Empirical Articles

First Information Parents Receive After UNHS Detection of Their Baby's Hearing Loss

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The first information parents receive after referral through Universal Newborn Hearing Screening (UNHS) has significant consequences for later care-related decisions they take and thus for the future of the child with a hearing loss. In this study, 11 interviews were conducted with a representative sample of Flemish service providers to discover (a) the content of the information provided to parents and (b) the service providers' assumptions and beliefs concerning deafness and care. To do this, we conducted an interpretative phenomenological analysis, followed by a discourse analysis. Results showed that parents receive diverse information, depending on the reference center to which they are referred. Moreover, all service providers used a medical discourse. We suggest that there is value to be gained from closer consideration of the nature of follow-up services provided in response to UNHS in Flanders and from auditing the professional preparation of service providers that are involved in providing information to parents.

Universal Newborn Hearing Screening (UNHS) programs have been established in many countries across the world. This has had an important impact on opportunities for early intervention for parents and their children with congenital hearing loss. Despite the apparently positive impact of earlier identification—and consequently earlier intervention (Nelson, Bougatsos, & Nygren, 2008)—on outcomes such as

spoken language development (Hyde, 2005; Kennedy et al., 2006; Van Herreweghe, 2004; Yoshinaga-Itano, 2003; Yoshinaga-Itano, Sedey, Coulter, & Mehl, 1998) and psychosocial development (Sass-Lehrer, 2012), questions and concerns have been raised regarding the impact of UNHS on other domains, such as early parenting. Young and Tattersall (2007), for example, identified the potential for parents to experience some negative reactions to the early identification of hearing loss, whereas Fitzpatrick, Angus, Durieux-Smith, Graham, and Coyle (2008) described the concerns of some parents regarding the nature and availability of follow-up services after UNHS. Hearing parents may feel bewildered and confused as a consequence of the very early identification of their child's hearing loss and may, as a consequence of encouragement to ensure that the advantages of early identification are not lost through lack of action, feel pressured to comply with a virtual decision-making timetable (McCracken, Young, & Tattersall, 2008; Young & Tattersall, 2007). The required "action" typically involves early fitting of a hearing aid to seek to ensure potentially positive outcomes in terms of speech development. However, some authors have argued that the promise of normalization through prompt action could result in the denial of important feelings during the adjustment process (Kurtzer-White & Luterman, 2003; Young &

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Tattersall, 2007). The information that is provided to parents once their child is diagnosed seems to play a role in later reactions and actions.

First Information

An important aspect of Early Hearing Detection and Intervention (EHDI) programs, of which UNHS is an integral component (Hyde, 2005; Joint Committee on Infant Hearing [JCIH], 2007), is the information parents are given after a positive screening result (see Hyde, 2005). The period of time when a hearing loss is suspected, but not confirmed, is very important, because the foundations on which parents will make later decisions are already being laid. Because of the existence of alternative medical and cultural–linguistic perspectives on deafness, the information that is provided to parents can imply considerable difference in the parenting of deaf children. Within a medical model[1] which, according to Power (2005), may be called a "*hearing world*" view of congenital deafness (original italics), deafness is perceived as an impairment, with treatment consisting of intensive auditory and speech training in order to make spoken language accessible. In the cultural–linguistic model—sometimes also called a "*constructionist*" model—being deaf means belonging to a cultural minority community rather than a "disability group" (Power, 2005, italics in original), with a corresponding focus on visual possibilities rather than auditory deficits. For a more thorough exploration of these models, see Power (2005) and Table 2 of this article.

Several authors have considered the possible influences of the first information given to parents. Kurtzer-White and Luterman (2003) suggested that parents who are still in the diagnostic phase are already confronted with a lot of information and the requirement to make decisions about a broad range of options. The nature of the first information that parents receive after a referral from UNHS is, therefore, significant for subsequent steps in the care trajectory. This is supported by Porter and Edirippulige (2007), Moeller, White, and Shisler, (2006), and Sass-Lehrer (2012), who all stress the importance of the provision of comprehensive information.

Previous research has demonstrated that first impressions during the presentation of information are very powerful (Young, Jones, Starmer, & Sutherland, 2005) and that parents who receive first information within a medical setting are inclined to consider only this kind of information in further actions (Kluwin & Stewart, 2000). Additionally, other studies based on parental report data indicate that the medical perspective of deafness seems to be predominant in many early discussions with parents (DesGeorges, 2003; McCracken et al., 2008; Young & Tattersall, 2007) and that it is often only at a later point in time that some parents get to know about alternative perspectives and approaches (Young et al., 2006). Power (2005) noted that parents "are rarely given the opportunity to explore the socio-cultural view of deafness" (p. 452).

