf and Hard-of-Hearing Children? An Ethnographic Study Based on the Experience of Hearing Parents

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Abstract: The right of people with disabilities to access services and supports they need is internationally recognized by the United Nations' Convention (CRPD) on the Rights of Persons with Disabilities. However, deaf and hard-of-hearing children face obstacles to access services requested by their parents. As part of a broader ethnographic research project focused on the experience of Francophone hearing parents of deaf and hard-of-hearing children, this study explores the obstacles encountered by parents in their struggle to ensure that the needs of their children are met. 117 parents from Canada (n = 52), Belgium (n = 15), France (n = 23), and Switzerland (n = 27) participated in an in-depth interview. The main findings show that parents face important difficulties to access the available services due to their rural location, situated far from the main health services and due to the long wait times. Also, the unavailability of some of the rehabilitation and educational services represent another important obstacle that leads parents to become the main advocates for their children rights. Finally, some lines of action to implement the CRPD provisions are drawn to contribute to the right of deaf and hard-of-hearing children to access to the services they need.

Keywords: deaf; hard-of-hearing; children; hearing parents; rights; access; services; ethnography

1. Introduction

The Convention on the Rights of Persons with Disabilities (CRPD) adopted in 2006 by the United Nations [1] is a 'testimony to the significant need for specific human rights instruments when it comes to certain categories of humanity whose condition has made them uniquely vulnerable to human rights violations and who are insufficiently protected by the existing, mainstream vocabulary of right' [2] (p. 515). Quinn argues that the CRPD represents not only a case that recognizes the rights of a particular group, but a statement that refers to everyone's equal rights [3].

One of the successes attributed to the CRPD is that it represents an instrument that can guide individuals and States on the interventions that could enable persons with disabilities to exercise their rights [4], especially to those 177 countries that have currently signed and ratified the Convention. Another success is the CRPD's embrace of the social model of disabilities that directly highlights the need to foster a more accessible, inclusive, and equitable society. The CRPD not only proposes to eliminate the obstacles that prevent people with disabilities to fully exercise their rights on an equal basis as others, but also encourages the States to provide the supports and the services to achieve the CRPD objectives. Furthermore, according to Harpur, the CRPD can also help individuals that have to deal with the impact of their disabilities by ensuring them assistance with every aspect of their life [5].

In spite of the international recognition and assumption that supports and services must be provided to people with disabilities, there are still several obstacles that remain. According to the World Report on Disability [6], some of these obstacles are related to the lack of services available, the barriers to general health care, to rehabilitation, to assistance and support, and also, to education. These barriers not only highlight the lack of supports that persons with disabilities still encounter around the world to access the services they need, but also the inadequacy and the poor quality of some of the services that are available.

1.1. The Access to Services and Supports of Deaf and Hard-of-Hearing Children

During the last decades, the access to early intervention programs and educational services has been considered vital for the healthy development of deaf and hard of hearing (DHH) children [7]. In fact, after being diagnosed, DHH children and their parents are usually involved in several health, rehabilitation, and educational services that vary according to the mode of communication chosen and the use of sensory devices. In all cases, parents of DHH children play an important role not only in taking important decisions regarding language, technologies, education, and identity [8], but also ensuring that all their developmental needs are met.

In spite of this, little research has been done exploring the experiences of parents and DHH children when trying to access to the necessary services that could support their development, such as health care, rehabilitation, or educational services. The available studies on this topic focused mainly on how parents value the access to diagnosis and early intervention [9,10], to early literacy [11], or to the mainstream schools through the adequate provision of educational services [12]. From these studies, it can be highlighted that DHH children and their families are still facing important obstacles to access the necessary services, such as: important delays in the first diagnosis and treatment of hearing loss [9]; poor communication of hearing screening results, inconsistencies in healthcare information from primary care providers, and lack of local resources [10]; an inadequate access to literacy during preschool activities [11]; or a lack of collaboration with special educator in mainstream schools [12].

Besides these studies, there is a small number of studies that, despite not being mainly focused on access to the supports and services that DHH children could need for their development, provide valuable information about this topic from the parents' point of view. This is the case of Flaherty [13] and Wood et al. [14], who explored the experience of being a hearing parent of a DHH child after diagnosis, and Dionne et al. [15], who studied the life experience of being a parent of a child with disabilities, including deafness. In Flaherty's study [13] the poor information received about the child's deafness is highlighted as an important barrier experienced by parents at the time of diagnosis and difficulties in finding ways to better meet their children's needs. Wood and colleagues [14] point out that some parents have negative experiences due to the limited access to support services as well as to pay for the costs of sensory devices, therapy, early intervention programs, and other required assistance. In some cases, parents also have to advocate for access to the desired options and for collaborating with professionals in the decision-making process. Finally, in the study conducted by Dionne et al. [15], parents of children with deafness report different barriers, such as the long waiting lists to receive the required services and aids and the lack of specialists for DHH children (such as doctors, speech therapists, or occupational therapists). They further experience the continuous change of relevant professionals, the lack of organized activities for the children as well as meager information about all the available services.

