

MDPI

Article

Parent-to-Parent Advice: What Can We Learn by Listening to Parents of Deaf Children

Linsay Flowers ¹, Louise Duchesne ² and Charles Gaucher ^{1,*}

- School of Social Work, Université de Moncton, Moncton, NB E1A 3E9, Canada
- ² Speech-Language Pathology Department, Université du Québec à Trois-Rivières, Trois-Rivières, QC, G8Z 4M3, Canada
- * Correspondence: charles.gaucher@umoncton.ca

Abstract: Parent-to-parent support is an important component of early hearing detection and intervention (EHDI) programs for deaf and hard of hearing (DHH) children. In this study, we asked parents of DHH children what advice they would give to new parents in their situation. Seventy-one hearing parents of DDH children living in Canada, Switzerland, France, and Belgium participated in interviews that included the following question: "What advice you would give to parents who just learned that their child is deaf?". We performed a thematic analysis and developed three overarching themes, revolving around the importance of trust, the need for reassurance, and finally, the quest for help. The findings allow to better understand how parental expertise can be used to improve early intervention services for DHH children.

Keywords: parent of deaf children; deafness; advice



Citation: Flowers, L.; Duchesne, L.; Gaucher, C. Parent-to-Parent Advice: What Can We Learn by Listening to Parents of Deaf Children. *Societies* **2022**, *12*, 152. https://doi.org/ 10.3390/soc12060152

Academic Editor: Gregor Wolbring

Received: 20 September 2022 Accepted: 28 October 2022 Published: 2 November 2022

Publisher's Note: MDPI stays neutral with regard to jurisdictional claims in published maps and institutional affiliations.



Copyright: © 2022 by the authors. Licensee MDPI, Basel, Switzerland. This article is an open access article distributed under the terms and conditions of the Creative Commons Attribution (CC BY) license (https://creativecommons.org/licenses/by/4.0/).

1. Introduction

Parents of deaf and hard of hearing (DHH) children play an important role, not only in making important decisions regarding language, use of technologies, education and identity for their children [1], but also in ensuring that all their developmental needs are met. They have developed a unique expertise regarding parenting and managing family dynamics surrounding the DHH child. Therefore, they see themselves as active contributors to the services offered to their children [2].

Most of the available studies on parents of DHH children focus on access to newborn screening and early intervention [3,4], early literacy [5], or mainstream schools providing adequate educational services [6]. These studies point out that DHH children and their families are still facing important obstacles in terms of access to necessary services, such as: (1) long delays to obtain the first diagnosis and treatment of hearing loss [3], (2) poor communication of hearing screening results, (3) inconsistencies in healthcare information from primary care providers, (4) lack of local resources [4], (5) inadequate access to literacy during preschool activities [5], and (6) lack of collaboration with special educators in mainstream schools [6].

There are fewer studies that focus on the experience of being a hearing parent of a DHH child [7,8] or being the parent of a child with disabilities [9]. These studies highlight several challenges that parents encounter. For example, Flaherty [7] pointed out that a lack of information about the diagnosis and difficulty finding ways to better meet their children's needs constitute important barriers for parents at the time of diagnosis. In another study, Wood et al. [8] stated that some parents struggle with limited access to support services as well as the need to cover the costs of sensory devices, or intervention programs and other forms of professional support. Authors of this study also noted that in some cases, parents must advocate for access to the desired services and for their right to be included in the decision-making process, along with professionals. Finally, in the study conducted by Dionne et al. [9] parents of DHH children deplored being placed on

Societies **2022**, 12, 152 2 of 11

waiting lists to receive required services and support, a lack of specialists for DHH children (such as ear-nose-and-throat (ENT) doctors, speech-language therapists or occupational therapists), a constant turnover in professionals, a lack of organized activities for DHH children, and a lack of information about all the available services.

Although these studies provide valuable information about the parents' point of view, to date, few formal studies have examined parents' advice to other parents and professionals. However, the importance of including parents' expertise in interventions is well known [10], and parent-to-parent support is an important component of early hearing detection and intervention (EHDI) programs [11]. So far, the scientific literature on the subject has focused on the identification of themes and constructs that should be included in formal parent-to-parent support programs according to past research as well as according to experts' committees [11]. However, what do parents have to say to other parents with regard to parenting a DHH child? This paper aims to explore the advice parents of DHH children would give to new parents in their situation. By doing so, we aim to better understand how parental expertise can be used to improve early intervention services and to increase communication development and social participation of DHH children.