Kurtzer-White and Luterman (2003) stated that parents might filter information and pick up only what they want to hear according to their current emotions regarding the hearing loss of their child. Moreover, when too much information is given too early, in combination with the unfamiliarity of hearing loss and uncertainty about the future, this can cause parental confusion. This in turn results in insecure parenting, inhibiting parents' desires or capacities to take responsibility for the complex choices ahead of them and encouraging them to hand over this responsibility to professionals (Kurtzer-White & Luterman, 2003). It cannot be assumed, however, that sufficient knowledge will guarantee that care-related decisions will be easier for the parents to take (Young et al., 2005b). Psychological issues, such as adjustment to the diagnosis, may also have an important influence. Supporting families of newly diagnosed babies is therefore not only about providing information. Hyde (2005) noted, "families may need psychological support to cope with the diagnosis and to progress to the point of being willing and able to make informed decisions about options for hearing and communication development (pp. S74–S75)."

Informed Decision Making

The approach to deafness applied by service providers in general, and the characteristics of the first information that is provided to hearing parents after diagnosis of a hearing loss in particular, are closely connected to debates about deaf children's language development and the best interests of the child. Not surprisingly, the

issue of informed decision making has received substantial attention in the literature from an ethical perspective (Berg, Herb, & Hurst, 2005; Berg, Ip, Hurst, & Herb, 2007; Porter & Edirippulige, 2007; Young et al., 2005b, 2006). Starting from the simple description of principlism (i.e., respect for patient autonomy, beneficence, nonmaleficence, and justice—see p. 33), Beattie (2010) highlighted many possible points of ethical consideration for EHDI programs. Those points were

1. *Autonomy*, which concerns respecting the individual.
2. *Beneficence*, referring to "doing good for others" (p. 34).
3. *Nonmaleficence* or doing no harm. Possible areas of harm for parents include (a) the delivery of the news, which could be insensitive, (b) the provision of support, information, or guidance, which could be inadequate, and (c) the screening itself, which could be "a genesis for inadequate parent–child bonding or a stress–related mental health issue" (p. 35).
4. *Justice* refers to nondiscrimination, fairness, and equality.

This area is, as Beattie points out, a complex matter in light of newborn-hearing-screening practices. Questions such as "can a parental decision about the Newborn Hearing Screening process be made without pressure or consequence?" come to the fore with reference to the last principle. These considerations would tend to suggest that, apart from being able to make choices without perceived pressure, parents should be informed in regard to all possible intervention options for their children. In providing this information, "professional bias for particular options must be avoided, so the parents can make an informed choice based on the available evidence" (Beattie, 2010, p. 46).

Clearly, informed decision-making processes are a complex matter within which a lot of factors should be taken into account. These factors include sufficiency of knowledge (Young et al., 2005b) and degree of knowledge and understanding (Young et al., 2006). Kurtzer-White and Luterman (2003) noted that professionals and parents often hold strong opinions and biases when investigating the various options. This has important consequences for the choices parents make

in relation to their parenting. Parents' decision-making processes with regard to different aspects of care have received considerable attention in research, including, for example, examination of decisions made in regard to (a) cochlear implantation (Hardonk et al., 2010; Incesulu, Vural, & Erkam, 2003; Kluwin & Stewart, 2000; Okubo, Takahashi, & Kai, 2008); (b) early care and auditory management (Young & Andrews, 2001; Young & Tattersall, 2005, 2007); and (c) rehabilitation (Brown, Bakar, Rickards, & Griffin, 2006; Fitzpatrick et al., 2007). These studies have demonstrated that a range of personal variables play a role in decision-making processes. For example, parental and family values, beliefs, preferences, perceptions, and expectations apparently influence parents' perceptions of the effectiveness, significance, and value of service providers' actions in early intervention (for a review, see Young, Gascon-Ramos, Campbell, & Bamford, 2009; Sass-Lehrer, 2012).

In the aforementioned studies, hardly any researchers have focused on the role of service providers' own views on deafness or their perception of what comprises effective or valuable service provision to parents in their investigation of the nature of early intervention for this group. This is in spite of the fact that all "professionals bring to their work vastly different personal, professional and cultural backgrounds which inevitably will influence their working practices, professional values and inherent assumptions" (Young, 1999, p. 160). Moeller et al. (2006) investigated primary care physicians' knowledge, attitudes, and practices in regard to UNHS using a standardized questionnaire. Young et al. (2005a) investigated the perspective of professionals through thematic content analysis. Attention was drawn to the language use of the screener and its consequences for the parental experience of the screening in a discourse analytical study of the interaction between parent and screener by Poon, Jamieson, Buchanan, and Brown (2008). Despite all of this, however, the ideologies and ideas of service providers who provide first information for parents in early intervention settings have not, to our knowledge, been investigated through discourse[2] analysis.

The aim of this study is to investigate, through interviews with service providers, not only the nature of the initial information that is provided to parents

following identification of hearing loss through UNHS, but also the discourse or ideology to which service providers adhere while providing that information. Underneath the formal or political ideology, there is a "lived ideology" (Bos, 2007) that is not necessarily concurrent with the formal one. By taking a closer look at these ideologies, we hope to contribute, from a different point of view, to the understanding of the processes of information provision and their underlying ideological aspects. As a pioneer in UNHS, the Flemish region of Belgium is well placed to investigate the impact of service providers' assumptions regarding deafness and care in their professional practice.