1.2. Aim of the Study

The review of the literature showed that DHH children and their parents, mainly from Western countries, are still facing significant obstacles to access necessary supports and services that promote their child's development and wellbeing. Also, it shows that exploring the experience of parents, as the main experts of their child's needs, is key to analyze to what extent the children's needs are met by health, rehabilitation, and educational interventions and supports.

Even so, despite having some indications that DHH children have to face different obstacles to access the services they need, there is still an important lack of studies focused on determining the nature and the cause of these obstacles in Western countries from the point of view of hearing parents. Statistics about parental hearing status among DHH children are rarely available, but Mitchell and Karchmer's [16] have shown that hearing parents represent more than 90% of parents of DHH children in the United States. Furthermore, it is wellknown that hearing parents could experience important challenges after their child's diagnosis, not only because in most cases they lack previous experience in deafness, but also because they have to make several vital decisions concerning their DHH child's care in a short period of time while they are still facing the impact of their child's diagnosis. As Flaherty [13] notes, hearing parents have to go through several stressful and confusing experiences such as the deafness diagnosis of their child as a traumatic event and the later grief process, the lack of information about deafness, or the choice of the communication mode, among others. These challenges place the parents in a vulnerable situation before the professionals and experts.

The present study aims to provide a thorough examination from the point of view of hearing parents of the obstacles they face in their search for appropriate supports and services for their DHH children. This study will further shed light on some of the measures that could contribute to the full exercise of the rights of DHH children.

2. Materials and Methods

2.1. Aim and Context of the Study

This study is part of a broader ethnographic research project [17] designed to explore the experience of Francophone hearing parents with DHH children in Canada, Switzerland, France, and Belgium. In these countries, although many writings on transformations teaching philosophies and deaf identity are available [18–20], little research has been done to understand how these changes have influenced the Francophone parents' engagement experience in services offered to their child living with deafness. Currently, although each of these countries has a public system of health, education, and social services that covers financially several services and supports (e.g., early detection, early intervention, audiological monitoring, sensory devices, rehabilitation, speech therapy, interpreters, and support teachers in the mainstream school, among others) for DHH children it is necessary to point out that Canada (in 2010), France (in 2010), Belgium (in 2009), and Switzerland (in 2014) ratified the CRPD, which legally obliges them to establish the necessary measures to apply its postulates.

Of all the dimensions explored in this research project (e.g., the announcement of the disability, the decisions made on the mode of communication, the parents' involvement, among others), we used data on the experience of parents with accessing to the services and supports offered to their DHH child.

2.2. Participants

Since the research project undertaken was exploratory and international (Canada, France, Belgium, and Switzerland), a great diversity of parents with DHH children was encountered. The participants of this research were selected according to the principles of theoretical sampling (open sample, variational sample, and selective sample) [21], and then we proceed with the "snowball" principle. This sampling technique allowed us to collect data from participants in the four countries investigated by ensuring that a broad spectrum of experience is covered by the documented realities.

Different local organizations from these countries helped with the recruitment of family members of DHH children. Parents were sent a solicitation letter, and those who were interested were invited to contact the researchers' team. The aims of the study were explained to the professionals of these organizations and their help was requested to select hearing parents of DHH children that were interested in sharing their personal experience. Afterwards, the selection criteria was gradually redefined in order to document the experience of different family realities, different intensity of service and, finally, different environments (rural or urban) of residence.

Of a total of 117 selected parents, 52 were from New Brunswick and Quebec (Canada), 23 from France, 15 from Belgium, and 27 from Switzerland. Two main sociodemographic characteristics of participants need to be highlighted to better understand the data presented in the following section: many participants (44 out of 117) lived in rural areas and most of the parents (102 out of 117) received a substantial amount of services since their child lives with moderate to profound deafness.

