



Communication, Information, and Support for Swedish Parents with Deaf or Hard-of- Hearing Children

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RESEARCH



ABSTRACT

Communication is an important but complicated issue for parents to deaf and hard-of-hearing (DHH) children. Professionals have debated whether a DHH-child should have opportunity to learn spoken language, sign language, or a mixture of both. Two perspectives dominate: the medical (viewing deafness as a disability) vs. the cultural-lingual (viewing DHH-people as a cultural and linguistic minority). Parents have to handle these conflicting perspectives while they would need support and information about parenting a DHH-child. This article investigates preferred communication in the families, whether parents get information about STS, attend STS-courses, if parents get adequate support and information. 118 parents responded on a survey focusing on these issues, and the results show that spoken Swedish was preferred, but that STS or sign-supported Swedish often was used in parallel. Most parents without previous knowledge of DHH-people were satisfied with the information and support received, while parents with previous knowledge had negative experiences.

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Communication is a particularly important issue for deaf and hard-of-hearing (DHH) people. With absent or limited hearing, developing and using spoken language is problematic, and sign language may be an alternative or a more accessible complement. However, when and how to teach spoken and sign language to DHH children has been a controversial issue. Professionals and researchers in various countries have debated whether a DHH child should be taught only spoken language, only sign language, or a mixture of both, whether as separate languages or as a simultaneous expression (i.e., sign-supported speech).

Over the last few decades, this issue has become even more complicated in many countries because of the increasing number of cochlear implant (CI) surgeries and the new opportunities for deaf children to acquire a spoken language with the help of the new technology.¹ With a greater focus on spoken language acquisition, many children may not be provided with opportunities to learn a country's sign language (as a main or additional language) or might have fewer opportunities. However, DHH children's opportunities to choose among suitable communication forms depending on the context highly depend on their parent's opportunities to learn sign language and how much they develop this language (cf. McKee & Vale 2014).

COMPETING PERSPECTIVES ON DEAFNESS

As with Disability Studies, models representing different perspectives on deafness are apparent. Most commonly, scholars in the field mention the medical perspective versus the cultural-lingual perspective, because these two perspectives often directly oppose each other (Bagga-Gupta 2016; Blume 2010; Holmström 2013; Lane 2010). Throughout history, attempts have been made to cure deafness, considering it a disability. From this medical perspective, deafness is an individual impairment that needs to be treated or cured. This view is an outsider's perspective (i.e., hearing professionals, parents, teachers, etc.) that says deaf people are lacking something important (i.e., hearing) and this lack causes difficulties in many contexts, such as acquiring spoken language, schooling, getting information, and taking part in society. Therefore, hearing aids and CIs are seen as solutions that allow deaf people to be part of hearing society.

The cultural-lingual perspective on deafness takes an entirely different standpoint: deaf people are a cultural and linguistic minority within a majority (spoken language) society. Deaf people share the experience of living as deaf, and their use of national sign languages connects them. This connection creates a community of practice—the Deaf community. The cultural-lingual perspective can be regarded as an insider perspective: it is how deaf people view themselves, not as disabled but as people who are equal to hearing people and proud of their sign language and culture. This perspective competes with the medical perspective, and advocates for the cultural-lingual perspective, which often views the medical perspective as oppressive, because it treats deafness as a problem and does not allow deaf people to be perceived as good enough as they are. Furthermore, advocates of the medical perspective often do not understand that deaf people might not desire to do anything to become less deviant and to fit better into mainstream society.

Hearing parents of a DHH child, without any previous knowledge of DHH children, usually meet medical professionals before they meet DHH people. As a result, the parents learn the medical view on deafness first. Consequently, they may be relieved to learn that hearing aids or CI surgeries can help their child become less disabled. Parents may later learn that sign language (or other sign-based systems, which will be described further below) exists and could be a way to communicate with their child. Some parents also get to know DHH adults and acquire role models for their children who provide a cultural-linguistic perspective.

In many countries, non-governmental organizations (NGOs) for DHH people and parents of DHH children exist. Many of these NGOs provide a medical perspective, while others provide a cultural-linguistic perspective (Holmström & Bagga-Gupta 2013; Jacobsson 2000; Lane 2010). For example, there are two NGOs for parents of deaf children in Sweden, namely DHB (the national

¹ Cochlear implant surgeries on children started in different times around the world and at different rates. Therefore, through the decades that have passed, more and more children have been operated on as the implants have developed and become more accessible. In Sweden, through 1 January 2021, a total of 1,431 children below the age of 18 have received cochlear implants since the first surgery in 1991 (see http://www.barnplantorna.se/wp-content/uploads/2021/12/STATISTIK-BARN_fram_till_1januari2021.pdf).

association for deaf, hard-of-hearing children, and children with language disorders and their families), and Barnplantorna (the national association for children with cochlear implants and children with hearing aids). DHB has a cultural-linguistic perspective, whereas Barnplantorna has a medical perspective (Holmström & Bagga-Gupta 2013). Parents can choose to become members of one or both NGOs, as each provides different activities and information.

Over the years, these NGOs and their advocates have been suspicious of each other, claiming that the other does not provide parents adequate information to make informed choices regarding whether to have CI surgery or whether to learn sign language. For example, advocates for the cultural-linguistic perspective often express doubt that parents of DHH children have received adequate information about Swedish Sign Language (STS) or that they have been encouraged to sign with their children (Adams Lyngbäck 2016; Jacobsson 2000). This is an essential issue for the Swedish deaf community, who experience STS as necessary for participation in society and quality of life. This community is worried that young DHH children may not learn STS (in parallel with spoken language for those who can benefit from hearing). Advocates for the medical perspective argue that DHH children need to be trained to perceive sounds using hearing aids and to produce speech. These advocates advise parents to wait to see whether speech development progresses adequately before learning STS.

This study investigates whether parents are provided information about STS, whether they attend STS courses, whether they get adequate support and information from professionals and NGOs, and what communication forms are used in families. Moreover, this study examines these issues from the parents' perspectives without the influence of established perspectives on deafness.

STUDIES ON PARENTS' EXPERIENCES

Discovering their child's hearing loss may be a life-changing experience for parents. They have to learn new ways to communicate and live with their child. The conflicting communication orientations between spoken and sign languages described above make it hard for parents to navigate information and advice and to make informed decisions (Adams Lyngbäck 2016). Parental involvement is crucial for a child's language development, but the process can be extra challenging for parents who have no previous knowledge about hearing loss or sign language. Hence, the information and support provided by professionals are essential as is the experience of other parents. Several international studies have examined parents' experiences with DHH children regarding such issues (Adams Lyngbäck 2016; Bruin 2018; Crowe et al. 2014; Hyde et al. 2010; Narr & Kemmerly 2015; Young 2002; Young & Tattersall 2007; Åkerström & Jacobsson 2009).