2. Method

2.1. Context of the Study

The data used in the present study was collected within a broader ethnographic research project [12] designed to explore the experiences of francophone hearing parents with DDH children in Canada, Switzerland, France and Belgium. Although various studies examined transformations in deaf education and deaf identity in these countries [13–15], little research has been conducted thus far with the goal of understanding how these changes have influenced francophone parents' engagement in services for DHH children in these countries.

In this research project, we explored several dimensions (e.g., learning that the child is DHH, decisions regarding communication, parental involvement). However, for the purpose of this article, we only analyzed the data pertaining to advice parents would give to other parents of newly diagnosed children. Participants

Since the research project was exploratory and conducted internationally (Canada, France, Belgium and Switzerland), parents with DHH children were very diverse. Participants for this research were selected according to the principles of theoretical sampling [16]. This sampling technique allowed us to collect data from participants in the four aforementioned countries while ensuring that a broad spectrum of experiences was documented.

Different local organizations from these countries helped out with the recruitment process. Parents were sent a letter inviting them to contact the research team should they be interested in participating. The goals of the study were explained to professionals within these organizations and their help was solicited to select hearing parents of DDH children that may be interested in sharing their personal experiences. The selection criteria were gradually redefined throughout the process in order to document different family realities, different types of services as well as different residential contexts (i.e., rural or urban).

A total of 117 parents from 4 countries were recruited: Table 1 illustrates the number of participants from each country, Table 2 shows a breakdown of participants according to various sociodemographic characteristics. Note: the majority of parents interviewed are highly educated and socioeconomically advantaged, as such it does not reflect the challenges that may be faced by socioeconomically disadvantaged parents.

Table 1. Participants (N).

Canada	France	Switzerland	Belgium
52	23	27	15

Societies **2022**, 12, 152 3 of 11

Table 2. Sociodemographics.

	Canada	France	Switzerland	Belgium			
# of participants	52	23	27	15			
Mothers	36	19	20	10			
Fathers	16	4	7	5			
Not indicated	25	2	11	11			
Family situation							
Two parent	16	19	15	13			
Single parent	0	3	_	2			
Blended	2	_	_	_			
Level of education							
University	12	20	12	5			
College or equivalent	5	1	_	8			
High school	2	1	2	2			
Apprenticeship	_	_	13				
# of children							
1	_	10	_	2			
2	13	7	11	10			
3	4	1	2	2			
4	_	_	2	1			
5	2	_	_	_			
# of DHH children							
1	12	9	1	2			
2	7	6	6	13			
3	_	1	1	_			
Twins	_	2	_				
Communication method							
Oral	14	11		_			
Sign Language	_	2	unknown				
Both	5	5	unknown	12			
Implant/hearing device							
Implant	12	17	unknown	13			
Hearing device	17	5	unknown	2			

2.2. Instruments

For this research we conducted semi-structured interviews, in order to give a voice to the hearing parents of DHH children. According to Rabionet [17], this technique is a way to explore actors' experiences by giving them the opportunity to explain their reality in their own words. We developed an interview guide to document these experiences, based on recommendations for conducting exploratory interviews [18], in collaboration with Services for Students with a Sensory Disability and the Quebec Association for Children with a Hearing Problem (AQEPA; Montréal, QC, Canada), the Association of Parents of Francophone Hearing Impaired Children (Belgium), and the Swiss Association of Parents of Hearing Impaired Children (Switzerland).

We first conducted exploratory interviews (n = 10), which allowed us to decide on the main themes that would be included in the interview guide: (a) participants' general experience as parents of DHH children, (b) types of services their children receive as well as their participation in planning service delivery; and (c) perceptions of their contribution to these services. The first interview guide included 17 questions on these three topics and was pre-tested with a parent from each country. It was then adjusted to reflect the reality of the participants according to nationality. The revised versions of the interview

Societies **2022**, 12, 152 4 of 11

guide included 15 or 16 questions, depending on the site (the Belgian and Canadian guides included a question concerning their satisfaction vis à vis collaborating organizations). Interviews provided the opportunity to document the subjective experience of parents in general and also provided a rich testimony about the challenges related to accessing services. One of the questions specifically targeted peer-to-peer advice. Parents were asked: "What advice you would like to give to parents who just learned that their child is deaf?". Of the 117 participants, 71 responded to this question.