2.3. Instruments

For this research it was relevant to use semi-structured interviews in order to give voice to the hearing parents. As mentioned by Rabionet, this survey technique is a privileged way of exploring the actors' experiences by giving them the opportunity to depict their reality with their own words [22]. To document this experience, we developed an interview guide based on exploratory interviews [23], in collaboration with Services for Students with a Sensory Disability and the Quebec Association for Children with a Hearing Problem (AQEPA) for Canada, the Association of Parents of Francophone Hearing Impaired Children (APEDAF) for Belgium, the Swiss Association of Parents of Hearing Impaired Children (ASPEDA) for Switzerland, and Switzerland Association Two Languages for Education (2LPE) for France.

These exploratory interviews led to the emergence of three main themes included in the guide on the experiences of hearing parents of a DHH child: (a) Their general experience as parents of children living with deafness, (b) the types of services their children receive and their participation in planning the service provisions; and (c) their perception of their contribution to these services. The first interview guide included 17 questions on all three topics and was pretested with a parent from each country. It was then adjusted according to each of the countries where data collection took place in order to reflect the national reality of the participants. The new versions of the interview guide included 15 or 16 questions, depending on the site (Belgian and Canadian guide has a question concerning the satisfaction toward the organization collaborating to the study). From a phenomenological perspective, the interview allowed to document the subjective experience of parents in general but provided a rich testimony about the challenges related to access to services.

2.4. Procedure

Following the initial contact with the organizations, researchers conducted semi-structured interviews with hearing Francophone parents. The interviews were conducted between 2015 and 2016 and the average duration was 60 min. The place to conduct the interview was agreed between the researcher and the participant in each country.

All participants signed the informed consent document and agreed to be recorded. Prior to the interview, participants were reminded that they had the right not to answer any question and to end the interview if they so wished. Regarding the ethical issues of this research, the study forms part of a research project funded and ethically approved by the Ethics Committee of the Université de Moncton (approval 1415-020).

The interviews of the data corpus were transcribed and analyzed according to the principles of content analysis [24]. The interviews were named under a coding principle, the figures following the extracts allowed to find the extracts used in this article. For example, 12-505-1, the number 12 allowed us to identify the province or region (12 for Quebec, 11 for New Brunswick, 2 for France, 3 for Belgium, and 4 for Switzerland), the 505 indicates the identification number of the interview, and the 1 digit the sex of the interviewees (1 for women and 2 for men, and 3 for men and women that were interviewed together).

2.5. Data Analysis

The initial analysis revealed two categories of experiences in parents' participation in the services offered to their DHH child. This categorization work was done using the Nvivo data analysis software [25]. All the material divided into categories was re-read to identify the nuclei of meaning

that constituted the essence of the phenomenon studied. This task was performed in parallel by three researchers. This step was meant to provide triangulation among researchers [17]. Particular attention was paid to the elements that went against the main trend, the implication of parents as something self-evident, to bring nuances to multiple spaces and forms of commitment. This approach helped to avoid relying on a single point of view and instead addressed the diversity of parents' forms of engagement and the relationships they have with the actors who are involved with their children.

The question of access to services was addressed from several angles in the interviews and was listed in various categories of the coding book, categories that were used to produce the analysis presented in this article. The three main categories used to formulate our thinking about access to services were: "Access to the available services", "Access to the desired services", and "Parents' struggles to access services". The analysis of the collected data produced interpretations of the obstacles that were met by parents in their attempt to access services for their DHH children.

3. Results

In accordance with the final themes obtained during the analysis procedure of the information, the results of this research are organized as follows: (1) Access to the available services, (2) Access to the desired services, and (3) Parents' struggles to access services.

3.1. Access to the Available Services

Gaining physical access to the services needed for the DHH children is a basic condition to guarantee their healthy development and wellbeing. In that sense, two parents (4-411-2 and 12-513-1) have highlighted to what extent it is important for them to have transport facilities (e.g., receiving financial aid for a taxi service) as well as itinerant services that move close to the families that live in rural areas. This is the case of participant 12-513-1, who has expressed her satisfaction when the rehabilitation center started offering weekly its services in the village hospital. This relocation avoided having to travel long distances to gain access to the required programs.