The parents have different experiences of the information and support they receive from professionals. Many parents experience it as being good and varied, while others report it being lacking or limited (Crowe et al. 2014; Decker et al. 2012; Meadow-Orlans et al. 2003; Young 2002). The information provided includes issues on deafness, legal rights for the children, child development, choices for future school placement, and sign language. However, the many studies that focus on communication issues reveal that professionals often advise parents to focus on spoken language and avoid or delay learning sign language (Adams Lyngbäck 2016; Crowe et al. 2014; Decker et al. 2012; McKee & Vale 2014). Focusing on spoken language development often means that the parents must train with their children to ensure good spoken language development. Many parents find being responsible for their child's spoken language development overly demanding as they become trainers or teachers rather than parents (Bruin 2018). Therefore, Bruin (2018) concludes there is a need to rethink the parents' role and to discuss how professionals can support the parents so that they can remain parents.

Similarly, Humphries et al. (2019) believe the advice to focus on spoken language needs to be changed as children need opportunities to learn language, whether it is spoken or signed. Deaf children need to be exposed to language from birth, so they need to start with sign language, because it is the only accessible language, at least until hearing aids or CIs are introduced. Therefore, they argue that parents should start to learn sign language as soon as the child's hearing loss is detected to ensure the child's language development is not delayed and they do not experience linguistic deprivation. However, children can also learn a spoken language after receiving hearing aids.

Several studies show that parents who desire to give their children a range of opportunities for the future choose to learn sign language (Crowe et al. 2014; Hyde & Punch 2011; McKee & Vale 2014; Weaver & Starner 2011). However, opportunities to attend courses vary between countries and regions, and courses designated for parents (i.e., aimed at parent-child interactions rather than adult-adult interactions) are sparse (McKee & Vale 2014; Napier et al. 2007; Snoddon 2015). Other barriers to learning sign language are a lack of instructional guidance and learning material (McKee & Vale 2014).

One way to facilitate the learning and use of sign language is to participate in deaf environments, such as deaf centres where different activities and education are provided. Åkerström and Jacobsson (2009) found that parents positively responded to such participation. These experiences provide opportunities to become integrated into a community with peers and with deaf people of different ages. For new families with DHH children, moving into such environments promotes the children's access to the Deaf community and provides the children opportunities to be with other DHH children (cf. Weaver & Starner 2011). However, moving into deaf environments is not solely a positive experience. Åkerström and Jacobsson (2009) found that conflicts, annoyances, and condemnation occurred in such milieus when parents compared their situations and opinions. Some parents think others are too ideological or too passive. Parents also found that professionals gave them different advice and support.

Although several studies have found that parents of DHH children strive to provide their children the best communication opportunities, most parents hope that their children will develop spoken language, because it is the parents' language (McKee & Vale 2014). Many children do, and several studies report the dominant language in families with deaf children is spoken language (Crowe et al. 2014; Hyde & Punch 2011; McKee & Vale 2014).

In Sweden, research on DHH children and adults has been conducted for decades in psychosocial, linguistic, and educational disciplines, but only a few studies in Sweden (Adams Lyngbäck 2016; Åkerström & Jacobsson 2009) have focused on families and their experiences, difficulties, and language choices. This study aims to contribute to a greater knowledge from this perspective.

SIGN LANGUAGE COURSES FOR PARENTS IN SWEDEN

For several decades, Sweden has had a sign-bilingual approach at deaf schools that is quite well-known internationally. This approach means that DHH children should have the opportunity to learn and develop both Swedish (spoken and/or written according to their abilities) and STS in parallel. Consequently, parents in Sweden have been offered the opportunity to learn STS along with their children.

County councils in Sweden are required to provide parents with introductory STS courses, although the length of these introductory courses vary greatly between counties. A governmental report (SOU 2006:54) found that STS instruction varies between 25 and 250 hours, although it is usually between 50 and 60 hours. The number of hours is not fixed, and the county councils report that the need of the parents determines the length of the course.

After participating in an introductory course, the parents can proceed with the government-funded STS course TUFF (Sign language courses for certain parents), which has been offered since 1998. TUFF consists of three courses: basic, intermediate, and advanced. The purpose of the instruction is for parents to use STS in daily communication with their children. Educational organizers give the courses at different locations in Sweden, all following a common curriculum. Each parent can take up to 240 hours of TUFF education (SFS 1997:1158). However, most parents do not use all these hours. According to the National Agency for Special Needs Education and Schools, most parents only use approximately 50 hours of instruction. Branting (2015) concluded that the most common reason for this underuse is that the parents perceive that their child's spoken language has evolved better than they initially thought it would. Signing is used merely as support to spoken Swedish, so the parents do not feel that they need to learn more STS and they think that it takes too much time or that the courses are too advanced. A parent's choice not to take full advantage of STS instruction together with the decreasing number of pre-schools offering STS environments (Lyxell 2014, 2021) may impact the vitality of STS.

THE SURVEY

This study builds on a survey conducted in fall 2019 that was directed toward parents with DHH children, with the aim to learn about their experiences regarding information, communication, and support. The survey was created as a Google form with seven sections and a total of 69 questions. The first two sections focused on the parents' backgrounds, the child's age, whether the child had hearing aids, and so forth. The remaining five themes were as follows: 1) communication forms at home, 2) different forms of information received, 3) education provided in sign-based communication and the experience of it, 4) experience of treatment from different actors, and 5) other information. The questions included both fixed answer options and free-text responses. The survey took 15–30 minutes to answer, depending on time for the free-text responses. To ensure that the questions were sensible and not too sensitive, and nothing was missed, the questions were first sent to a parent of a DHH child for consultation. After receiving comments from this parent, the questions were adjusted.

In Sweden, where no official registries for parents of DHH children exist, it is hard to create a representative group of parents who agree to participate in research studies. As this study aimed to learn from parents, it depended on parents' interest to share their experiences. To reach parents, the survey was distributed as a link through various channels together with a short text asking for participation in the study. The link was initially spread through the author's social media channels and asked readers to share the link further. Next, one of the NGOs for parents of DHH children agreed to spread the link and information among their members, as did the Agency for Special Needs Education and professionals in two habilitation teams. The spread of the survey as a link rather than directed toward specific parents made it possible for parents to anonymously learn about the survey before deciding whether they wanted to share their experiences. In addition, the parents could complete the survey anonymously and choose to leave the survey incomplete. Therefore, it is impossible to determine how many parents saw the survey or how many parents chose to answer or not.