Hearing Screening in Flanders

Flanders pioneered a UNHS program in 1998 on the basis of the automated auditory brainstem response (AABR) testing at the age of approximately 4 weeks. The program, carried out by "Kind en Gezin" (Child and Family, a governmental institution for child and family health), covers almost 97% of the target population (Van Kerschaver & Stappaerts, 2008) and has become a key feature in early preventive child and family care (Van Kerschaver, Boudewijns, Stappaerts, Wuyts, & Van de Heyning, 2007).

   The program's protocol fits within the recommendations of the JCIH (2007), involving initiation of the screening procedure by a local Child and Family Nurse who visits the mother of every newborn between childbirth and discharge from the maternity ward to inform parents about early hearing screening. The test is conducted with the "Algo Portable" device during the third consultation (i.e., when the child is 4–6 weeks old) and takes place in the home of the family or at the local Child and Family Clinic.[3] When the test yields a "refer" code or an abnormal result, a second test is performed within 48 hours in the presence of a pediatrician of Child and Family. When the "refer" result is confirmed, the parents are shown a list of 22 certified reference centers, without any additional information being provided about the prevailing approach of the centers. Parents choose a reference center, mostly on the basis of distance from their home, and a UNHS coordinator ensures that the parents engage with a center for further diagnosis within 14 days (Hardonk et al., 2011). These reference centers comprise

(a) services for educational support at home linked to a rehabilitation center (five), (b) multidisciplinary rehabilitation centers (seven), or (c) ear–nose–throat (ENT) departments of hospitals (10). First on the agenda is confirmation of the hearing loss through at least Brainstem Evoked Response Audiometry (BERA). Subsequently, further audiological assessment is undertaken while the first information is conveyed and a planning takes place for integral guidance and rehabilitation. Depending on the kind of reference center, parents can be referred to other reference centers to these ends. The UNHS program is aimed at completing diagnostic activities before the age of 3 months and initiation of multidisciplinary rehabilitation before the age of 6 months.

Method

Participants

By means of purposive sampling, we selected a group of participants, experienced with respect to the research topic and the aim of our study (Groenewald, 2004). Participants were recruited from the 18 largest of the 22 UNHS-certified reference centers (six rehabilitation centers, seven ENT departments of hospitals, and five educational support services linked to rehabilitation centers), which covered 98% of all referrals in the years 1997–2002. In total, 11 interviews were conducted with service providers from 11 centers in all five Flemish provinces. These centers cover 58% of all referrals. In each of these centers, we determined which service providers were most closely involved in the information-provision process for parents and asked them to participate. In just more than half of the interviews, more than one service provider participated. Table 1 provides an overview of the participants and the type of reference center in which they worked.

Interview Scheme

The semistructured interview schedule was designed to gather information on the professionals' views on the needs/questions of parents who were recently referred and the information and practices offered in response to that referral. The interview was started by the opening question "When parents are referred to this reference center because of a positive result on the Algo

Table 1 Overview of the participants

Interview	Participants (number, expertise)		Type of reference center the participant works in
1	1	Social worker	ENT department of hospital
2	1	Special educational psychologist	Educational support at home
3	1	Audiologist	Rehabilitation center (within a hospital)
4	4	Special educational psychologist, audiologist, social worker, speech therapist	Educational support at home plus rehabilitation center
5	2	Speech therapist, director (speech therapist)	Rehabilitation center
6	2	Speech therapist, psychologist	Rehabilitation center
7	3	Social worker, speech therapist, audiologist	Rehabilitation center[a]
8	1	Audiologist	Rehabilitation center[a]
9	4	Two speech therapists, clinical psychologist, audiologist	Rehabilitation center
10	1	Audiologist	Educational support at home plus rehabilitation center
11	2	Social worker, speech therapist	Rehabilitation center

[a]These centers also have services for educational support at home, but the participants all worked exclusively in the rehabilitation department.

test, what are their questions/needs?" Other general questions that could be turned to were "What are the concerns most often expressed by parents?" "Which questions do parents mostly ask?" "Which information do you give in response to these questions?" "Is there a fixed procedure to be followed when informing parents?" and "What are the topics that are sure to be addressed?" This starting point was used to gather information about the responses participants gave to parents, and consequently, the way parents were informed. Other topics such as general development, education, home guidance, emotional support, language in general, sign language, social–emotional development, communication, decision making, cochlear implantation (CI), and rehabilitation were raised and expanded upon as the interviewer considered it was relevant. The interview ended with the following closure question: "Are there other informational aspects that parents should most definitely be informed about in your opinion?" All questions were formulated as open questions, in a neutral, nonsuggestive way, to give the respondent the opportunity to talk as much as possible while control from the interviewer was kept to a minimum.

Interviewing

Interviewing was done under close supervision of the first two authors, by a final-year master's student in clinical and special educational psychology. The interviews were all conducted in the centers and had an average duration of 45 min. All interviews were audio-recorded on a minidisk. All participants signed an informed consent form, through which they gave permission for the researchers to analyze and process the data anonymously.