In spite of this, physical access to the services remains an enduring challenge for some parents. For example, participants 4-409-1, 11-201a-2, and 12-514-1 have reported that all of the health professionals they need to consult on a frequent basis (otorhinolaryngologist, audiologist, etc.) are located far from their home. The following extract from participant 12-514-1's interview illustrates how the itinerance of the services can be helpful for families living in rural areas, but also, the several challenges they still face to access the necessary services for their DHH children:

"We did not live in "the main city", we lived in the north, 18 hours by car from "the main city". It is an isolated region. So, services are available, but further. (. . .) For the audiologist, it was at 45 min by car, it was ok, for the speech therapist it was ok too, she could move to our city and that was great. For the otorhinolaryngologist, in theory, there was one 45 min away, but staff is continuously changing, they did not have time to hire nobody else, nobody wanted to go to work there, so we left. This was a real struggle, it happened often that it was necessary to go down to "the main city" by plane to be told that it has too many otitis and then we were told "I cannot see anything, put some drops and come back to see me". We had both taken vacation for this and paid for the plane tickets.
(Participant 12-514-1)

The waiting time to receive the necessary services can also determine their accessibility. For instance, some parents (11-208-3; 11-701-1) have stressed the importance of being provided timely services that meet the needs of their child, especially when the services included health and literacy early interventions. Nonetheless, several parents (11-201-a, 11-201-b2, 12-105-1, 12-106-1, 12-304-1, 12-514-1, and 12-516-2) have reported the long waiting lists that prevent them from receiving health, rehabilitation, and educational support services. For participants 11-201-1 and 11-201-b-2, the delay is due to the fact that in the Canadian province where they live, when a child who benefits from different services (i.e., audiologic or speech therapy) starts school, these services are no longer managed by the

health department, but rather by the department of education. This change in service providers has caused long waiting lists that can go beyond a year and a reduction in available supports:

“When your children start school, there is almost nothing available because the waiting lists are so long that your child may be seen once a year if you are lucky, whereas before he was 5 years old or before going to school, there was an appointment almost every week at each service. That makes a big “WOW!” when you arrive at school. And you ask... How is that possible that he cannot do physiotherapy anymore? How is that that he can no longer do occupational therapy anymore? How can he not do speech therapy anymore? (...) It makes you also angry because you see the progress your child has made until now and then all of a sudden, boom! Everything stops and this is something that needs to be fixed in my opinion.” (Participant 11-201a-2)

Finally, some of the parents interviewed, especially parents located in France, have reported feeling abandoned by the service providers that were once responsible for the care of their DHH children. According to the parents, this abandonment is due to a lack of enough monitoring that could be crucial for an earlier diagnosis (2-706-1 and 2-707-1), the lack of support to help parents make decisions during the first years after the deafness diagnosis (2-805-1), and the lack of educational services even though they had been previously granted and planned with the school’s professionals to facilitate the child’s inclusion in the mainstream class (2-804-1 and 2-805-1).

3.2. Access to the Desired Services

Sometimes, the parents who have participated in this study have struggled with the lack of services they consider essential for the development and wellbeing of their DHH children. According to participant 12-507-1, this was due to the way in which the health system establishes the criteria for accessing services such as orthopedagogy. In that case, despite the request of the family, the fact that their child had additional disabilities led to a prioritization of some supports over others. However, for the participant 2-707-1, the problem was that hearing aids and ongoing support, funded by the health system, were far from the quality expected, causing important impediments to the child’s quality of hearing.

Another important problem faced by DHH children has been the lack of services that promote their development in different areas of their lives. In this case, parents have reported a lack of audiologists (11-701-1), specialized services for DHH children with cochlear implants (4-401b3), deaf interpreters in ordinary schools (12-105-1 and 12-106-1), speech therapy (2-706-1), and necessary educational adaptations and supports to guarantee the child’s participation and development on an equal basis with his/her peers in mainstream schools (4-403b-1 and 2-711-2). In some cases, the lack of the necessary services was attributed to an insufficient public investment in the services for the DHH children, as participant 11-701-1 stated:

“There are not enough audiologists and resources for the current number of deaf children. The government sometimes thinks that there are only a handful of deaf children and they do not allocate the resources needed for current demand.” (Participant 11-701-1)

Finally, parents have reported difficulties in their selection of the professionals that can best meet their child’s needs, even when the assigned professionals were deemed as not sufficiently competent to help. This has been the case for participant 2-805-1 with the interpreter assigned by the school, participant 12-1505-1 with the speech therapist working at their home, and participant 12-304-1 with the surgeon in charge of her implanted child. As participant 12-304-1 pointed out:

“I feel frustrated and helpless. This is the limit of anger. Just not having the choice, I have to select a surgeon for my daughter who knows only her ears, it’s frustrating. (...) He never spoke to her, just for the cochlear implant when my daughter asked him ‘Will I hear the same if it does not work?’ There he was taken aback ... ” (Participant 12-304-1)

3.3. Parents' Struggles to Access Services

According to the parents interviewed, the lack of physical access to the available services and also the lack of services that fit the family and DHH children's needs not only have had an important impact on the development and wellbeing of their child, but also on the parents' wellbeing. In that sense, several parents have explained how the extent of their difficulties to access services have led them to struggle to ensure their children's rights are protected.

