Bioethical Inquiry (2017) 14:109–121
DOI 10.1007/s11673-016-9752-y

ORIGINAL RESEARCH

Saving Deaf Children? Screening for Hearing loss as a Public-interest Case

Sigrid Bosteels · Michel Vandenbroeck ·
Geert Van Hove

Received: 6 November 2015 / Accepted: 17 August 2016 / Published online: 19 October 2016

Abstract New-born screening programs for congenital disorders and chronic disease are expanding worldwide and children "at risk" are identified by nationwide tracking systems at the earliest possible stage. These practices are never neutral and raise important social and ethical questions. An emergent concern is that a reflexive professionalism should interrogate the ever earlier interference in children's lives. The Flemish community of Belgium was among the first to generalize the screening for hearing loss in young children and is an interesting case to study the public justification of early interventions for families with deaf children. This article uses a critical lens to study the archive of the government child healthcare organization in Flanders in order to uncover underlying constructions of childhood, deafness, and preventive health. We focus on two interrelated themes. The first is the notion of exclusion of the human factor through the mediation of technology. The second is the idea of deafness as endangering a healthy development, an impairment that can nevertheless be treated if detected early enough. It is argued that, since deafness cannot be viewed as a life-threatening condition, the public interest which is implicitly defended is not the rescue of deaf children rather the exclusion of otherness.

Keywords Newborn screening · Childhood deafness · Early intervention · Health technology · Medicalization of childhood

Introduction

The field of newborn screening is expanding worldwide, with its goal of identifying infants with treatable congenital conditions before they become symptomatic in order to ensure comprehensive care for the child and the family (Newborn Screening Authoring Committee 2008). The trend towards screening for developmental problems in children at the earliest possible stage emerged after the second World War, when infant mortality was slowly decreasing. The World Health Organization (WHO, founded in 1948) promoted primary healthcare worldwide, broadening the definition of health to include broader developmental and mental aspects of well-being. At the end of the twentieth century, the WHO stated that a future challenge for all nations would consist of reducing the burden of congenital disorders and chronic disease by developing simple, cost-effective, and evidence-based interventions (World Health Organization 1999). Globally, groups at

S. Bosteels (✉)
Department of Social Work and Social Pedagogy, Howest University College/Ghent University, Rijselstraat 5, 8200 Brugge, Belgium
e-mail: Sigrid.bosteels@howest.be

M. Vandenbroeck
Department of Social Work and Social Pedagogy, Ghent University, Henri Dunantlaan 2, 9000 Gent, Belgium
e-mail: Michel.vandenbroeck@ugent.be

G. Van Hove
Department of Special Needs Education, Ghent University, Begijnhoflaan 464, 9000 Gent, Belgium
e-mail: geert.vanhove@ugent.be

risk should be identified as early as possible and mass screening methods developed accordingly (World Health Organization 1999). It is now acknowledged that the social and ethical implications must also be addressed (World Health Organization 2013). Timmermans and Buchbinder (2012, 2013) argue that not all early screening practices are justifiable under all circumstances. New conditions at the crossroads of health and lifestyle, or "diseases of civilization" such as obesity in young children, are becoming the object of national screening programs in which bodies are weighed and charted (Chang and Christakis 2002; Devisch 2014).

The work of Armstrong and Eborall (2012) shows that screening raises important social and ethical dilemmas and can be viewed as a social intervention as well as a medical one. Neither is it a neutral practice, since the whole population comes under surveillance and is seen as being potentially at risk (see Armstrong 1995). Children with disabilities, diseases, and deficiencies are categorized using nationwide tracking systems (Verhaeghe 2012), yet uncertainty is a major theme implicit in most empirical work on screening (Armstrong and Eborall 2012; Grob 2008). Kelle (2010) demonstrated that routine screening and diagnostic practices tend to support normative and normalizing constructs of a child's development, often resulting in unquestioned and compulsory medical, pedagogical and therapeutic interventions. Medicine, with its techniques of measurement and classification and its prosthetic devices, intervenes in the lives of children with disabilities and their families in a way that affects them profoundly. One emergent concern in the richer countries of the world, including Western European welfare states, is that a reflective professionalism should think again about the ever-earlier interference in children's lives and the medicalization of childhood (Grob 2008; Vandenbroeck 2009; Vanheule 2008; Verhaeghe 2012).