2.3. Procedure

Following the initial contact with the organizations, 5 researchers (2 Canadian, 1 Belgian, 1 French, 1 Swiss) conducted semi-structured interviews with the parents. The interviews were conducted between 2015 and 2016 and were 60 min long, on average. The location of the interviews was decided based on a mutual agreement between the researcher and the participant, either at home or another quiet, private setting chosen by the participant.

All participants signed an informed consent document and agreed to be recorded. Before starting the interview, participants were reminded that they had the right to not answer any question and to end the interview at any time. This study is part of a research project funded by the Université de Moncton and was approved by the institution's ethics committee for research involving humans (file 1415-020).

The interviews were transcribed and analyzed according to the principles of content analysis [19]. Each interview was assigned a code to allow for the easy identification of the interview. For example, in 12-505-1, the number 12 identifies the province or region (12 for Quebec, 11 for New Brunswick, 2 for France, 3 for Belgium and 4 for Switzerland), 505 indicates the identification number of the interview, and 1 specifies the sex of the interviewees (1 for women, 2 for men, and 3 for men and women that were interviewed together).

2.4. Data Analysis

During the initial stage, the analysis revealed 15 categories of experiences in parents' participation in the services offered to their DDH child. Categories were created using the N'Vivo data analysis software. Then, we re-read all the material divided into categories, in order to identify the core meaning of the studied phenomenon. Three researchers performed this task independently, which is meant to provide triangulation among researchers [12]. We paid particular attention to both the elements that did not correspond with the main trends, and the perception that parents' involvement goes without saying, in order to nuance the multiple areas and types of involvement. This approach allowed us 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.

Advice provided by parents with lived experience to parents of a child with a newly identified hearing loss was coded in one category that became the core of the data analysis for this article. Then, we identified the following three overarching subcategories through thematic analysis: (1) nurture trust, (2) do not catastrophize, and (3) ask for help. It is important to note that we did not count the frequency of occurrences, opting instead for an in-depth qualitative analysis by allowing themes and sub-themes to emerge from the data. Each theme will be presented and analyzed according to the fundamental concept of self-efficacy [20], which can be used to better understand how to engage parents of newly identified DHH children. Self-efficacy refers to a person's belief in their ability to exercise control over their own actions, the events that affect their lives and succeed in a particular situation. These beliefs play an important role in how we perceive and respond to situations. People with a strong sense of self efficacy are more resilient to adversity and stress, are more motivated to tackle challenges and are more likely to have a positive sense of well-being and personal accomplishment than those with a weak sense of self-efficacy.

Societies **2022**, 12, 152 5 of 11

3. Results

3.1. Nurture Trust

3.1.1. Parents Need to Trust Themselves

Participants emphasized the need for parents of children with a newly identified hearing loss to trust their ability to parent their child. Although deafness may be "new, strange and unknown" (3-301-1 ¹) to hearing parents, they consider themselves the experts when it comes to their child, their situation, their family, and their means. Therefore, parents consider themselves best positioned to make decisions. In that respect, participants offered tips on making decisions with confidence and ensuring that their point of view is considered by others, which requires both assertiveness and perseverance.

Three strategies were outlined in terms of confident decision making: (1) trust your instincts; (2) educate yourself, and (3) exercise caution with regard to advice from others. Regarding the first strategy, parents were encouraged to trust in their own judgment and to let their instinctive ability to make appropriate choices guide them, especially with regard to implementing solutions that fit both the needs of the child and those of the family: "It's an adventure. They should follow their instinct (. . .) it's you who knows best your child, your personal situation, your means" (3-301-1).

Participants suggested a second strategy to assist parents with the decision-making process: educate yourself with regard to "what can be done" (12-103-1). Several interview excerpts touched on the importance of consulting multiple sources of information and considering a variety of options and resources. As one parent recommended, "never limit yourself to one opinion" (2-707-1), so as to be equipped to make well-informed decisions. Participants offered a variety of suggestions in this regard, for example: "be proactive" in terms of staying up to date about new developments as well as what is being done elsewhere (12-105-1); be actively involved in the child's activities (11-210-3); ask for a second opinion, or several, when necessary (4-406-3).