For instance, a few Canadian parents (12-110b-3, 12-106-1, 12-302-1, and 12-515-2) have reported that the provision of available services and supports was not always offered to them immediately. Instead, parents had to constantly ask what was available for their children. Participants 12-110b-3 and 12-302-1 complained about the fact that schools, despite having funds to cover the costs of different supports that promote their DHH children's inclusion, did not offer these, unless parents requested and insisted:

"At the school where I sent my son, I really saw it was all about the money. A disabled child means a more funding and more funding means they have more money in their pockets. They do not necessarily have to give all the resources to the parent who is entitled, because if the parents do not know about their rights, why would we give it to them? Seriously, I think there are a lot of schools like that. (...) I know that we have the right to a support teacher. At one point, I talked to the teacher and he said 'yes, yes, it will be done'. OK. I asked my son 'Who is your support teacher?', 'My what?', 'The person who comes into the class'. He does not have anyone coming into the classroom." (Participant 12-302-1)

"She has the right to a phone. With the list of all that there is she only has the right to a phone and headphones for TV. And I said well I want them. You tell me that I have the right I want them. But you know I had to ask for the right to receive them because they were not offered to me." (Participant 12-110b-3)

Sometimes, parents experienced long and exhausting struggles to receive the necessary services that could support the development of their DHH child, as explained by participants 4-415-1, 11-701-1, 12-502-1, 12-505-2, 12-507-1, 12-516-2, 2-709-3, 2-804-1, and 2-708-3. For example, regarding the school supports for the inclusion of DHH children, participants 4-415-1 and 2-804-1 had to write several letters and make incalculable appeals to ensure their child's right to receive an interpreter and a support teacher in the mainstream classroom. In the case of participant 11-701-1, parents struggled on many occasions with teachers that refused to wear the microphone for the FM system because they thought that their daughter could hear them well enough. Other struggles were reported by parents who tried to access rehabilitation and health services. For example, participant 12-516 lodged several complaints to the complaints commissioner due to the loss of speech therapy services in the rehabilitation center and no access to alternative arrangements for their child. It took eight months until their child could benefit again from speech therapy.

Despite having achieved most of the times successful results after fighting for their child's right, a few parents confessed that they are always on the lookout for what might happen regarding the service provision. As participant 12-505-2 remarked: *"Battles start over and over again"*.

4. Discussion

Under the CRPD provisions, DHH children have a right to quality care that meet their needs. Parents play an essential role to ensure these rights are met. The purpose of this study was to investigate the experience of Francophone parents from different countries in their search for appropriate care for their DHH children. There is evidence that the CRPD provisions are not reached for many of the Francophone participants in this study. Parents experience a lack of services and describe their struggles for appropriate care for their DHH child.

4.1. Bringing and Adapting the Services to the Rural Settings

Parents explain the different ways that they experience service inaccessibility for their DHH child. In many cases, although services were available, they remained elusive for parents who lived in remote areas. As research has shown [9,10], living in a rural or remote geographical locations limits the access to social and health services and put families at risk. There are models of hearing-health care for children who live with their families in remote areas where services are found to be cost effective. For instance, Nguyen et al. [26] assessed a community-based mobile telemedicine service that, in collaboration with the local health services and schools, aims to facilitate the early identification and monitoring of Indigenous children from a rural area in Australia who are at risk of developing ear disease. According to the authors, some of the benefits of this service include easy access to specialist care in the local community and the reduced need for travel away from home. Even so, as Cohn and Cason [27] pointed out, it is also necessary to note that telepractice requires digital skills, a challenge for some individuals, especially if these technologies are not cognitively and sensorially accessible.

4.2. Reducing Wait Times for Assessment and Treatment

Yet, even when services were available in one's location, parents report long waiting times to access health, rehabilitation, and educational services for their child. This was particularly true for parents from Canada and France. In an international survey of wait times for care, Canadians rank among those who experience the longest wait times for access to health professionals [28]. The wait time is particularly lengthy for access to specialists and many Canadians turn to the emergency department for health challenges [28]. Benchmarks for wait time to assessment and treatment have been provided by the Pan Canadian Alliance of Speech-Language Pathology and Audiology Organizations [29] depending on the risk status category and the child's age. In all cases, authors suggest that information provided to patients about the duration of the wait and the fairness of the method of prioritizing patients for service is an important factor in managing expectations and improving satisfaction. These benchmarks should be considered as part of the CRPD provisions and accountability measures for professionals would be desirable.