ANALYSIS

When the survey was closed in December 2019, all responses were downloaded to an Excel file through the Google form tool. The responses were listed in rows in time order, with columns for each question and free-text responses. With the help of Excel, the responses were sorted according to the children's ages, and all responses pertaining to people younger than 20 years were copied to a new sheet in the same document. Next, a qualitative analysis of the responses was conducted and compiled on a new sheet. Each question was analysed, and the responses were categorized. For example, for a question about the child's hearing aids, the respondents reported 'cochlear implants', 'bone-anchored hearing aids', 'outer hearing aids', and 'do not use hearing aids'. Also, some respondents said that the child used different hearing aids on each ear. Thus, the responses were categorized into different hearing aids or combinations. Some questions were easy to categorize, and several questions had pre-listed choices that made it easy to sort the answers. However, the free-text answers required a thematic analysis to identify recurring answers. In several answers, common themes could be found and categorized. The free-text answers gave a deeper understanding of the parents' experiences and could be used to illustrate the respondent's reflections, experiences, frustrations, and so forth.

DEMOGRAPHICS OF RESPONDENTS AND CHILDREN

In total, 138 parents, mostly women, answered the survey. The parents had children ranging from less than 1 year old ($n = 1$) to older than 30 years ($n = 6$). As this paper focuses on children born in the 2000s, the answers were filtered so 118 parents remained who had children under the age of 20. The backgrounds of the responding parents can be found in [Figure 1](#).

The parents were also asked to explain their self-estimated STS skills. The number of parents with different STS skills is shown in [Figure 2](#).

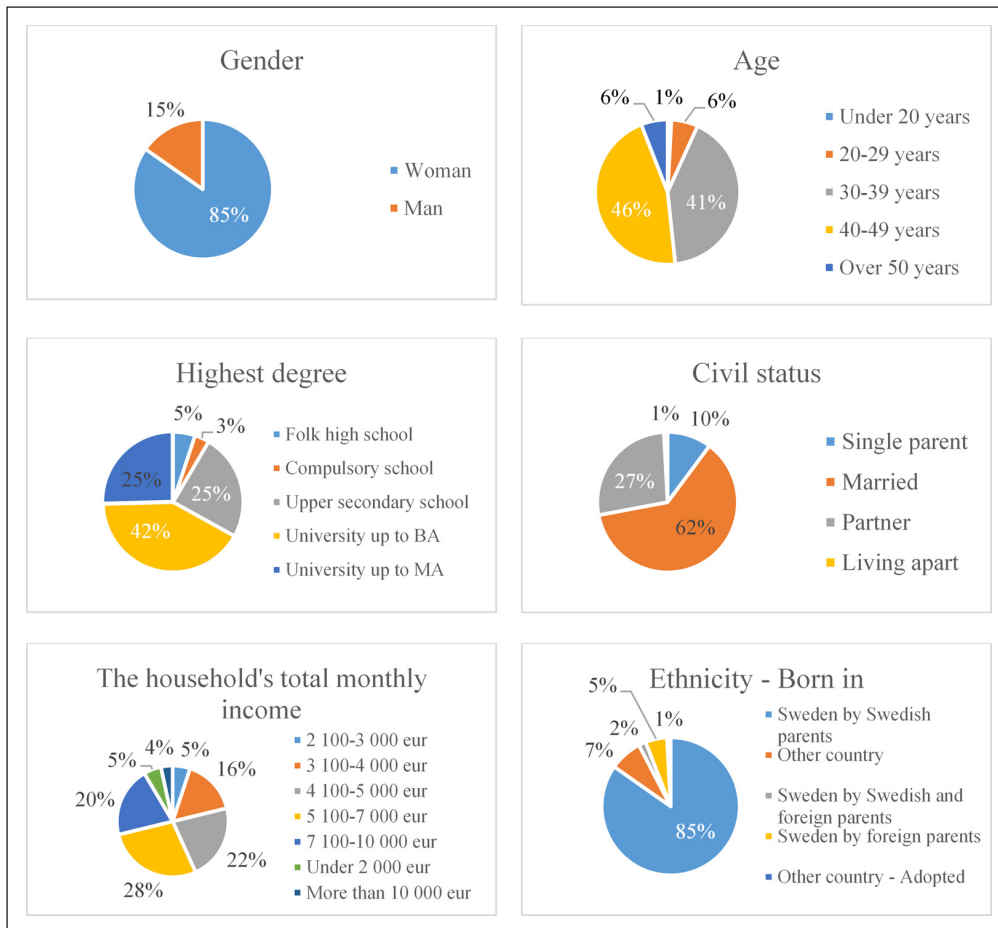


Figure 1 Respondents' background.

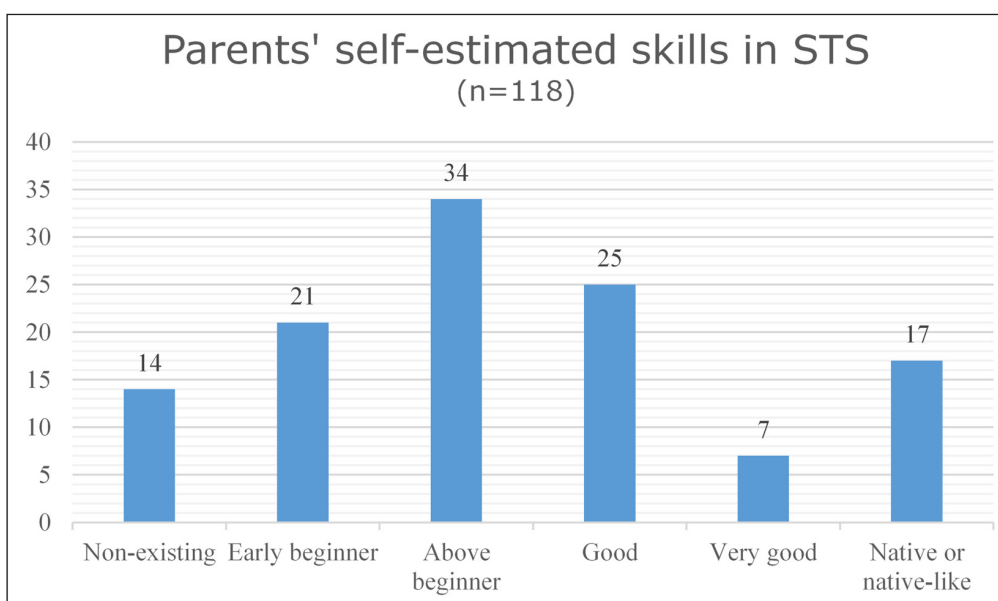


Figure 2 Parent's self-estimated skills in STS.