Analyses

This study revolves around two research questions. First, what is the content of the first information provided to parents by the service providers that parents meet shortly after UNHS? Second, what assumptions and beliefs concerning deafness underlie the service providers' first information they convey to parents? Because we were interested to identify any themes in the kind of first information provided to parents, interpretative phenomenological analysis (IPA; Smith & Osborn, 2003) was considered an appropriate method of analysis in regard to the first question. To answer the second research question, discourse analysis was used to provide insights into the lived ideology that underpins the information that service providers conveyed to parents. Here, the concept of ideology does not refer to the content of the conversation, but to the way in which it is "experienced" (Bos, 2007). We followed a Foucauldian approach to discourse analysis, as

described by Willig (2001). This approach was founded on the understanding that ideology is intrinsically connected with power and is reflected in discourse through dominant representations of what is normal, desirable, or good, and what is not.

The interviews were transcribed verbatim by the interviewer, following notation agreements provided by Hutchby and Wooffitt (1998). In the first stage of the IPA procedure, one interview was thoroughly and repeatedly read by two researchers—the interviewer and the second author—separately. Meaningful passages were highlighted and noted as emerging themes in the left margin, regularly interlinking with the research questions (Giorgi & Giorgi, 2003). Based on these themes, core themes of a higher abstraction, with a closer connection to the common terminology, were written in the right margin. These core themes were then listed in order of appearance in the interview and were eventually synthesized in a few themes of a still higher abstraction. This procedure was conducted by the two researchers independently, to improve validity. Both theme lists were compared, discussed, and agreed upon. The theme list that resulted from this procedure was then applied to the next interview transcript and again discussed and modified by the researchers. This procedure was repeated until the researchers reached consensus that the theme list was exhaustive (i.e., after application to the fourth interview). Based on this final theme list, further coding and analyses were done by using the MAXQDA software package for qualitative analysis.

An additional discourse analysis was applied by the first author, a hearing PhD student, who graduated as an educational psychologist and anthropologist. Analyses were considered on a regular basis with the second author, a hearing professor in psychology who graduated as a psychologist and anthropologist, with a PhD in deaf studies. Both have worked in several services in deaf education across different perspectives and communication methods.

We followed the six stages of Foucauldian analysis as outlined by Willig (2001). After identifying the different ways in which deafness is constructed in the utterances of the interviewees (Stage 1), we tried to locate them within wider discourses (viz., the medical and cultural–linguistic discourse; Stage 2). We then focused on the gain or function of constructing deafness in this particular way (Stage 3) and on the participant positions offered by the various constructions of deafness (Stage 4). This was followed by the exploration of the ways in which the constructions of deafness and the participant positions contained within them opened up or closed down opportunities for action (Stage 5). Finally, we took a closer look at the consequences of taking up certain participant positions for the participants' subjective experience (Stage 6).

In the next section, only a very brief summary of the results of the IPA will be given in order to allow more focus on the results of the discourse analysis.

Results

IPA Results

A number of themes with regard to first information provision were distilled. Perhaps most noteworthy were the differences in information provision among the various types of reference centers. Service providers within the ENT departments of hospitals clearly provided much more positive perspectives and information about CI than service providers in services for educational support, who clearly sought to inform parents about both the advantages and possible disadvantages of CIs. In rehabilitation centers, service providers seemed to take a position in between being very positive about the CI and being cautious about making promises to parents with regard to functioning and development with a CI. These differences were also observed in other topics of information.

Service providers in services for educational support at home elaborated on spoken communication, simultaneous communication (i.e., a form of sign-supported Dutch or Signed Dutch accompanied by speech), and Flemish Sign Language (VGT), whereas service providers of some multidisciplinary rehabilitation centers and ENT departments at hospitals did not mention VGT, except when the parents explicitly asked questions about it. In most multidisciplinary rehabilitation centers, the use of signed communication was mentioned to the parents as something that could be used in speech therapy, but only as a means of advancing spoken language development. ENT departments hardly used or promoted signs at all, except for some

"natural signs" or gestures that one would use with any baby—hearing or deaf.

The differences among centers were also apparent in regard to information provision related to educational options. When considering the possibilities for mainstream education for deaf or partially deaf children with no additional impairments, service providers in services for educational support at home were more likely to canvass the possibility of children commencing in a school for the deaf and then transferring to mainstream education later (i.e., when the child is academically and psychosocially ready to do so). Such a transition was typically proposed to be, at latest, by the age of 6 years at the commencement of primary education. In contrast, service providers in the other two types of centers were more likely to propose direct enrolment in mainstream educational placement for children with no additional disabilities.

A similar trend was noted in regard to the provision of information about Deaf culture and the Deaf community. Service providers in centers that were linked to schools for the deaf (i.e., mostly services for educational support at home and some rehabilitation centers) provided information of this kind more often than providers in other centers. Overall, this topic was addressed only minimally.

Discourse Analysis

Stage 1: Discursive constructions. The first stage of the Foucauldian discourse analysis consisted of highlighting every utterance in the interviews that had an implicit or explicit link to the way in which deafness is constructed in the narratives of the participating service providers.