Finally, the third and most discussed strategy developed by participants was to exercise caution in accepting practical advice from anyone, including from other parents and professionals. A few participants recognized the paradox, making them openly reluctant to provide any advice when asked during the interview process, stating that doing so would be presumptuous: "every case is so different; what advice could you give? What works for us won't work for others because the family situation isn't the same" (3-308-2). Nevertheless, some participants argued that it is important to be discerning with regard to suggestions when it comes to parents who have lived similar experiences: "Don't even take advice from other parents. Observe. Take some and leave some, but it's you who knows your child" (3-301-1). In that respect, one parent warned others to avoid being influenced by negative, radical, or strong opinions in favor of one approach to communication as opposed to another, for example spoken language vs. sign language. Whereas a few participants recounted encounters with other parents who advocate strongly for a specific approach, a few others openly vocalized their support for letting the parents choose for themselves and their family in terms of communication mode. Given the different realities faced by families, most participants that addressed this issue argued that there is no "one size fits all" solution. Additionally, a small number of participants pointed out the importance of being especially cautious regarding advice from professionals. Three participants shared difficult experiences with professionals that contributed to or reinforced their belief that professionals do not necessarily have all the answers, for example being given "flawed" advice with regard to communication options (4-402-1). Some other participants pointed out that professional rhetoric imposes restrictions and might have an overreaching motive (2-710-1), and that scientific information is in constant and rapid evolution (2-708-3). As such, one cannot implicitly trust that professionals propose the most efficient solutions and have the most up to date information. Conversely, two participants verbalized the importance of trusting the system. For example, one of them suggested new parents to "trust the system. The system in place works perfectly well. I wouldn't dare criticize it, it would be disrespectful to all of those people (...) they give you everything" (4-410-2). Societies **2022**, 12, 152 6 of 11

Another parent (11-208-3) felt that it is important to have confidence in audiologists and to take their advice seriously.

Participants also offered advice for parents to follow once decisions are made: assert yourself and be perseverant. Parents verbalized the need to be confident in their own decisions and to actively assert themselves vis à vis professionals, for example "doctors who are not necessarily very open minded" (4-406-3) regarding different points of view. In that respect, a certain emphasis was placed on affirming their position, insisting that professionals of all sorts should respect their rights as parents and ultimately, wanting their final decisions with regard to their child respected:

Don't be afraid to slam your fist on the table. Don't be afraid to say: I don't agree with that, suggest something else, something that fits my needs, something that is possible for my child. Parents need to revolt, say: NO, I don't agree! (4-413-1).

Similarly, two participants discussed the importance of demanding recognition of their role within the team of professionals involved with their child, insisting on being regarded as an active member of the team, as opposed to an outsider passively waiting to be told what will happen. Participants also emphasized the importance of being perseverant in this endeavor. Three parents declared that the journey that follows the announcement that your child has a hearing loss is hard and as such, it is important that parents stay strong and "never, never, never give up" (11-201a-2). As one participant stressed, making your voice heard with regard to access to services is not always easy; in fact, it requires a great deal of determination and perseverance:

Services exist in (city), you just have to make a little noise and you can access them (...) We need to go for it, then take it a step further. If we always believe in what we are fighting for we can have it (12-109-2).

One participant added that being perseverant will teach the child to be perseverant as well: "not to quit. It's hard, it's not easy and it takes patience, but (\dots) you can't give up (11-204-1).

3.1.2. Parents Need to Trust Their Child

Parents need not only to trust their ability to parent effectively, but they also need to trust their child. The key argument raised by the participants is that parents do not necessarily have to impose their will, but rather provide the child with appropriate support as they make choices. Participants highlighted the importance of allowing children to express themselves as well as the parents' responsibility to promote their child's independence.

Regarding the first element, three parents discussed the importance of "giving the child a voice" (3-302-1) specifically when it comes to decisions regarding their preferred methods of communication. Participants argued that children should be presented with a variety of options and be allowed to choose, for example by exposing them to deaf and hard of hearing (DHH) people and hearing people (3-312-1). One participant added that when a child is too young to make their own decisions, parents need to be attentive and open to what the child demonstrates is best for them and use their judgment to make appropriate choices (2-804-1). Some other participants spoke to the importance of fostering independence in all aspects of life. Parents were cautioned to avoid spoiling and overprotecting their child, instead, as one parent suggested "be there to support the child but let them stand on their own two feet" (3-312-1). Doing so requires parents to have confidence in their child's abilities. In this regard, two participants (11-210-3; 12-516-2) stated that parents should refrain from imposing arbitrary limits upon their child, and instead allow them to engage in activities that are of interest to them and that they are able to do. For example, one set of parents explained that when their child was 10 or 12 years old, he wanted to be responsible for the game clock at his sister's ringette games. The parents were initially hesitant because they worried he would not be able to hear the whistles due to background noise, but the child was insistent on proving he was capable. "We stayed close in the beginning to help him, but he really was able to do it on his own" Societies **2022**, 12, 152 7 of 11

(11-201-3). Another (4-411-2) added that parents should "resist people who want to set barriers" (e.g., professionals) and believe that "nothing is impossible".