4.3. Moving Towards Integrated and Person-Centered Services

Lack of access to the desired services for their DHH children, such as audiology, deaf interpreters in schools, speech therapy, or educational adaptations in mainstream schools, was a common feature of the experience of parents. Parents further report a clear lack of essential services. This reality runs counter to the CRPD provisions and shows that the rights of DHH children are not met for some of these youth. The lack of integrated services that meet the different needs of DHH children at different stages and areas of their lives is reported by parents. If these different needs are not met, DHH children will lag in certain areas of growth and could ultimately experience segregation from their mainstream peers. For instance, in a study conducted by Mellon and her colleagues [30], there are benefits for an approach that features "developmental synchrony" (p. 224). In this approach, as the authors suggest, educational programs provide a richer, more natural social environment and consistent exposure to hearing peers who can model age-appropriate language and social development. All in all, this particular strategy would require the health and educational systems to work in a collaborative and person-centered manner. These qualities would ensure that the DHH children and their family receive quality and appropriate care at each of the key stages of development.

4.4. Parents as Advocates of Their Children's Rights

Parents in this study describe their experience with the system as a constant battle. Often, these parents had to advocate on behalf of their DHH children to ensure that their needs are met. Although very little research on stress of DHH parents has been conducted and the few studies that have been provided mixed results [31], our findings have clearly shown that parents who face a health

and educational system that is not responsive to the needs of their child, feel stressed, abandoned, and helpless. Parents describe how they feel alone in their struggle before a very large, complex, and rigid system. Naturally, the lack of resources and services represent important stressors that can undermine the health and quality of life of parents and families with DHH children [32]. Our research highlights that this is especially true for hearing parents that have to constantly struggle to ensure their children's rights. While advocating for the DHH child's rights can be the source of frustration, for some parents, it has been viewed as a positive experience [33]. In the study conducted by Szarkowsky and Brice [33], parents of DHH children describe their advocacy work as empowering (p. 255): "It is empowering being an advocate for your own child". According to these authors, the participants benefited from advocacy work in many ways, including gaining the opportunity to teach others about deafness and developing a closer relationship with their child. These different ways of experience advocacy work as a "battle" or as "empowering" need to be further explored to ensure that parents are equipped with the tools they need to face situations when the CRPD provisions are clearly unmet.

4.5. Limitations and Avenues for Future Research

While this research has shed some light on the challenges that parents face in ensuring that their DHH child receives quality care, it does contain some limitations. Firstly, this research was focused on the experiences of hearing parents with DHH children, so the challenges faced by deaf parents were not addressed in this study. According to this, further research focused on their experiences is needed because, as Blume [34] pointed out, deaf parents also have to face important obstacles, such as giving in, or not, to the use of the technology of cochlear implantation which can represent a critical threat to the culture of the deaf community. Furthermore, knowing in-depth the experiences of deaf parents can allow us not only to determine in what extend services and supports are accessible to them and their DHH children, but also to obtain a more detailed view on how services and supports could be improved to ensure all DHH children's rights. Secondly, we did not include the features that would significantly affect the parent's experience, such as the age of the child, the family's socioeconomic status, or the gender differences in parent care, just to name a few. Taking into account the gender differences in caring for a DHH child in further research could allow us to explore the possible measures that could benefit the parents' involvement in the services offered to their DHH child [35]. Nevertheless, it is noteworthy that despite the heterogeneity in our sample pool, parents were able to report similar or recurrent accessibility challenges for care. Finally, our study did not investigate the extent to which participants were familiar with the CRPD. Therefore, it is possible that for parents who did not understand their child's rights to appropriate care, experiences with unmet healthcare needs were under-reported. Further research is needed to examine whether parents are well informed of the provisions contained in the CRPD.

Parents are important champions for their DHH child. The CRPD is designed as a shield to protect everyone who advocates for social participation of people with disability, as well as hearing parents in their search for appropriate care for their DHH child. Our findings suggest that the CRPD provisions are not always met and parents often bear much of the weight of the advocacy work. To further support this role, workers from health, education, and social fields, and parents should be better informed of the CRPD provisions. In fact, we suggest that accreditation for those establishments and professionals could include whether the CRPD is met. Including benchmarks and accountability measures may also help to ensure that the CRPD is respected. To guarantee its success, a truly participatory process and a human rights approach that includes all the actors involved (hearing parents, deaf parents, DHH children, the deaf community, professionals related to deafness, among others stakeholders) is suggested [36]. In addition, research has already uncovered some benefits from the development of models and practices for collaboration and partnership between parents and professionals that could ensure that DHH children's needs are met [14,37,38].