In this article we examine and contextualize the practice of new-born hearing screening, showing how these efforts at identification came into being historically, discursively, and in policy. The discourse on early intervention in a deaf child's life can be considered a socio-pedagogically relevant theme, since it mirrors the public gaze and results in a way of thinking about how to cope with, intervene in, or adjust to a human condition that deviates from the norm (Devisch 2008). The debate on tests and treatment for deafness embodies differing perspectives on how to do this (are we doing things right?) and why we do it (are we doing the right things?). In line with the work of Kermit (2010, 2012) and Blume (2010) we have positioned our study as a moderate, critical investigation of the non-medical, non-physical aspects of early interventions in the deaf child's life. One could say that investigating the social relations and sources of legitimacy behind new-born screening can contribute to a better understanding of changing interactions and power dynamics within families and between parents and healthcare providers (Grob 2008).

From a medicalized and normalizing perspective, deafness can be treated or even "cured" by means of technological and biomedical enhancements (e.g. the debate on cochlear implants—CIs). In this context, deafness is an impairment and screening is the first step potential towards "making" the deaf child hear (e.g. Van Kerschaver 2013; Kerschner 2004). As a consequence, the earlier the assessment, the greater the chance that negative effects of defective hearing can be compensated for (Kerschner 2004) and the child can be prepared to participate in a hearing world. On the other side, there is the socio-cultural perspective of deaf communities striving for recognition of a rich and complex environment typified by distinctive ways of "being in the world" and a unique mode of communication (the naturalness of sign language). In this context, deafness is not a hearing impairment but rather a way of existence (e.g. Davis 1995; Van Cleve 2007*)* typified by sociocultural and linguistic differences, and screening is the first step in potentially denying a deaf child's birthright (e.g. Lane and Bahan 1998; Nash and Nash 1982). As argued by Kermit (2012) in the bioethical debate on paediatric cochlear implant surgery, both frameworks still blur the discussion of what exactly is meant by the best interests of the deaf child. From a critical deaf theory perspective, Valente (2011) speaks of a whirlwind of diagnostic rituals which set in motion a deficit-oriented way of processing the child and a loss of parental competence and trust. Matthijs and colleagues (2012) found that the first information parents receive after detection of hearing loss in their babies is incomplete and coloured by personal beliefs and values, and is delivered by service providers that adhere almost exclusively to a medical discourse. This may result in an attempt to push parents towards therapeutic parenting duties, with less and less time for the affective aspects of parenting (Bosteels et al. 2012). As demonstrated by Blume (2010), the reality of the people involved (deaf individuals, clients, and caretakers) is complex and multidimensional and healthcare policies should address the full scope of conflicting ideas instead of assuming that the potential of science and technology is limitless.

With these critical voices in mind, we studied the specific case of screening for deafness in babies in Flanders (the Flemish community of Belgium), since this region was among the first to experiment with, and generalize screening for, deafness in neonates. The main question that emerges is: what do those responsible for developing and implementing the early hearing screening service think they are preventing? And how do they justify it as beneficial?

The Case of Flanders

Flanders is a world pioneer in screening for hearing problems and is an interesting case for investigating how concepts of childhood deafness, prevention, and disability are constructed in recent history.