3.2. Do Not Catastrophize

Parents with lived experience want parents of newly identified children to be reassured that there is "no need to worry", that everything "is going to be fine": "there is a light at the end of the tunnel. There is always a solution" (12-510a-3). Participants described a journey filled with emotion that lead to an eventual sense of normalcy and provided advice with respect to coping.

Four participants attested to eventual normalcy, assuring new parents that in the end the child "will lead a *normal* life" (3-309-1). Their child will be happy, "be able to express themselves, be like others" (2-804-1). On a side note, three participants commented on the relationship between technological advancements (e.g., cochlear implants) and the possibility of living a "normal life". However, at least six participants also agreed that the process is not easy and a sense of normalcy is not instantaneous; rather, there is a period, after having learned that their child is DHH, that is filled with shock and grief. One participant described and normalized feelings related to grief:

As a parent we aspire to have perfect children, who will become adults with the least difficulties possible. When our child is diagnosed with something like deafness, we grieve perfect health or a perfect child. You need to go through the grieving process, it is normal to be angry, not to want to ask for help. Feelings of distress are legitimate. (. . .) If you are angry, in pain or losing hope, it is normal. All these feelings are legitimate when you learn your child's diagnosis, it feels like a slap in the face (12-507-1).

Participants also offered some concrete advice to help parents of newly identified children cope with the initial shock and avoid getting discouraged, for example: "process the information in your own way, at your own rate" (3-303-1), "there is no use seeing it as a mountain", take things one day at a time, one step at a time (12-303-1). Participants also pointed out the need for parents to reframe their thinking with regard to the new reality. In this regard, participants reiterated on several occasions that "it is not catastrophic" (3-309-1), meaning that "the child is not in mortal danger, it could be worse" (12-303-1).

3.3. Ask for Help

Parents emphasized the role of people with lived experience while somewhat minimizing the role of professionals and other resources when it comes to receiving help and support. Parents seem likely to find more comfort and a genuine understanding from people who have had similar experiences.

As one participant explained, deafness is often trivialized by people who have little to no experience with it. As such, it is advisable to "find support, but not from just anyone, from someone who has been through the experience of having a child diagnosed with a disability, someone who has lived a similar experience" (12-516-2). It is important to note that a few participants also identified DHH individuals as a valuable source of support. Parents were encouraged to actively reach out to people with lived experience for support, albeit as mentioned above not necessarily for practical advice. Participants pointed out several benefits related to connecting with people with lived experience, including fostering positivity, hope, and motivation, providing reassurance, breaking isolation and finally, receiving support from "appropriate" people.

Participants highlighted the main advantages related to seeking support from people with lived experience. The first advantage is related to an increase in positivity, hope, and motivation. Participants claimed that surrounding themselves with parents in similar situations gave them the opportunity to see success stories as well as to see how things work at school and in daily life. Witnessing children for whom "things are going well" (3-308-2), helps you to remain positive (12-103-1), motivates you to push forward (12-516-2; 11-210-3), and fosters hope (12-508-2). The second advantage is the appreciation of the fact that people who have lived the experience gave them comfort. For example, one participant shared their

Societies **2022**, 12, 152 8 of 11

experience meeting a "profoundly deaf" young adult that was functioning well both socially and academically, "it was so relieving" (12-515-2). In addition, two participants shared that in the beginning "you feel so alone" (11-210-3), and communicating with people who share common experiences, for example other hearing families with a deaf child, helped them feel less isolated. Finally, people with lived experience can offer support. Participants valued the opportunity to connect with people who understand, to discuss options, experiences, challenges, and obstacles, which ultimately left them feeling supported and understood.