The survey did not ask about the parents' hearing status, but the answer options include, for example, 'I knew STS in advance, so there was no need to learn the language'. When the parents started to answer, it became clear that a smaller number of deaf parents and CODAs (children of deaf adults) had answered through free-text comments, such as 'Because I am deaf myself [...]', 'My parents are deaf [...]', and 'From my own experience, I know that [...]'. Of the 118 parents, 17 could be identified as having a deeper knowledge of STS before the child's birth and may be deaf or be CODAs (categorized as native or native-like in Figure 2). In this article, these parents are referred to as 'signing parents' and the others are referred to as 'newly-signing parents'. Some of the newly-signing parents may have learned and been using STS for several years, but others may not have learned STS at all or only to a limited degree.

Therefore, there is no evaluation of the level of STS skills or choices of communication forms in the term 'newly-signing parents' used here.

The 118 parents with DHH children under 20 years also reported their children's demographic backgrounds (Figure 3). Most children (71%) were between 1 and 10 years old when the parents responded to the survey. The hearing loss was mainly identified during their first year of life. Approximately 84% of the children used CIs, other hearing aids, or a combination of different aids, and 16% reported not using any hearing aid. In addition, 42% of the parents reported that their children have additional disabilities, such as NFP or visual impairment.

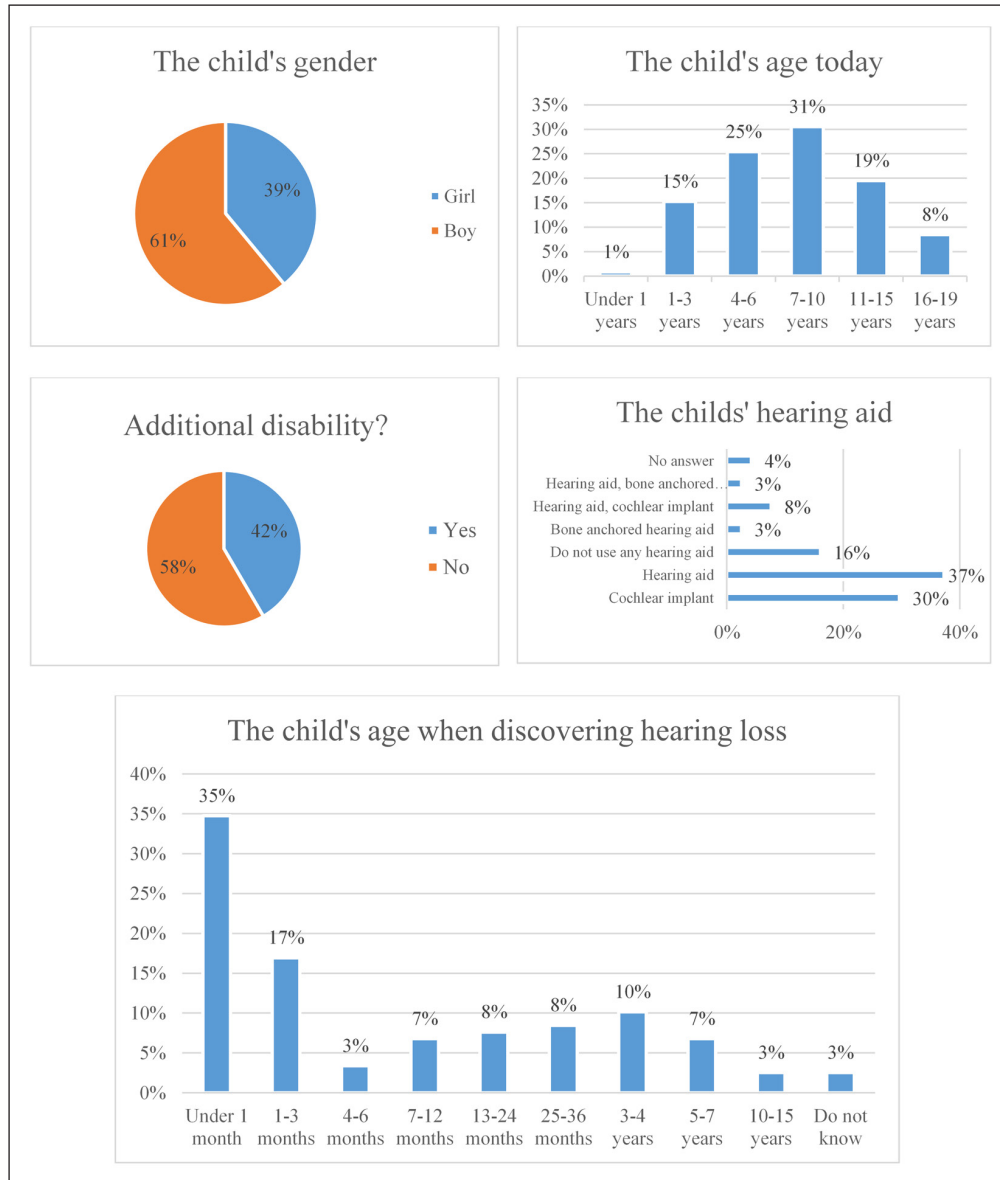


Figure 3 The demographic background of the children.

FINDINGS: PARENTS' EXPERIENCES

This paper builds on the parents' responses to the survey to reveal whether they have been provided information about STS, whether they have attended STS courses, whether they feel they have gotten adequate support and information from professionals and NGOs, and what communication forms they use within the family. In addition, some other reflections, experiences, and thinking that the parents expressed in the last free-text response have been analysed. As this study presents experiences of the 118 parents who responded to the survey, the findings cannot be generalized to all parents of DHH children in Sweden. Also, the findings rely solely on the parents' perspectives (i.e., professionals or NGOs may have other experiences).

Before examining the responses, the concept of 'forms of communication' used here needs to be explained. Communication is involved in the various ways people meet and interact. People can use (one or more) spoken languages, sign languages, written languages, bodily expressions, gestures, and a mix of different resources simultaneously. In the DHH field, one way to communicate is to mix resources from a spoken and a sign language, or a spoken language with a number of created signs as support. In Sweden, in addition to STS, there are two commonly used systems for mixing speech and sign: TSS ('Sign as support') and TAKK ('Sign as alternative and augmentative communication'). Both use Swedish as a matrix language and borrow signs from STS to support speech. These communication systems will be referred to as 'sign-supported Swedish' in this article. However, 'communication forms' will be used to cover both the use of different languages in varied modes (Swedish and STS) and constructed communication systems such as TSS and TAKK. Here, no other modes are included in the concept and no evaluation of the different ways to communicate is made.