Stage 2: Discourses. In the second stage, differences between all discursive constructions were analyzed and placed in broader discourses. The discourses that are typically identified in the literature on Deaf studies are the medical and the cultural–linguistic discourses on deafness. As these types of discourses provided a framework for contextualizing and interpreting the various discursive constructions marked, we chose to use this conventional medical/cultural–linguistic discourse distinction as a starting point for our structure analysis. It should be noted, however, that for further interpretation, we did not wish to limit ourselves to this dichotomy and the emergence of other discourses was deemed possible.

All utterances leading to discursive constructions belonging to the medical discourse were highlighted in boldface type and all utterances with a link to constructions belonging to the cultural–linguistic discourse were underlined. Table 2 reveals which constructions were conceived as belonging to either the medical discourse or the cultural–linguistic discourse.

The medical discourse constructs deafness as a disability, in need of repair. From this perspective, the focus is on the training of listening skills as the basis for the development of spoken language as the first and only language of the deaf child. The standard to be achieved is to be as-close-to-a-hearing-child as possible, whereas the use of sign language and participation in the Deaf culture are not portrayed as valid alternatives. In best cases, signing is considered a means of supporting spoken language development. In contrast, the cultural–linguistic discourse places value on Deaf culture and the deaf child's use of sign language as their first or primary language, nevertheless still acknowledging the importance of the development of the language and culture of the dominant hearing population. CIs or hearing aids are not eschewed, but rather they are perceived as devices that can provide some communication support. Communication and social well-being are central considerations in a cultural–linguistic discourse.

The analysis revealed mainly utterances based on the medical discourse across all centers. Closer examination, however, revealed that two groups could be differentiated. The first group was primarily "aural–oral" in focus, having no more than one utterance that could be located in the cultural–linguistic discourse (7 of the 11 interviews). The second group contained utterances belonging to the medical as well as the cultural–linguistic discourse (4 of the 11 interviews), although no reference center could be said to speak predominantly from a cultural–linguistic point of view.

In this second stage, we restricted ourselves to locating the utterances and consequent constructions in the main discourses and we did not analyze exactly what had been said. Although all interviews from both

Table 2 Overview of the utterances located in either medical or cultural–linguistic discourses

Medical discourse Every utterance of an interviewee that	Cultural–linguistic discourse Every utterance of an interviewee that
Fits in with the idea that deafness is an impairment because the hearing organ does not function as it should	Cites or recognizes the importance of sign language for the overall development of the child
Raises the idea that repairing the hearing is the most important goal	Cites or recognizes the importance of sign language and Deaf culture for the child's (socioemotional) development
Concentrates on the fact that training of hearing gets the most attention	Speaks respectfully about Deaf adults
Presents CI as a solution for deafness	Speaks respectfully about Deaf culture
Equates deaf children with 'CI Cchildren'	Speaks respectfully about an equal combination of both languages and cultures, or assigns a (slightly) more important value to sign language and Deaf culture
Equates language with spoken language	Cites Flemish Sign Language and Deaf culture as a right for deaf and hard-of-hearing children
Is negative or dismissive toward deaf or Deaf children or adults	Sets store by the socioemotional well-being of the children and the possibility of fluent communication instead of good listening-skill development
Is negative or dismissive of the cultural–linguistic standpoint	Makes clear that Flemish Sign Language is seen as an equal language, next to Dutch, not as a 'helping device'
Sees sign language merely as a helping device to assist in spoken language development or as a second-rate language when spoken language is not (fully) accessible	Refutes a purely medical view on deafness
Denies the socioemotional aspects of child development in focusing solely on the hearing problem	Describes CI clearly as nothing but a helping device
Bears evidence of being didactic in how to address the child's deafness (aural–oral)	Considers the child itself central, not its hearing loss

groups were analyzed, the constructions of the second group were of particular interest because some constructions appeared to contradict the results from the IPA which indicated that service providers in this group provided complete and balanced information to parents. In the following paragraphs, the information between brackets refers to the corresponding source for each interview excerpt, the group the center was assigned to (Group 1: ural–oral focus, Group 2: medical as well as cultural–linguistic discourse), and the professional profile of the interviewee. To chart the "official" ideology, if any, that the centers represent, we visited their respective websites to look for information on the types of therapy or guidance that they provided. We also examined websites that they referred to (i.e., "links") to assist in the determination of each group's ostensible aims and vision. Based on this information, we divided all centers involved into three groups: (a) Centers that clearly promote sign languages and Deaf culture and are in favor of a bilingual–bicultural educational program (Interviews 2 and 10); (b) Centers that mention signs rather than sign language and have links to sites regarding Deaf culture but are aural–oral in emphasis (Interviews 4 and 11); and (c) Centers that put a clear emphasis on aural–oral treatment and therapy goals and either do not mention or are negative about signs and/or Deaf culture (Interviews 1, 3, 5, 8, and 9). Interviews 6 and 7 could not be placed in any of these groups, because we found no information on vision or therapeutic goals, although one center (Interview 6) did have links to Deaf organization sites on their website.