> Through this project we prove the significance that we can have as a small community. Many countries envy our well-developed preventive health care system for young children. Nowhere else in the world can this be done at the moment. This project is a first in the world, an innovation in preventive care (Minister of Health Luc Martens in 1997, on the introduction of the new Algo test to screen for early deafness)[1]

Preventive healthcare for families with young children in Flanders is in the hands of *Kind en Gezin,* (K&G—Child and Family), the government organization responsible for preventive neonatal healthcare and infant and toddler consultation schemes. At present, K&G offers home visits and infant consultations in 342 local centres in the Flemish Community of Belgium. In these consultation schemes vaccinations are administered and the hearing test is performed in 95 per cent of all newborns. Ninety-two per cent of all mothers in Flanders receive an introductory visit from a preventive health nurse (PHN) in the maternity hospital. During the first three months of the newborn's life, 97 per cent of the parents receive at least one home visit from the PHN and 88.3 per cent make use of the infant consultation schemes. At eighteen months of age, two out of three toddlers have received all vaccinations through K&G (Kind en Gezin 2012).

The first discussions on generalized screening for hearing problems in Flanders date back to the early 1970s. From 1978 on, the first experiments took place using the Ewing test, which was administered to babies between nine and twelve months in a separate room as an extension of the consultation. While the baby sat on its mother's lap and visual materials were presented in front of the baby (e.g. coloured blocks), quiet sounds were produced by a preventive health nurse behind the baby (e.g. a soft noise from a rattle, gently rubbing a spoon over a porcelain cup), while the PHN also noted the baby's reactions (Kind en Gezin 1987). In this period, the introduction of the Ewing test provoked some territorial conflicts about who was entitled to administer the test. The University Colleges argued that only trained speech therapists were able to perform the test (Proot-Cocquyt 1978). Ear, nose, and throat (ENT) specialists in turn claimed that the hearing test should be administered earlier at the maternity ward, as most children could be found there (Clement 1980). It took more than a decade (1978–1992) before the introduction of the Ewing test in all K&G regional settings was established.

Much dissatisfaction remained over the alleged subjectivity of the test, the logistics (i.e. the fact that a separate room and trained staff were needed) and the frequent false results (Kind en Gezin 1997b). As a result, Dr. Van Kerschaever (the then head of the medical department and developer of the new hearing test) proposed to replace the Ewing test with an adapted version of an existing Automated Auditory Brainstem Response Audiometry (AABR) test that was labelled the Algo test. This Algo test was generally administered by the preventive health nurse in all infant consultation schemes to all babies at age four to six weeks from 1998 onwards (Van Kerschaver and Stappaerts 1998). Since its introduction, more than 95 per cent of all babies have undergone the Algo test. For this Algo test, electrodes are put on the baby's head (the baby can be asleep during the test), signals are sent to the brain and the machine registers the feedback and gives a clear and prompt opinion to the parent: "pass" (normal hearing) or "refer" (possibility of defective hearing). In case of a refer result, a second test is administered no more than forty-eight hours later in the presence of a medical doctor. In case of a second refer, the family is advised to see an ENT specialist in one of the specialist referral centres for early monitoring, diagnosis, and integral

---

[1] All quotes used in this article are translated by the authors

rehabilitation in Flanders. The validity of the Algo test is claimed to be exceptionally high (sensitivity of 99.7 per cent and specificity of 98.7 per cent). Theoretically, this implies that even after the first test all deaf children could be traced and almost no false positive referrals would occur (Kind en Gezin 1997b).

As a result of using these tests, rather consistent figures reveal that one to two children per 1000 births are born with a substantial degree of bilateral hearing loss. For Flanders, this implies that approximately seventy children are born deaf every year (Van Kerschaver et al. 2007). About 90 per cent of these children are born to hearing families (Moores 2001). Compared to the other conditions for which newborns are usually screened (e.g. cleft lip and palate, spina bifida, Down's syndrome) deafness is considered to be one of the commonest congenital disorders (Declau et al. 2008; Kerschner 2004; Van Kerschaver et al. 2007).

Methodological Decisions

What can studying a pioneering introduction of this form of hearing screening in Flanders teach us?