INFORMATION ABOUT STS

As noted, parents without previous experience with DHH and STS may not know what STS is, what it can be used for, or why they should learn it. Advocates of the cultural-linguistic perspective often assume that the hearing habilitation teams do not sufficiently inform newly-signing parents about STS as a language and the positive outcomes of learning it. However, the survey revealed that 65% of the responding newly-signing parents received such information, and 91% said that the hearing habilitation team provided information. As medical professionals provided most parents with information about STS, the assumption by cultural-lingual advocates may be wrong. However, the signing parents' free-text responses revealed a quite different experience:

Those at the audiology clinic barely mentioned anything about sign language, etc. CI was the only thing they talked about as 'the child's only opportunity'. Nothing else. At all. Very bad. They patronized and said terrible things about the school and really stated that deaf people would disappear and that the child thus would come to the same class as impaired children.

Advocates of the cultural-lingual perspective often know STS. This signing parent's experience may explain the assumption that the hearing habilitation team has a medical perspective and does not provide information about STS.

COURSES IN SIGN-BASED COMMUNICATION

As described above, there are various courses in sign-based communication in Sweden aimed at parents. Therefore, the study wanted to examine which courses the parents usually participated in and what they wanted to learn—STS or sign-supported Swedish (see [Figure 4](#)). When the children's hearing loss was discovered, the responses showed that most newly-signing parents (59%) were offered the county councils' introductory STS courses. However, some respondents said they had to repeatedly appeal to the hearing habilitation team in order to get the opportunity to attend courses.

Several newly-signing parents reported they had attended more than one type of course, such as both the introductory course and TUFF or other combinations of courses. Interestingly, 25% of the responding newly-signing parents reported not being offered the county councils' introductory STS course because it required joining a TUFF course later.

Most responding newly-signing parents said they learned or wanted to learn STS (rather than sign-supported Swedish). This finding is interesting as it is common in Swedish DHH contexts to assume that parents prefer to learn and use sign-supported Swedish. However, this study indicates this is not the case.

As other studies have found, the most common reason for attending courses was, according to the responding parents, that they wanted to ensure effective communication with their child, for example, when technologies fail or do not work in certain environments or the child becomes sick. The respondents wanted several communication choices. A broader repertoire makes communication easier and gives the child opportunities to develop both sign and spoken languages in parallel:

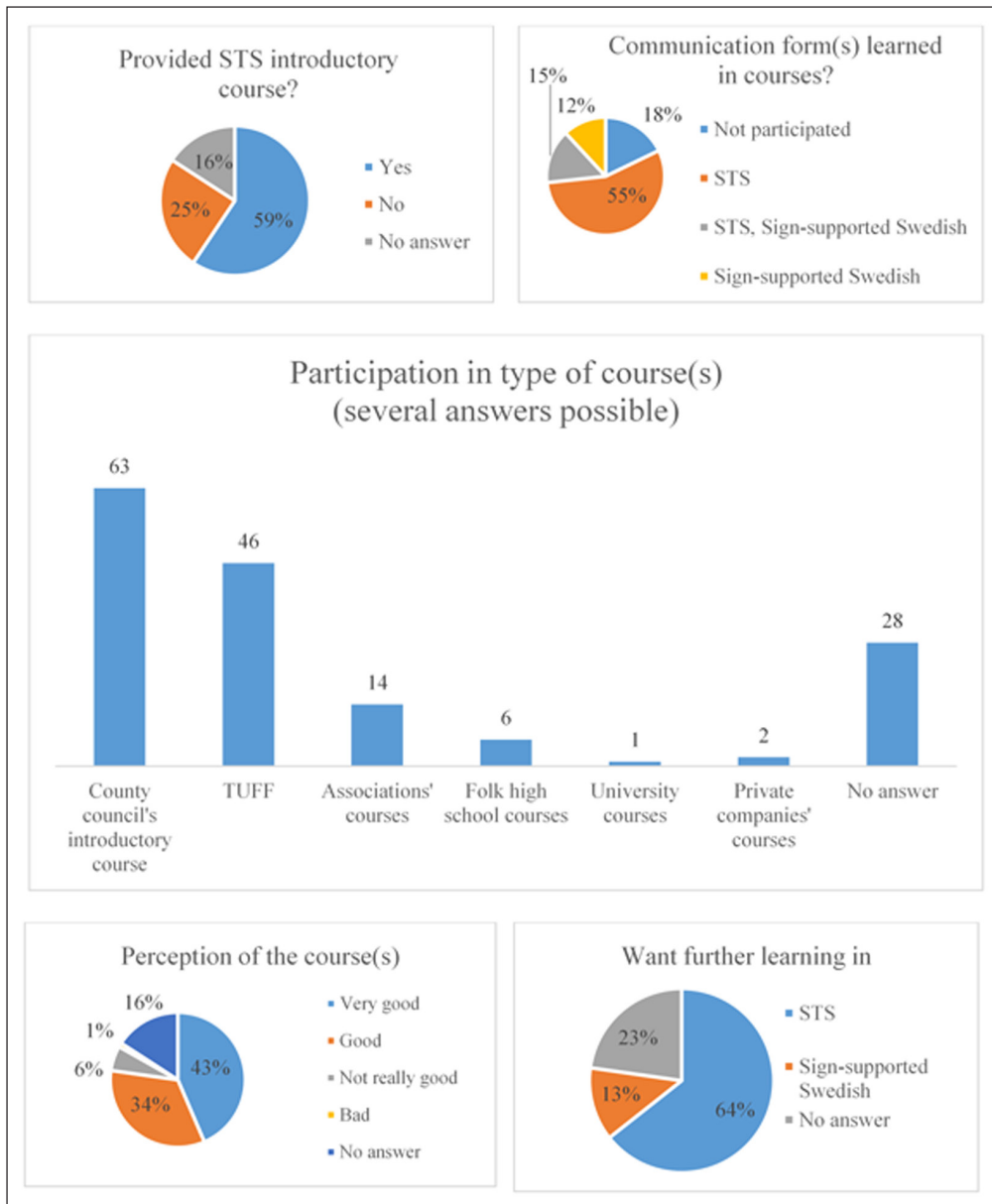


Figure 4 Courses in STS/Sign-supported Swedish.

I always want to have working communication with my child, whether there is any technology or not, and I want him to have the opportunity to choose which language he wants to use. However, in order for him to make a real choice, we must be able to use sign language in the family.

Chose CI for our son to increase his options, chose to sign for the same reason. If the technology does not work or if he simply does not feel comfortable with CI later, it should be 'easy' to opt-out.