Stage 3: Action orientation.

Yeah, yeah they immediately start thinking about the future . . . you know, I can be quite reassuring about those concerns, you know, like look, erm, it's not because your child is hard of hearing that it wouldn't be able to go to school normally.

(Interview 5, Group 1, speech therapist)

In this example, the service provider seems to be trying to meet the parents' need for reassurance instead of providing alternative perspectives on the nature and conceptualization of deafness. This apparent strategy

seems to be used to shield service providers from uncomfortable situations in which they not only have to compete against the parents' strong wishes to have a "normal" child, but also against the societal idea of normalization, which is very much present in Flanders. A number of service providers expressed their personal concerns about pursuing such a conceptualization of deafness but indicated that they believed that the parents themselves evoked this normalization principle by asking questions like "Will my child be able to speak normally?", "Is a normal integration in society achievable?", and "Will he/she be able to go to a regular school?".

Two utterances from the same service provider within 1 min of the interview also caught attention because of the inconsistency between them:

> and that is what I think is very special about our way of working indeed, that we actually don't say— you know, it's and [spoken language]—and [sign language], it's always a combination

Preceded by

> for some children that [sign language] is a passing phase which they live through quickly and in which they abandon that quickly, and for other children that is, well, something they need much longer and for other children that is something they will always need

(Interview 4, Group 2, special educationalist)

The first utterance suggests an acknowledgement of both spoken language and sign language and an acceptance of the notion of bilingualism as a desirable and possible state of being for deaf children. In contrast, however, the use of the word "need" in the second utterance suggests the perception of a linguistic hierarchy—that sign language is something that is only relevant "if needed" and that it is effectively a "second choice" that is only offered when the first choice (spoken language) is deemed to not be achievable. On face value, these two perspectives would appear to be irreconcilable. It is possible that this apparent discrepancy was engendered by the service provider seeking to provide what they believed were "acceptable" or "appropriate" answers during the interview (i.e., suggesting that they adhered to a bilingual–bicultural approach,

whereas their actual practice is more aural–oral). Alternatively, it is possible that this discrepancy represents a genuine dissonance between their ideational ambitions and their actual words and actions. Either way, there is significant potential for confusion on the part of the parents concerned. Especially so, if parents believe to have contacted a center that clearly promotes sign language and Deaf culture and is in favor of a bilingual–bicultural educational program, as our website search revealed to be the case for the center concerned in this utterance. This potential confusion is likely to be present in other centers also, because the "official discourse" of a number of centers did not always prove to be in line with the results of our analyses.

Stage 4: Positionings. Discourses come with possible subject positions, which in turn imply certain rights and duties. When parents—as mentioned earlier—expect service providers to "solve the problem," they tend to assign to service providers the role of the expert, who is able to provide them with the best solutions for their problem.

Although some of the service providers we interviewed indicated that they would want to eschew this role, other service providers appeared to be comfortable being put in this role of the expert who knows best.

> Interviewer: Once they know CI is an option, do they sometimes ask for some consideration time, the parents?
>
> Interviewee: Well, I had it happen once that the, but that was, that was with regard to her second implant, so she was entitled to a second implant, because minister X had composed such a trial group of 44, but the parents they were a bit opposed to it, but I had still put her on the list right away because I say to myself they will regret it later, and at a certain moment the parents came up to me like we would like to do it anyway, but then it would have been too late, then I just said, I already put you on it, so yeah, sometimes that's the way it is, like, that they say should we let our child undergo that surgery yet again, and …

(Interview 5, Group 1, speech therapist)

The expert position implies some duties for the service providers, like "knowing best" and providing

solutions. The service provider in the excerpt above strongly asserted that CI was the best solution to offer to parents and she took up her duty as an expert by enrolling parents without their knowledge on a list for reimbursement of a bilateral CI through a pilot study funded by the federal government. From a medical discourse perspective, the service providers' actions could be justified, because they were in the best interest of the child. If the service provider is convinced that bilateral implantation is the best possible option for a deaf child, enrolling the child in the program is in line with her duty. However, from an ethical perspective, these actions could be questioned in terms of the rights of the parents as the principal decision-makers on behalf of their child. The positions of service provider versus parent within the medical discourse are comparable to a doctor–patient relationship. As a consequence of the expert–laymen division, service providers are invited to take the expert position of curing the child who is in need of a cure. When service providers would, from a parenting and educational perspective, take a position as a supporter of parents, guiding them through the available information—from both medical and cultural–linguistic perspectives—and supporting them in raising their child, possibilities for acknowledging the child as a full member of a cultural and linguistic society are opened up. In our sample, we did not find evidence of service providers informing parents from a cultural–linguistic discourse. We did find "information on" sign language, the importance of putting communication with the child as the central issue ahead of any one language or mode of communication, the benefits of not denying the deafness, and the idea that CI is not a cure for deafness. Having noted that, however, it should be remarked that these few informational elements from the cultural–linguistic discourse were provided to parents within a generally medical discourse and were not predominant in the interactions with parents of any of the participants in the study.