This study is part of a broader research project in which the implications of early interventions in families with deaf children are studied. The present study is based on research carried out in the archives of the government child healthcare organization *Kind en Gezin* (K&G). The archives contain a total of 3000 pages of texts on preventive health measures in the period from 1970 to the present. Five hundred of these contained information on detection, support, and services for deaf children since the implementation of the hearing test. The final selection for the present analysis was made on the basis of a content analysis to include all documents containing information on how and why the national preventive child healthcare organization in Flanders decided to organize national hearing screening. This final selection of relevant data consisted of: reports from the medical advisory board that takes all strategic decisions on preventive health (1980–1984); reports of the overseeing medical committee; recommendations concerning the hearing test (1997a,1997b,1997c, 1998, 2003); reports from the head and coordinator of the medical department concerning the Ewing test (1970–2003); statistics on the Ewing test (1987–1999); editorials from K&G and short notes in its journal, *Het Kind* (The Child), addressed to preventive health nurses, which was discontinued in 1997 (1982, 1983, 1984, 1986, 1991); leaflets on Algo hearing screening (1997, 1998, 2000); internal documents of the coordinator of the hearing test(s.d. 1997, 1998); and annual reports on hearing screening published on the K&G website (2008–2013).

The qualitative research design for this study was based on content analysis. The application of this intensive approach focusses on the interpretation of the characteristics of the content or contextual meaning of a large quantity of text data. Through an inductive classification process, a feasible number of meaningful categories can be described with the purpose of gaining insight in a phenomenon for which the existing theory or research literature is limited (Hsieh and Shannon 2005). In this case, the procedure of analytical induction implied that the researchers stayed as close as possible to the archival material in order to explore sensitizing concepts derived from specific to more general patterns of thought (Bowen 2006). A combination of conventional and summative content analysis of the archival documents was carried out. The latent content of contextual information that initiated the central questions for this study was derived from prior research findings on deafness and neonatal screening. The primary content of themes and main ideas that are formulated in this article were obtained through a step-by-step analysis of the written policy documents. Inductive categories were developed from the interpretation of textual data and then presented by the first author to the other authors and subsequently discussed and reviewed in the research team, to ensure their trustworthiness (Mayring 2004).

The first theme we describe here emerged from a conventional content analysis, approaching the whole corpus of policy documents without preconceived categories or theoretical perspectives. Through repeated immersion in the data, the researchers were allowed to gain insight in labels that are reflective for more than one key thought (Hsieh and Shannon 2005). This tentative process resulted in a description of the reasoning for implementing a new hearing test and generated the idea of exclusion of the human factor through the mediation of technology.

The second theme was obtained through a summative content analysis that worked through selected parts of the policy documents. Analysis of a specific context of the data associated with the usage of words or phrases, provided the researchers with an unobtrusive tool for demonstrating that textual evidence was consistent with the interpretation (Hsieh and Shannon 2005). This exploratory process aided understanding of the contextual meaning of the overall content and specific words used in the public justification for generalized early screening (with a focus on the late 1970s). The underlying construction of deafness as a personal tragedy endangering healthy development will be interpreted in the final results section.

We describe the two issues separately, although they are deeply interrelated.

Results

Despite some territorial quarrels about who should administer the test, the public health system in Flanders rarely questioned the need for neonatal hearing tests since deafness in babies, although not life-threatening, was considered a serious health problem internationally as well as locally (cf. WHO report 1999; Grandori and Lutman 1998).

Excluding the Human Factor as a Major Advancement

The interpretation of the human factor implies that every reference to peoples' involvement (children, parents, professionals, and the relationships between them) in the procedure for early hearing screening, is taken into account.