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References

1. United Nations. *Convention on the Rights of Persons with Disabilities*; United Nations: Geneva, Switzerland, 2006. Available online: <http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf> (accessed on 20 March 2018).
2. Megret, F. The Disabilities Convention: Human Rights of Persons with Disabilities or Disability Rights? *Hum. Rights Q.* **2008**, *30*, 494–516. [CrossRef]
3. Quinn, G. The United Nations Convention on the Rights of Persons with Disabilities: Toward a New International Politics of Disability. *Tex. J. Civ. Lib. Civ. Rights* **2009**, *15*, 33–52.
4. García-Iriarte, E.; McConkey, R.; Gilligan, R. *Disability and Human Rights. Global Perspectives*; Macmillan International Higher Education: London, UK, 2016; ISBN 1137390689.
5. Harpur, P. Embracing the new disability rights paradigm: The importance of the Convention on the Rights of Persons with Disabilities. *Disabil. Soc.* **2012**, *27*, 1–14. [CrossRef]
6. WHO—World Health Organisation. *World Report on Disability*; WHO: Geneva, Switzerland, 2011; ISBN 978-924068521-5.
7. Clark, D.M.; Hauser, P.C.; Miller, P.; Kargin, T.; Rathmann, C.; Guldenoglu, B.; Kubus, O.; Spurgeon, E.; Israel, E. The importance of early sign language acquisition for deaf readers. *Read. Writ. Q.* **2016**, *32*, 127–151. [CrossRef]
8. Siegel, L. The educational and communication needs of deaf and hard of hearing children: A statement of principle of fundamental educational change. *Am. Ann. Deaf* **2000**, *145*, 64–77. [CrossRef] [PubMed]
9. Alyami, H.; Soer, M.; Swanepoel, A.; Pottas, L. Deaf or hard of hearing children in Saudi Arabia: Status of early intervention services. *Int. J. Pediatr. Otorhinolaryngol.* **2016**, *86*, 142–149. [CrossRef] [PubMed]
10. Elpers, J.; Lester, C.; Shinn, J.B.; Bush, M.L. Rural family perspectives and experiences with early infant hearing detection and intervention: A qualitative study. *J. Community Health* **2016**, *41*, 226–233. [CrossRef] [PubMed]
11. Kristoffersen, A.; Simonsen, E. Communities of practice: Literacy and deaf children. *Deaf. Educ. Int.* **2016**, *18*, 141–150. [CrossRef]
12. Checker, L.J.; Remine, M.D.; Brown, M.P. Deaf and hearing-impaired children in regional and rural areas: Parent views on educational services. *Deaf. Educ. Int.* **2009**, *11*, 21–38. [CrossRef]
13. Flaherty, M. What we can learn from hearing parents of deaf children. *Australas. J. Spec. Educ.* **2015**, *39*, 67–84. [CrossRef]
14. Wood, C.; Traub, R.J.; Turnbull, A.P. Parents' experiences with childhood deafness. *Commun. Disord. Q.* **2008**, *29*, 82–98. [CrossRef]
15. Dionne, C.; Rousseau, C.; Vézina, C.; McKinnon, S. Expérience des familles dont un enfant présente une incapacité: Perceptions et besoins actuels. *Serv. Soc.* **2006**, *52*, 65–77. [CrossRef]
16. Mitchell, R.E.; Karchmer, M.A. Chasing the mythical ten percent: Parental hearing status of deaf and hard of hearing students in the United States. *Sign Lang. Stud.* **2004**, *4*, 138–163. [CrossRef]
17. Reeves, S.; Kuper, A.; Hodges, B.D. Qualitative research methodologies: Ethnography. *Br. Med. J.* **2008**, *337*, 512–514. [CrossRef] [PubMed]
18. Carbin, C.F. *Deaf Heritage in Canada: A Distinctive, Diverse, and Enduring Culture*; Deaf Press: Winnipeg, MB, Canada, 1996; ISBN 0075513781.
19. Gaucher, C. *Ma Culture, c'est les Mains. La Quête Identitaire des Sourds au Québec*; Presse de l'Université Laval: Montréal, QC, Canada, 2009; ISBN 978-2-7637-8938-5.
20. Delaporte, Y. *Les Sourds, C'est Comme ça*; Édition de la Maison des Sciences de L'homme: Paris, France, 2002; ISBN 2735109356.