Stage 5: Practice. The way in which deafness is talked about not only offers certain subject positions, it also opens up or closes down opportunities for practice. For example, when all the stress is put on the rehabilitation of hearing, it may close down opportunities to focus on other language and communication options.

One method is not the method for all children, the method is the method adjusted to your child and that method we need to discover together and what is connected to that like a guide line from the beginning is the challenge of audition by already reacting to it [the child] by means of speech, by organizing a comfortable sound environment for that family and those, then, are points of focus

(Interview 4, Group 2, special educationalist).

Although this service provider claims to sensitively search for the method adjusted to the child, the common theme is always hearing and speaking. All the efforts parents can make to adjust to a visual disposition are neglected. This means that not all modalities to enhance early linguistic development and effective communication (e.g., vision, hearing, and touch) are considered in the process of choosing what is best suited for a particular child (see Sass-Lehrer, 2012).

The dominance of the medical discourse is also reflected in the use of the term "language." Almost all service providers use the term language when they refer to spoken language only, whereas "signs" are considered a means to speed up spoken language development.

In the beginning there is no language yet, and we use signs, you know, support language with signs, together and as the child evolves we see that we can drop one or the other or that we still have to offer it together

(Interview 8, Group 1, audiologist).

This excerpt is only one of many demonstrating how signing is not seen as a language or a starting point for the development of a (sign) language: "there is no language yet, so we use sign."

The success of promoting different communication modes is dependent on the discursive position of service providers. When they give parents the implicit message that sign language is not valued in the same way as spoken language, this could result in parents using it only when it is necessary pragmatically or in relation to spoken language development (De Bolle, 2007; Sass-Lehrer, 2012). Moreover, De Bolle (2007) found that the use of sign language was also influenced

by the parents' perception of Deaf culture. In the current study, we found only sporadic positive utterances on Deaf culture (i.e., utterances in which that culture was valued and considered important for deaf children to be part of). Service providers from one hospital made certain comments about the Deaf community, which clearly do not function to support parents in becoming acquainted with the Deaf community.

> . . . there are still definite attempts from non-implanted adolescents as well to urge implanted ones to abandon the implant as a whole anyhow and to return to the deaf community. We have someone like that now, that is just one case, that was a good user, he did start pretty late but he is doing very well, it was a kid of six seven years old when he was implanted, so that is very late, you know, and erm, god yes he doesn't wear the implant anymore, it's finished, he got involved with a group of convinced anti–implant deaf fellow–sufferers and erm . . . well, it's finished now.

(Interview 3, Group 1, audiologist).

In this service provider's discursive position, the child's autonomy in decision making is not valued. The competition between the medical and cultural–linguistic view that is pronounced in this and numerous other excerpts prevents any possibility of a child or family being encouraged to explore both worlds.

Stage 6: Subjectivity. In this last stage, we analyzed the psychological realities that may be constructed by a medical discourse that positions professionals as experts in relation to parents who can be considered as patients. This stage is, of necessity, the most speculative stage of the Foucauldian discourse analysis, which yields no more than general impressions on "what *can* be felt, thought and experienced from within various subject positions" (Willig, 2001, italics in original).

In a setting of experts versus patients, parents may feel guilty if they were to question the experts' advice, or if they fail to follow up on that advice. However, a strong emphasis on the discursive positions of service providers and parents could result in a lack of attention to the influence of the larger social environment (e.g., policy and the media—see Power, 2005). The medical discourse is reflected in many aspects of society, thus creating a possible barrier to the implementation of early intervention

from a cultural–linguistic perspective. It is possible that the service providers in the current study feel supported by the mainstream (medical) construction of deafness that is predominant in society. They might even feel a certain pressure to comply with this construction and feel reluctant to abandon it. Possibly, parents would attach less credibility to the service provider simply because it does not fit with the expert's role in the predominant medical model. Indeed, Flanders has a strong culture of normalization and medicalization. In Western society, the authority of medically schooled professionals has become virtually unquestionable (Miller, 2005). This implies that approval of these professionals may be viewed as "the highest and most authoritative form of praise" (May, 2008, p. 480). What is more, as Hardonk (2011) argues, the medical model not only dominates Western thought, it has succeeded in becoming "the only conceptualisation imaginable" (Hardonk, 2011, p. 354). In sum, complying with the predominant discourse gives service providers a familiar and safe working environment.

Nevertheless, our analysis also revealed that some professionals are indeed searching for opportunities to implement a cultural–linguistic framework in their professional practice.

> So despite the hype that sometimes arises in the media concerning erm . . . all the advantages of the CI, it remains a child with a severe hearing loss that must not be denied at all. For example, at night, the child is sick, there may be many, all sorts of situations arise that on their own ((unclear)) adding that deafness to the mix, the CI doesn't work or can't work or has been put off, it is still a deaf child, that cannot be denied a lot of the times I think . . . And that would be a mistake, denying the own nature of the child.