A few participants offered strategic advice with regard to meeting people with lived experience. They recommended that new parents carefully choose the people upon whom they rely for support. In some cases, participants advised parents to seek variety, for example one participant (3-310-1) suggested interacting with several parents or families who have followed different paths, to see how different options play out in a real-life context (3-310-1). Similarly, another participant (4-409-1) 2) recommended engaging with people with varying "levels of deafness" to help with relativization. In contrast, two participants suggested limiting interactions to people with similar experiences. One participant recommended engaging with parents that have children in the same age range, due to the fact that the reality of parenting a DHH child evolves as rapidly as technology and scientific information (3-313-1). Moreover, one participant emphasized the importance of meeting people with similar backgrounds (for example, education) suggesting that it facilitates a better mutual understanding (2-80501-b).

In a few cases, participants expressed the importance of seeking help from a professional. Two participants encouraged fellow parents to consult a therapist as needed, for either themselves or another family member that may be having a hard time coping with the situation. Two other excerpts touch on this matter. The first encourages parents to surround themselves with "a good team, in whom you have confidence" (3-301-1) and to ask for help when needed. The second describes teachers as precious resources on whom you can count for help (11-205-1).

Finally, participants identified some other noteworthy sources of support. Whereas one participant recommended soliciting help from the natural support network: "ask for help from the family, ask them to take over the parenting duties and take some time on the weekend without children, to disconnect" (2-706-10), another strongly advised new parents to obtain and make use of resources designed specifically to help parents navigate their new reality (12-508-2).

4. Discussion

The present study examined advice provided by parents with lived experience to parents of a child with a newly identified hearing loss. Overall, our findings suggest that experienced parents would like new parents to believe in their ability to exercise control over the events that impact their lives and successfully parent their DHH child. In other words, they are encouraging new parents to develop their self-efficacy abilities [20]. For the participants in the present study, it is important that parents feel that they possess both knowledge and competence in their roles as parents of a deaf child [21]. Findings also suggest that in order to become efficient and be able to formulate their goals, justify their decisions, and express their demands, parents have to be involved and to assert themselves, especially when facing professionals that might be reluctant to offer services that suit their needs and their pace. These findings resonate with the conceptual framework for parent-to-parent support proposed by Henderson et al. [11] in which the learning parents (i.e., the new parents) will develop their competence and confidence by their engagement, decision-making, and parenting.

For hearing parents, having a child with a hearing loss can present many challenges, starting with the diagnosis. Participants in this study remind us of the state of upheaval in which they often find themselves when their child's hearing loss is initially identified. Parents of children who are diagnosed with any type of disability, including DHH, are in fact often faced with feelings of grief, shock, denial and guilt, which can lead to serious

Societies **2022**, 12, 152 9 of 11

crises or disruption of family life [7,22]. Nevertheless, parents have to learn about the nature and implications of the diagnosis and adjust to the situation. They are often overwhelmed with information and then asked to make numerous decisions regarding technology (e.g., hearing devices), communication options, education and identity [7].

Despite the challenges faced, the message underlying participants' discourse is one of hope and resilience: trust yourself and your child. They do not perceive themselves as powerless, but rather as highly competent individuals, capable of making decisions for their child and their family. In this sense, parents who have recently learned their child is DHH are encouraged to avoid becoming "passive recipients of care" [23], and instead take an active role in the early intervention process. According to the participants of the present study, parents need to proactively educate themselves, via multiple sources, in order to be involved in every decision and every stage of the early intervention process. Indeed, parental involvement is an essential component of many early intervention programs for children with hearing loss and their families (e.g., [24–26]) and can contribute positively both to deaf children's development as well as overall parental well-being [21]. Several parents interviewed encouraged other parents to stay calm, and think of being DHH as a difference, not a catastrophe. In a slightly different vein, participants also argued the importance of including the child in decision making processes. For example, in response to the debate surrounding which methods of communication best promote language acquisition for a given child, a crucial issue for parents [27,28], participants suggested that parents be attentive to the child's response to different communication methods and to make choices accordingly.

For the participants in the present study, parental involvement also referred to being fully engaged and focused on action and mobilizing resources in order to ensure their voices are heard and their choices are acknowledged. Results show that experienced parents encourage new parents to not only seek information, but also to demand for what they feel is right for their child. These findings are again in line with the conceptual framework developed by Henderson et al. [11] in which advocacy and system navigation constitute knowledge that is essential to new parents and can be provided by experienced parents.