Why wouldn't you? To be able to communicate with my son in every way possible to help him succeed in life.

To be able to communicate with my son in situations hearing aids are not sufficient or do not work.

According to Branting (2015), most parents attend TUFF courses for less than 50 hours. Therefore, it was of interest to examine to what extent the responding parents attended courses. However, this question received varied answers, and it is impossible to give a clear and overarching picture. For example, some parents reported between 20 and 300 hours of instructions (one parent guessed he had taken approximately 700 hours during his son's childhood). Other parents mentioned their attendance in courses in days, weeks, and semesters: '10 weeks', '3 semesters', 'biweekly for 3 years', and '3 full days per month'.

Because newly-signing parents often lack knowledge about STS and DHH people, it may be essential to meet DHH adults in different contexts, such as in health care, school, or leisure activities. Therefore, having DHH teachers in STS courses can provide parents with role models and give them an idea of what it means to be DHH in society (cf. Åkerström & Jacobsson 2009). In this study, 7% of the respondents reported having only deaf teachers, but 18% only had hearing teachers. The latter may be problematic as these parents do not meet DHH adults who could serve as role models. Overall, the parents were very satisfied with their teachers, their skills, and the teaching content.

COMMUNICATION FORMS WITHIN THE FAMILY

Although many responding parents reported participation in sign-based communication courses and mentioned the importance of having several communication choices with their children, it was not obvious that any sign-based form dominated in the families. Also, the choices may differ between the children and parents. Thus, the survey asked how common it was that the families only spoke Swedish (or another spoken language) at home, to what extent STS was used, and whether sign-supported Swedish or STS was more commonly used (Figure 5).

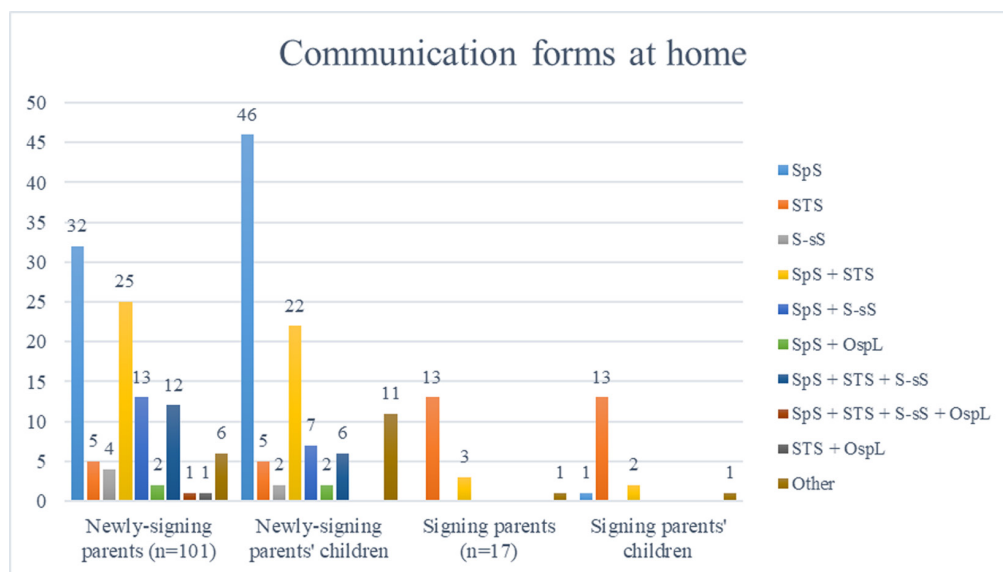


Figure 5 Communication forms used by parents and children (SpS = spoken Swedish; S-sS = Sign-supported Swedish; OspL = Other spoken language).

The responses revealed that Swedish was the dominant language spoken in families. Of the 101 newly-signing parents, 32 said that spoken Swedish was their preferred way to communicate with their child. Correspondingly, the responses showed that the children of most newly-signing parents used spoken Swedish to communicate with their parents (46 children). This finding supports the assumption by the cultural-lingual perspective advocates that oral language dominates while sign-based communication becomes subordinated.

Only five of the newly-signing parents said that STS was the preferred language (i.e., the choice by both the parents and children), and four parents and two children preferred sign-supported Swedish. However, the remaining 58 newly-signing parents and 32 children reported using several communication forms in parallel: they used both spoken Swedish and STS and/or sign-supported Swedish (and in two cases, an additional spoken language), indicating that the respondents had a more flexible view on communication. In the free-text responses, some of the newly-signing parents mentioned that the child decides how to communicate in the families:

Language choice depending on the situation, the child's mood, and the sound environment. The child decides.

Rarely signs to people he knows can hear even when CI is off, talks a lot but is interested and motivated to sign and has just started at school with TSS environment.

Communicates only in Swedish of own choice. She did not want to sign even though I had sign language skills and tried to give it to her as a first language. She refused to use it.

Signs in noisy environments and when he does not have CI.

The responding signing parents had a view nearly opposite to that of the newly-signing parents. Thirteen out of 17 parents stated they mainly use STS and that their child replies in STS. None of these parents used only spoken Swedish with the child, but three said they used both spoken Swedish and STS. One child used spoken Swedish only, and two used both languages. Thus, in this group of respondents, STS dominates, indicating a more robust cultural-linguistic view on communication.

SUPPORT AND INFORMATION

The information provided to parents after the birth of their DHH child may be important not only for parents without previous experience with DHH but also for those with their own experiences. For example, parents may need information about hearing loss, forms of support available, language acquisition, and associations for families with DHH children. Therefore, this survey examined whether the parents received enough varied information. Surprisingly, the analysis uncovered a difference between the newly-signing parents and the signing parents (Figure 6).

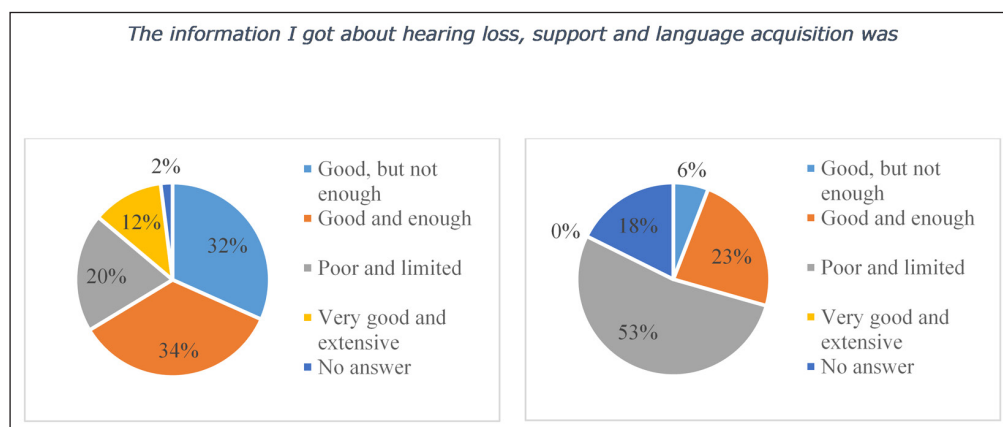


Figure 6 Difference between newly-signing parents (left) and signing parents (right) in the experience of information provided.