(Interview 6, Group 2, speech therapist)

Discussion

The aim of this study was to chart, from a thematic and discursive qualitative approach, the first information Flemish parents receive after a UNHS indication of a hearing loss. More specifically, we sought to investigate, from the service providers' perspective, the discourses present in the first information that parents of newly diagnosed deaf babies are confronted with. The choice

of a Foucauldian discourse analysis, although revealing invaluable additional information to the IPA, had limitations as well as benefits. In the conduct of the discourse analysis, the researcher is always present and his role is always meaningful. Despite having tried to present the logic of our interpretations as transparently as possible, the results of this study should be approached as a discursive construction on their own (see Willig, 2001). As a consequence, we have no intent to generalize any of the findings. Nevertheless, the method should be able to yield explanatory insights into other situations.

First, the results show that parents in Flanders receive diverse information dependent on the reference center to which they are referred. This can be explained by the fact that all services have their own particular mission, professional beliefs, and values. This has been noted in other studies (Young et al., 2005b) but still raises questions about the organization of EHDI programs. A supply-oriented way of providing information could result from this approach—an approach that actually undermines the fundamental goal of providing complete and unbiased information very early. We suggest that follow-up, first information, and support are best provided by service providers in independent and neutral agencies. These same concerns were noted by Hyde and Power (2000, 2006) and are in line with the JCIH statement on UNHS (JCIH, 2007).

Next, the discourse analysis indicated that the information provided was typically representative of a particular perspective. Indeed, all service providers were found to adhere to a medical discourse. Although some did use elements of the cultural–linguistic approach, they spoke and acted from within a medical discourse. On the other hand, however, some of the utterances could also be interpreted as evidence of the emergence of a new discourse, one that is neither purely medical nor cultural–linguistic but embraces both discourses. Maybe the appearance of cultural–linguistic elements within the medical discourse, which seems inconsistent at first sight, can be seen as attempts to resolve dissonance about the "either/or" nature that still seems to come along with the two traditional discourses. The fact that several interview excerpts could not comfortably be positioned in either

discourse (and thus were assigned to Group 2) supports this idea. It could indeed be more rewarding to envisage the two discourses as incommensurable. If deaf children are to be given the opportunity to benefit from both approaches, it is necessary for parents to be provided with this worldview and thus for professionals to adopt this new discourse as their own worldview. Seeds for this are found in our data; but such a situation is far from being completely realized. What is apparent is that, although service providers set themselves the goal of facilitating informed decision making by parents, this has not been fully achieved because of the continuing provision of either incomplete or biased information.

A starting point to support service providers in attaining this goal could be the auditing of the professional training of those service providers that will ultimately inform parents. First, it could be that potential providers themselves require more training about cultural–linguistic issues because, as Lane (2005) suggested, their limited provision of information to parents may simply be a result of their limited personal knowledge. It is doubtful, however, whether supplying service providers with "complete information" would be sufficient. We have already shown that beliefs and values have a very strong influence, mediating knowledge and information. Therefore, those beliefs should be addressed as well, and service providers should be made more aware of their discursive positions concerning the cultural and social discourses within which they work and live. Second, it may be productive to prepare professionals in a more structured and explicit way for the hard job of "bringing the bad news" and other challenging information to families. As we have already suggested, some professionals might go along with the wishes of parents for normalization, simply because they are unskilled or feel too uncomfortable in providing alternative and potentially more challenging perspectives on deafness. Third, service providers could be trained to be more aware of the possible shift in parents' interests (i.e., from expecting service providers to "solve the problem" and normalize their child, toward looking for tools to give themselves the best support for their child). Support for this idea can be found in the work of Roush and Harrison (2002) who concluded that many parents, although initially turning to

professionals for guidance in making choices, became the most knowledgeable and effective advocates for their child when given complete and unbiased information. Further support can be found in the commentary on this issue provided by Hyde (2005, p. S75) who stated that "families may need psychological support to cope with the diagnosis and to *progress to* the point of being willing and able to make informed decisions about options for hearing and communication development" (emphasis added).

Ideally, it would appear that UNHS programs should be organized in a way that they ensure (a) the provision of such psychological support—or at least adequate referral for it—and (b) that parents receive complete and unbiased information about all aspects of deafness. As highlighted by Beattie (2010), the entire process of screening and intervention is devalued and made less effective when any information or potential sources of support and assistance are omitted from what is conveyed to parents in the important period following identification of hearing loss.

Notes

1. By "model," we mean a set of viewpoints and/or presumptions that determine the way of seeing and reacting to deafness. For a description of these viewpoints and/or presumptions, the reader is referred to Table 2.

2. We do not interpret "discourse" linguistically, but align ourselves with Bos (2007) in interpreting discourse as being distinct from the larger social, political, and societal context on the one hand, and from the immediate context of action and interaction on the other hand; rather, it is interpreted as fulfilling a mediating role between those two contexts.

3. There are several reasons why this choice seems preferable to screening at the maternity ward, such as the difficulty of maximal reach of target group, the greater number of false positives shortly after birth, the vital importance of the identification and bonding process between the parents and their baby within the first weeks of life without the notion of a possible disability disrupting this, and the fact that rehabilitation is not offered before the second or third month anyway.

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