Somewhat surprisingly, professionals were not seen as trustworthy with respect to their capacity to offer appropriate support and to provide accurate information. Some participants even suggested that parents should be suspicious of professionals. Although various family-centered intervention models have been implemented throughout the world in the last 15 years, which stipulate that both parents and professionals are equal members of the team [29], results of the present study indicate that many parents seem to have experienced an "expert" model, in which parents are being told what to do instead of being provided information and encouraged to make decisions for themselves and their child. Past research that focused on parental experiences with early intervention services confirm that parents often encounter conflicting professional views [30,31] and overall are least satisfied with the provision of practical and unbiased information [26].

As noted above, participants did not feel as though they can entirely trust professionals. As such, they placed a great deal of emphasis on encouraging parents of children with a newly identified hearing loss to identify appropriate sources of support outside of the professional realm, notably people with lived experience. Surrounding themselves with people they can relate to can in fact help them cope with the grief that follows the initial discovery of their child's hearing loss [7] and feel more confident in their ability to make decisions. Overall, families with strong social support are better able to handle challenges [10].

One final point that arises from our findings is that everyone interacting with parents in the days, weeks and months following the initial identification of their child's hearing loss, including and especially professionals, need to be sensitive to the fact that stress has a large impact on both the ability to assimilate information and decision-making processes. As such, they should be mindful of the way that they offer support and impart information to parents. It is likely that participants in the present study may have been urged to

Societies **2022**, 12, 152 10 of 11

make important decisions and may have felt that professionals paid little attention to their emotional needs during a very difficult moment. In a recent viewpoint paper, David Luterman [32], argued that audiologists must exercise patience because parents "need time, compassion, and encouragement" (p. 3). Luterman advocates for a "client-centered practice" in which parents are encouraged to share their emotions and can decide on the quantity of information that is provided by professionals over time. As our analysis shows, we can only agree with Luterman and advocate for more consideration of new parents' pace and rhythm when faced with the challenges of parenting a DHH child.

Author Contributions: Conceptualization, L.F. and L.D.; methodology, and software C.G.; validation and formal analysis, L.F. and L.D.; investigation, resources, and data curation, C.G.; writing—original draft preparation, L.F.; writing—review and editing, L.D. and C.G.; visualization, L.F.; supervision, project administration and funding acquisition, C.G. All authors have read and agreed to the published version of the manuscript.

Funding: This research was funded by Social Sciences and Humanities Research Council.

Institutional Review Board Statement: This research has been approved by Université de Moncton ethic board, file no 1415-020.

Informed Consent Statement: Informed consent was obtained from all subjects involved in the study.

Data Availability Statement: Data is located on a Université de Moncton secure drive, for access please write to Charles Gaucher at charles.gaucher@umoncton.ca.

Conflicts of Interest: The authors declare no conflict of interest.

Notes

All quotes were translated as interviews were conducted in French.

References

- 1. 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]
- 2. Kirsch, S.; Piérart, G.; Gaucher, C. Posture des parents entendants d'enfant sourd au regard des services et des intervenants dans le domaine de surdité. *Nouv. Rev.–Éducation Société Incl.* **2021**, *89–90*, 159–177. [CrossRef]
- 3. 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]
- 4. 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]
- 5. Kristoffersen, A.; Simonsen, E. Communities of practicer: Literacy and deaf children. Deaf. Educ. Int. 2016, 18, 141–150. [CrossRef]
- 6. Checker, L.J.; Remine, M.D.; Brown, M.P. Deaf and hearing-impaired children in regional and rural areas: Parent views on educational services. *J. Deaf Educ. Deaf Stud.* **2009**, *11*, 21–38. [CrossRef]
- 7. Flaherty, M. What we can learn from hearing parents of deaf children. Australas. J. Spec. Educ. 2015, 39, 67–84. [CrossRef]
- 8. Wood, C.; Traub, R.J.; Turnbull, A.P. Parents' experiences with childhood deafness. Commun. Disord. Q. 2008, 29, 82–98.
- 9. 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]
- 10. Poon, B.; Zaidman-Zait, A. Social support for parents of deaf children: Moving toward contextualized understanding. *J. Deaf Stud. Deaf Educ.* **2014**, *19*, 176–188. [CrossRef]
- 11. Henderson, R.J.; Johnson, A.; Moodie, S. Parent-to-parent support for parents with children who are deaf or hard of hearing: A conceptual framework. *Am. J. Audiol.* **2014**, 23, 437–448. [CrossRef] [PubMed]
- 12. Reeves, S.; Kuper, A.; Hodges, B.D. Qualitative research methodologies: Ethnography. *Br. Med. J.* **2008**, 337, 512–514. [CrossRef] [PubMed]
- 13. Carbin, C.F. *Deaf Heritage in Canada: A Distinctive, Diverse, and Enduring Culture,* 1st ed.; McGraw-Hill Ryerson Limited: Toronto, ON, Canada, 1996.
- 14. Delaporte, Y. Les Sourds, C'est Comme Ça; Édition de la Maison des Sciences de L'homme: Paris, France, 2002.
- 15. Gaucher, C. La quête identitaire des Sourds au Québec. In *Ma Culture, c'est les Mains*; Presse de l'Université Laval: Quebec, QC, Canada, 2009.
- 16. Strauss, A.; Corbin, J. Grounded Theory Methodology. In *Handbook of qualitative research*; Denzin, N., Lincoln, Y., Eds.; Sage Publications: Thousand Oaks, CA, USA, 1994; pp. 273–285.