Figure 6 shows that the responding signing parents had a much more negative experience with the information about hearing loss, support, and language acquisition. Although 12% of the responding newly-signing parents reported getting 'very good and extensive' information and 34% 'good and enough' information, 53% of the signing parents reported the information received had been 'poor and limited'. The differences between the groups were also apparent when it came to the treatment by the hearing habilitation team (Figure 7).

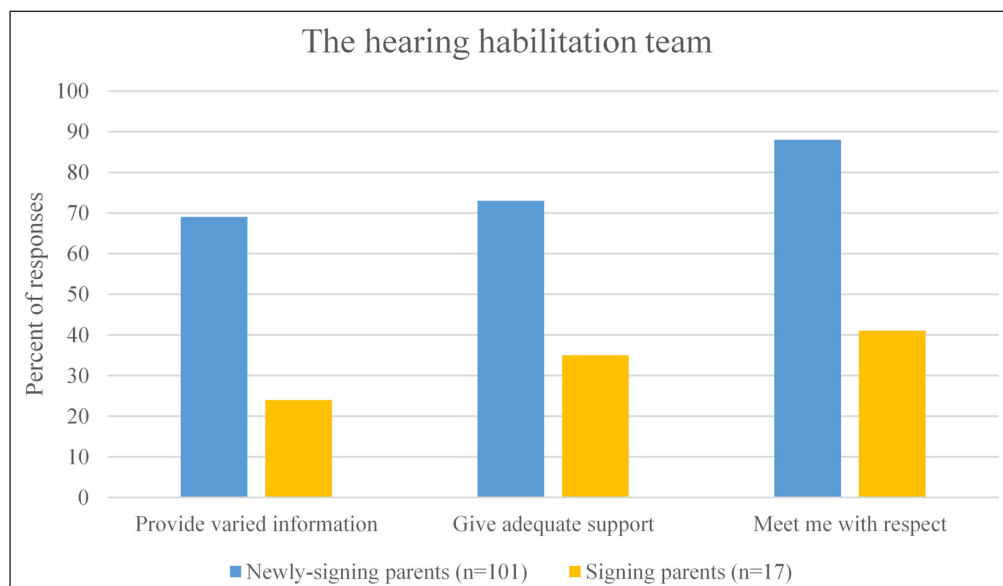


Figure 7 Treatment by the hearing habilitation team.

The difference in experiences between the two responding groups can be considered from the medical versus cultural-lingual perspectives. The newly-signing parents may have had better experiences because they initially viewed their children's hearing loss as an impairment and therefore experienced the habilitation team's efforts as helpful; whereas, the signing parents may have received information that was medically biased, resulting in a more negative experience. As shown in Information about STS above, one of the signing parents' free-text responses supports this view:

Those at the audiology clinic barely mentioned anything about sign language, etc. CI was the only thing they talked about as 'the child's only opportunity'. Nothing else. At all. Very bad. They were patronizing and said bad things about the school and actually stated that deaf people will disappear and that the child would be put in the same class as impaired children.

However, not all responding newly-signing parents were satisfied with the information given. Several parents wanted more information about language acquisition, STS or sign-based communication, support options, financial relief, associations/networks for parents, and the daily experiences of DHH people. Below is a selection of free responses from various newly-signing parents.

I had needed more support and advice about hearing loss initially when everything was new for me. I felt so lonely about everything. The health care needs to work faster with the investigation, so they can give a correct diagnosis. For us, it took 3 years before she got the right hearing aid! Then we had a lot of trouble with the health care and made our own referral to [hospital] when our county council did wrong on wrong on wrong.... it has been a terrible journey!

More support from a special needs teacher. Inadequate health care – the county council delayed everything, so it took 3 years before she got the right hearing aid.

A clearer communication about language. Belong to one county council but have our CI team through another county council. And these two have different views and messages about language development.

That sign language is a language and not an aid, to get in touch with the deaf, how the language development goes on for children who sign. I did not realize that my child signed until many years later, when I took a course on Children's Sign Language Development at [school]. Had I realized that my child's clumsy body movements were sign language, I could have continued to sign. It would also have been good to know the importance of visual contact, how to sign with the child on my knee, and much more.

How it would affect the child. I was looking for that info to a great extent to find out for myself, and the info we got came late, given that this [the hearing loss] was already discovered at [childbirth centre], but we got the information when he was more than a year old.

I lacked support when my son's hearing loss was found at [clinic]. Did not receive any support until we met the hearing habilitation team.

Had wanted more information and peace and quiet from the hearing centre when we were diagnosed. Many questions in the air took a long time to get answers to as we coped with seeking answers.

The survey also covered information about NGOs for parents with DHH children. Most responding newly-signing parents (52%) said they had received information about these NGOs, but 30% said they had not. The remaining 18% did not remember. For the signing parents, the situation was the opposite: 53% did not and 35% did receive information. However, the information about NGOs sometimes was experienced as biased. For example, some respondents said they got information about only one NGO for parents, which is crucial because the two main NGOs

(Barnplantorna and DHB) have quite different perceptions about hearing aids and language—the former has a medical perspective and the latter a cultural-lingual perspective:

We received most information about Barnplantorna. They do not have the same view on, e.g., CI – a ‘recreated sense’ vs. advanced technical tools vs. hearing aids. If you compare with, e.g., HRF [association for hard-of-hearing people] or DHB [association for families with DHH children], I would have liked more comprehensive information. Similarly, Barnplantorna does not encourage sign language, while DHB sees bilingualism as self-evident. As our child deviates from the ‘CI-norm’ regarding, e.g., speech, I could have ‘felt less unsuccessful’ if I knew about more ‘approaches’ or what to say.

Of the responding newly-signing parents, 72% reported being members of at least one NGO for parents or DHH people. Most respondents were members of DHB (41 parents) or Barnplantorna (23 parents). Ten parents belonged to the deaf NGO (SDR) and 10 to the hard-of-hearing NGO (HRF). Other NGOs were also mentioned, for example, deaf-blind NGOs and youth NGOs, but more sporadically. The responses from the signing parents are similar except for membership in Barnplantorna, which no parent from the signing group was a member. Seven parents were in DHB, seven in SDR, and five in HRF. These results are not surprising given Barnplantorna’s medical view on deafness.