In 1978, in a lecture for the medical advisory board of Kind en Gezin (K&G) three criteria were presented as decisive in determining the optimal strategy and method for assessing the auditory capacities of young children: 1) the test should be simple and performed on the spot; 2) the interpretation of results should be sound and cheap; and 3) implementation should be feasible on a large scale with the aid of medical supervisors (Kind en Gezin 1978). The Ewing test, as it was implemented from the late 1970s onwards, was subject to some criticisms, as it was considered not to be ideal on all these criteria. The test required the involvement of several skilled professionals and an acoustically adapted room and was therefore considered rather costly. Moreover, and more interestingly, there were doubts about its validity, despite the fact that in the introduction the responsible doctor recommended the Ewing test for resulting in less than 5 per cent false positives (Blancke 1977). The lack of validity was to a large extent attributed to the preventive health nurses who administered the test:

> The preventive health nurse is inclined (in order to reassure herself and the mother) to alter the procedure (e.g. by coming too close to the ears of the baby) (Kind en Gezin 1978, 3)

In addition, the doctor then responsible, claimed that nurses sometimes skipped the procedure or were inaccurate or even let volunteers perform the test in their place (Blancke 1980).

In short, this human factor meant that the Ewing test was later labelled as *subjective* with the word subjective carrying negative connotations (Kind en Gezin 1997b). The Ewing test was eventually replaced by an automated version, in the form of the Algo test described above (Van Kerschaver and Stappaerts 1998). Using this method, the babies' auditory capacity could be screened earlier: at birth or very soon afterwards. According to the latest scientific research and knowledge at the time, nine months was considered to be too late. It was argued that a baby of a few weeks old needed auditory stimuli to safeguard its future speech, language and cognitive development. At K&G it was decided to perform the new test four to six weeks after birth in order to give the mother the opportunity to bond with her baby before any technical interference occurred. While the time to a second test in case of referrals from the Ewing screening was four weeks after receiving the "bad news" about hearing loss, with the Algo test this waiting period was reduced to fourty-eight hours. Thus the Ewing test typically provided an indication of possible hearing loss when the child was between nine months and three years old, compared to four to six weeks with the Algo test. The annual reports published by Kind en Gezin during the transitional period as the Ewing was replaced by Algo test frequently complain about parents who failed to bring their child for a follow-up test or did so much later than was advised. The first Ewing test left many so called "failed babies" requiring referral, but many parents did not arrange a further examination of their child's hearing (Kind en Gezin 1997c). In the case of the Algo test, referral occurred shortly after a positive test score and as a result a larger proportion of parents followed the advice and entered the medical and therapeutic field (Kind en Gezin 2008).The automated version of the hearing test was considered to be objective and experts claimed a validity score of almost 99 per cent (Van Kerschaver and Stappaerts 1998).

The report by the head of the neonatal screening department explained the increased validity and efficiency of the Algo test by referring to the exclusion of human factors, meaning the baby, the mother and the preventive health nurse, as well as the exclusion of the relationships between them. In the Ewing test the baby needed to be awake and on the mother's lap, emphasising the status of the baby as a human subject in intimate physical contact with the mother. This contrasts with the Algo test, where the baby usually remains in its cradle, quiet or asleep. In this case, the participation of the parents is reduced to carrying out professional advice and complying with any referrals that are arranged (Van Kerschaver and Stappaerts 1998).

The old Ewing test demanded the active presence of a nurse, said by some to be less than objective because of her social relation with the mother, while the new Algo test delivers a clear and objective result. The facts and figures in the official reports testify to the increased validity of the Algo test (Kind en Gezin 2008). Fewer false positives and false negatives are reported and parents are more likely to comply with professional advice. Being sensitized to the importance of the hearing test was considered one of the major results of the change (Van Kerschaver and Stappaerts 1998). Parents being overwhelmed or insecure about the future development of the child could, however, be a regrettable side effect for which service providers were to be trained in communicating "bad news messages" (Stappaerts 1998). The agency initially considered preventive health nurses (PHNs) as the ideal professionals to carry out the test and support the parents (despite the criticism from ENT specialists). Later, however, the PHNs were criticized because of a "tendency to reassure themselves and the parents" that may have led to biased results (Kind en Gezin 1980).