Societies **2022**, 12, 152 11 of 11

17. Rabionet, S. How I learned to design and conduct semi-structured interviews: An ongoing and continuous journey. *Qual. Rep.* **2011**, *16*, 563–566.

- 18. Hsieh, H.F.; Shannon, S.E. Three approaches to qualitative content analysis. Qual. Health Res. 2005, 15, 1277–1288. [CrossRef]
- 19. Van Campenhoudt, L.; Quivy, R. Manuel de Recherche en Sciences Sociales, 4th ed.; Dunod: Paris, France, 2011.
- 20. Bandura, A. Self-efficacy: Toward a unifying theory of behavioral change. Psychol. Rev. 1977, 84, 191–215. [CrossRef]
- 21. DesJardin, J.L. Assessing parental perceptions of self-efficacy and involvement in families of young children with hearing loss. *Volta Rev.* **2003**, *103*, 391–409.
- 22. Kandal, I.; Merrick, J. The Birth of a Child with Disability. Coping by Parents and Siblings. *Sci. World J.* **2003**, *3*, 741–750. [CrossRef]
- 23. Bosteels, S.; Van Hove, G.; Vandenbroek, M. The roller-coaster of experiences: Becoming the parent of a deaf child. *Disabil. Soc.* **2012**, 27, 983–996. [CrossRef]
- 24. Ingber, S.; Dromi, E. Actual versus desired family-centered practice in early intervention for children with hearing loss. *J. Deaf Stud. Deaf Educ.* **2010**, *15*, 59–71. [CrossRef]
- 25. 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]
- 26. Stewart, V.; Slattery, M.; McKee, J. Deaf and hard of hearing early intervention: Perceptions of family-centered practice. *J. Early Interv.* **2021**, *43*, 221–234. [CrossRef]
- 27. Brown, P.M.; Abu Bakar, Z.; Rickards, F.W.; Griffin, P. Family functioning, early intervention support, and spoken language and placement outcomes for children with profound hearing loss. *Deaf. Educ. Int.* **2006**, *8*, 207–226. [CrossRef]
- 28. Humphries, T.; Kushalnagar, P.; Mathur, G.; Napoli, D.J.; Rathmann, C.; Smith, S. Support for parents of deaf children: Common questions and informed, evidence-based answers. *Int. J. Pediatr. Otorhinolaryngol.* **2019**, *118*, 134–142. [CrossRef]
- 29. Ambrose, S.; Appenzeller, M.; Al-Salim, S.; Kaiser, A. Effects of an Intervention Designed to Increase Toddlers' Hearing Aid Use. *J. Deaf Educ. Deaf Stud.* **2020**, 25, 55–67. [CrossRef]
- 30. DesGeorges, J. Family perceptions of early hearing, detection, and intervention systems: Listening to and learning from families. *Ment. Retard. Dev. Disabil. Res. Rev.* **2003**, *9*, 89–93. [CrossRef]
- 31. Young, A.; Tattersall, H. Universal Newborn Hearing Screening and Early Identification of Deafness: Parents' responses to knowing early and Their Expectations of Child Communication and Development. *J. Deaf. Stud. Deaf. Educ.* **2007**, 12, 209–220. [CrossRef]
- 32. Luterman, D. Counseling Parents at the Time of Diagnosis: Moving Toward Client-Centered Practice. *Am. J. Audiol.* **2021**, *30*, 226–230. [CrossRef]