21. Strauss, A.; Corbin, J. «Grounded Theory Methodology». In *Handbook of Qualitative Research*; Denzin, N.K., Lincoln, Y.S., Eds.; Sage Publications: Thousand Oaks, CA, USA, 1994; pp. 273–285, ISBN 0803946791.
22. Rabionet, S. How I Learned to Design and Conduct Semi-Structured Interviews: An Ongoing and Continuous Journey. *Qual. Rep.* **2011**, *16*, 563–566. Available online: <http://nsuworks.nova.edu/tqr/vol14/iss3/17> (accessed on 4 May 2015).
23. Van Campenhout, L.; Quivy, R. *Manuel de Recherche En Sciences Sociales*; Dunod: Paris, France, 2011; ISBN 2100563017.
24. Hsieh, H.F.; Shannon, S.E. Three approaches to qualitative content analysis. *Qual. Health Res.* **2005**, *15*, 1277–1288. [[CrossRef](#)] [[PubMed](#)]
25. *NVivo Qualitative Data Analysis Software*, version 10; QSR International Pty Ltd.: Melbourne, Australia, 2012.
26. Nguyen, K.H.; Smith, A.C.; Armfield, N.R.; Bensink, M.; Scuffham, P.A. Cost-effectiveness analysis of a Mobile Ear Screening and Surveillance Service versus an outreach screening, surveillance and surgical service for indigenous children in Australia. *PLoS ONE* **2015**, *10*, e0138369. [[CrossRef](#)] [[PubMed](#)]
27. Cohn, E.R.; Cason, J. Telepractice: A wide-angle view for persons with hearing loss. *Volta Rev.* **2012**, *112*, 207–226.
28. Canadian Institute for Health Information—CIHI. *How Canada Compares. Results from the Commonwealth Fund's 2016 International Health Policy Survey of Adults in 11 Countries*; CIHI: Ottawa, ON, Canada, 2017.
29. Rvachew, S.; Rafaat, S. Report on benchmark wait times for pediatric Speech Sound Disorders. *Can. J. Speech-Lang. Pathol. Audiol.* **2014**, *38*, 82–96.
30. Mellon, N.K.; Ouellette, M.; Greer, T.; Gates-Ulanet, P. Achieving developmental synchrony in young children with hearing loss. *Trends Amplif.* **2009**, *13*, 223–240. [[CrossRef](#)] [[PubMed](#)]
31. Sarant, J.; Garrard, P. Parenting stress in parents of children with cochlear implants: Relationships among parent stress, child language, and unilateral versus bilateral implants. *J. Deaf Stud. Deaf Educ.* **2014**, *19*, 85–106. [[CrossRef](#)] [[PubMed](#)]
32. Wood Jackson, C.; Turnbull, A. Impact of deafness on family life: A review of literature. *Top. Early Childh. Spec. Educ.* **2004**, *24*, 15–29. [[CrossRef](#)]
33. Szarkowski, A.; Brice, P. Hearing parents' appraisals of parenting a deaf or hard-of-hearing child: Application of a positive psychology framework. *J. Deaf Stud. Deaf Educ.* **2016**, *21*, 249–258. [[CrossRef](#)] [[PubMed](#)]
34. Blume, S.S. Histories of cochlear implantation. *Soc. Sci. Med.* **1999**, *49*, 1257–1268. [[CrossRef](#)]
35. Zaidman-Zait, A.; Most, T.; Tarrasch, R.; Haddad, E. Mothers' and fathers' involvement in intervention programs for deaf and hard of hearing children. *Disabil. Rehabil.* **2018**, *40*, 1301–1309. [[CrossRef](#)] [[PubMed](#)]
36. Tobin, J. *The Right to Health in International Law*; Oxford University Press: New York, NY, USA, 2012; ISBN 9780199603299.
37. Moeller, M.P.; Carr, G.; Seaver, L.; Stredler-Brown, A.; Holzinger, D. Best practices in family-centered early intervention for children who are deaf or hard-of-hearing: An international consensus statement. *J. Deaf Stud. Deaf Educ.* **2013**, *18*, 429–445. [[CrossRef](#)] [[PubMed](#)]
38. Blue-Banning, M.; Summers, J.A.; Frankland, H.C.; Nelson, L.L.; Beegle, G. Dimensions of Family and Professional Partnerships: Constructive Guidelines for Collaboration. *Except. Children* **2004**, *70*, 167–184. [[CrossRef](#)]



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