The strategic board of K&G put a lot of effort into ensuring that they made the right choice by implementing the mass screening program for the benefit of the general population of children and parents (Kind en Gezin 2003). Workshops and information sessions were organized to inform nurses how to carry out the test, how to handle the devices, how to position the baby, how to put a new roll of paper in the machine, how to transmit the results to the database, etcetera. From the 1980s onwards there was a clear emphasis on multidisciplinary cooperation between professionals and on parent participation during medical and paramedical care. The management reports from the college of medical advisors of Kind and Gezin raised few questions about the benefits of the early intervention practices for families with deaf children.

A speech given by the Health Minister to paediatricians at the inauguration of the Algo test is noteworthy for its frequent use of words such as "evidence-based," "measurable," "high-tech," "standardized," and "innovative" (Martens 1997). No less strikingly, however, hardly any attention was given in the management reports of the college of medical advisors to the way in which professionals interact and communicate sensitive findings to parents. The implication was that this was something to be dealt with afterwards, after objective procedures and protocols had been followed (Kind en Gezin 1997a).

One rare expression of concern for the parents came in a lecture given to K&G paediatricians in 1985 in which an ENT doctor of a Dutch university hospital pointed out the importance of the human factor:

> It is quite possible that the "disease" (means the worries and stress on the parents as a result of a referral) of the parents has a negative influence on the development of the child. (…) Fortunately in The Netherlands most deaf children are only diagnosed at nine, ten or eleven months (…). We are only partially conscious of our communication (…). We have the most wonderful devices and are all very aware of the importance of early detection, but we tend to forget that good diagnostics can be counterproductive for therapy. When deafness is detected at birth, one creates three patients with one stone (…). My request is therefore: make your diagnoses in such a way that therapy remains the most important thing. (Kuyper 1985, 5-7).

This warning, however, was not repeated or translated in any of the selected documents in this study. This suggests that the human factor is being pushed aside by technology and that this is unanimously considered as a major achievement and advancement. Particularly, the voice of parents is absent from this debate. Whereas the technical and medical information was described in some detail, psychological, social, or pedagogical arguments about childhood deafness remained largely absent from the agency documents. And when parents were a subject of concern (as described in the above speech), they might well be mistrusted:

> We have to teach parents to act normally again. It is just as difficult as a sexual therapist saying, "You shouldn't feel so tense and then you will not suffer from your impotence." The process is similar, you can't just act normally. You should explain that the child does not feel deaf and will notice if parents behave differently … Now, there will be three patients. Two of them (the parents) will be worse off than the third (the child). It is quite conceivable that the "disease" of the parents can have a bad influence on the deaf child's development. (Kuyper 1985, 4).

Optimizing objective standards of measurement and minimizing human errors continued to be the locus of attention of the child healthcare policy of K&G. From the end of the twentieth century onwards revolutionary screening technology had been celebrated and implemented in daily practice although its practical applications could have unintended consequences.

> Since human failure cannot be excluded and technique sometimes plays a part, even Algo devices can show inaccuracies. (Stappaerts 1998, 13).

Unfortunately, the latest version of the Algo testing device currently used for hearing screening in babies is again generating an increased number of false positive referrals in comparison to the original appliance. The struggle to replace human judgement with a definitive machine test is therefore starting all over again (Kind en Gezin 2013).

Deafness as Endangering Healthy Development

Since the very start of the debate on screening for hearing problems in babies, it has been assumed that the earlier detection takes place, the better. One of the first attempts to justify this can be found in a 1977 letter addressed to all doctors working in the consultation schemes:

> Hearing problems in children are to be detected as soon as possible, as you also believe. Early audiological training, i.e. before the age of two, prevents *numbing and dumbing* of hearing impaired or deaf children, to the extent that audiologists claim to be able to eradicate deaf-muteness. Moreover, character disorders and inappropriate behaviour can also often be prevented (Blancke 1977, a2, italics added).