OTHER REFLECTIONS, EXPERIENCES, AND THINKING

In the survey’s final section, the parents were given the opportunity to express further reflections, experiences, and thinking. However, only 34 parents wrote free-text responses, and the comments focused on different issues. One issue was about DHH children in Sweden not having any legal or formal right to learn STS; whereas, siblings and parents do:

My wish for all DHH children is that they get the opportunity to learn sign language. They are not born with that knowledge. There are courses for siblings and for parents, but not for the children themselves?! We live in [city], but for the child himself, there is NOTHING when it comes to sign language. He is not allowed to belong to a sign language pre-school or school, and in this way, he is forced into a hearing norm. It is difficult to motivate learning sign language when there is no opportunity to use it.

This comment points out a contradictory situation when it comes to DHH children and STS. The Swedish Language Act ([SFS 2009:600](#)) states that ‘the public sector has a special responsibility to protect and promote the Swedish Sign Language’ (§9) and that ‘those who are deaf or hard-of-hearing and those who for other reasons need sign language are given the opportunity to learn, develop and use Swedish Sign Language’ (§14) [my translations]. But in reality, few municipalities and schools offer government funded courses for DHH children compared to the courses offered to parents and siblings. Although only 34 parents gave responses, the parents have many issues, including the need for smoother systems, a variety of support, and more wide-reaching and varied information.

DISCUSSION

This study reveals that parents are exposed to information from both the medical and the cultural-lingual perspectives. Many of this study’s newly-signing parents (65%) report that they were provided with information about STS when their child’s hearing loss was discovered. Surprisingly, most received this information from the hearing habilitation team, as many cultural-lingual advocates assume that the habilitation team has a medical perspective on deafness. However, the responding parents also said that they received adequate information about other things connected to hearing loss, such as technical aids and various forms of support. These results indicate that the professionals who meet parents in the initial years of the children’s lives may have a view on deafness more nuanced than is commonly assumed by people and NGOs in DHH contexts.

However, the responding newly-signing parents also reported lacking information and support in some cases, and several parents expressed their desire to learn and receive more information than provided. This desire is not surprising as it is the usual reaction among parents whose

children receive such a diagnosis. The challenge lies in finding varied and nuanced information without being forced to choose between the medical and the cultural-lingual perspective. As revealed in this study, because parents may have an open mind and a positive attitude towards both views, they may have ambivalent feelings when meeting strong advocates from the two perspectives. Holmström and Bagga-Gupta (2013) found in their study of NGO periodicals that DHB may have a more nuanced position, welcoming both perspectives; whereas, Barnplantorna primarily advocates for the medical perspective. This result is also hinted at in this study's findings: none of the responding signing parents were members of Barnplantorna, and responding newly-signing parents who said that they had been members in Barnplantorna previously had left it because of its strict medical position on hearing loss. However, many respondents were members of both NGOs, which strengthens the conclusion that parents of DHH children can adapt both perspectives.

In addition, this study found that the responding signing parents experience much less support from the hearing habilitation team than the newly-signing parents, a finding that other studies, such as Meadow-Orlans et al. (2003), also published. The responding signing parents report that their needs were not met, that they received poor and limited information, and that the focus was on the choice to give the children CIs and the need for speech training. In other words, the signing parents believed the medical perspective they experienced was biased. Many of these parents might have had a cultural-lingual perspective, so the medical professionals might have been received as giving information and arguments primarily from the medical perspective. Although the assumed intentions of the medical professionals might be earnest, many of the signing respondents had negative experiences with these professionals.

Most of the responding newly-signing parents report that they chose to participate in courses primarily to learn STS and to some extent TSS/TAKK as well and that they wanted to continue to attend such courses. Therefore, the parents seem to see the advantages of sign-based communication in interactions with their children, for example, in situations when the hearing aids' batteries run out or are broken or when in a noisy environment. Furthermore, these parents express their desire to give their children all possible opportunities to communicate in different contexts (cf. Åkerström & Jaconsson 2009). Therefore, they used spoken language, STS, and TSS/TAKK. These findings strengthen the picture of parents having a standpoint apart from either the medical or cultural-linguistic perspectives. This is in line with previous research from other countries that have reported that parents want to use different communication forms with their children to give them opportunities to communicate in different contexts (e.g. Crowe et al. 2014; Hyde & Punch 2011; Weaver & Starner 2011).

Responding newly-signing parents also report that they mostly had positive experiences with STS courses and teachers, and they think it is an exciting, fun, and necessary challenge to learn STS. Furthermore, they report the courses were adapted to fit their needs, unlike some countries where courses are offered but are not aimed at or adapted to parents (e.g., McKee & Vale 2014; Napier et al. 2007; Snoddon 2015).

Like previous studies (e.g., Crowe et al. 2014; Hyde & Punch 2011; McKee & Vale 2014), this study showed that although many responding parents learn STS/TSS/TAKK and to various extents use sign-based communication, spoken language(s) is used most often at home by both the parents and the children, indicating that national sign languages for DHH children seldom have a natural place outside sign bilingual pre-school and school contexts. This lack of use influences the vitality of the national sign languages, which are important for deaf communities and highly valued in the cultural-lingual perspective. Although the parents' openness and willingness to learn STS preserves STS and there is a continued influx of new generations of DHH children using the language, it is important that Swedish society also offer STS as a primary language in specific contexts. Families need opportunities to naturally develop their STS skills (Åkerström & Jacobsson 2009). The decrease of sign language environments through, for example, the closing of pre-schools with sign language profiles (see e.g., Lyxell 2014, 2021 for the Swedish context), and the limited opportunities for DHH children to attend classes or other contexts where they can develop their sign language threaten not only the vitality of sign languages but also the children's ability to participate in society. Limited access to a sign language decreases opportunities to acquire it at a level that makes it a natural choice in contexts where the children experience spoken language as insufficient.

This study has revealed, according to the respondents, that parents mostly have an open mind for both the medical and the cultural-lingual perspectives, although they are often pressured by advocates of each perspective arguing that their perspective is the 'right' one. However, the responding parents, who strive to give their children the best possible opportunities in life, take a more flexible standpoint, 'a third position' (Bagga-Gupta 2016) that goes beyond the two normative positions. The responding parents in this survey seem to be looking for a more holistic view of their children's opportunities and difficulties, where the children also have the right to make choices.

COMPETING INTERESTS

The author has no competing interests to declare.

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