This excerpt illustrates the fact that from the beginning, hearing problems were regarded as a major deficit that might endanger all aspects of later development. Kind en Gezin introduced the hearing test in all child healthcare schemes from 1992 onwards, and justified this as "a case of public interest" for all children (Kind en Gezin 1992). The theme of deafness as a serious defect that jeopardizes the child's development in multiple areas continues in later documents:

> Hearing impaired children lack sensory stimulation, which is an essential condition for speech development. In addition, this handicap has a pernicious influence on the development of the personality and its social, emotional, intellectual and motor aspects. Moreover it also affects the process of education and parent-child interactions when auditory stimuli are missing (Kind en Gezin 2008, 4).

For more than fifty years, arguments in favour of mass hearing screening and early intervention have been based on the assumption that without professional intervention, most deaf children would be discovered too late (generally by mothers). "Too late" was described in terms of losing precious time for remedial therapy, which would compromise language acquisition and speech production. The importance of oral language development and speech appeared to be the central idea around which the professional intervention circle was set up. Paediatricians connected the ability to speak even to basic cognitive capacities:

> Speech is crucial for the overall development of a child. We assume that we speak because we think. Experience with children with a hearing disorder supports the conclusion that initially, we think because we speak. Without being mentally disturbed, it is therefore a well-known phenomenon that these persons have a lower than normal intellectual level. As a consequence of their handicap, they are not capable of understanding abstract concepts. A person with a hearing disorder can perceive and grasp everything he sees or feels.

> Yet, "freedom" he cannot see or touch, so he will not understand. (Kind en Gezin 1996, 23).

An earlier text fragment quoted above spoke about "numbing and dumbing," a translation of the original Flemish words *verdovings- en verstommingsprocessen* in deaf children. These terms appear in several texts as an argument for the importance of hearing screening in young children (Blancke 1977; Kind en Gezin 1980, 1993). *Verdoving* means *deafening* and thus indicates that these children will become more and more deaf. Interestingly, the Flemish word *verdoving* also has a second meaning, namely anaesthesia or numbness, suggesting that halting the process of becoming deaf in deaf or hearing-impaired babies is also a social process that will slowly imprison the child in a numb world of silence and apathy. The second part of the phrase, *verstomming* can also mean becoming numb, mute or speechless. Yet, this term also has multiple meanings, including the notion of falling silent or dying down. Another meaning of the word *stom* is stupid. The word *verstomming* therefore can be read as meaning a process of becoming numb (literally and metaphorically) as well as the process of becoming stupid and ignorant. This suggests that not intervening to offer therapy for deafness will not only imprison the child in a world of silence but also a world marked by passivity rather than active agency. Thus the child is constructed both literally and metaphorically as a child who has nothing to say, a stupid child, a less human child.

This position of Flemish policymakers who have determined the present early screening regime is consistent with that of international scholars who are readily quoted in the Flemish policy documents:

> Deafness in children is a serious concern because it interferes with the development of language—which sets human beings apart from all other living creatures … Early intervention actually saves money since hearing impaired children who receive early help, require less expensive special education later. When early identification and intervention occur, hearing-impaired children make dramatic progress, are more successful in school and become more productive members of society. (White 2003, 18).

The early intervention that is mentioned in the quote is nowadays readily associated with the promising possibility of having a prosthesis such as the cochlear implant. The head of the medical department of K&G and architect of the neonatal screening approach, stated in an interview at the end of his professional career that "all these deaf children are now saved" thanks to the cochlear implants they can receive at the age of one. Because of this medical treatment "they can hear and can go to a mainstream school. For them it makes a difference between night and day" (Van Kerschaver 2013, a7). Parents are urged to comply with the advice of medical doctors for the sake of their children.

> Denying a child access to the hearing world is something like immigrating to the United States while forbidding your child to speak English. In my opinion it comes close to child abuse. (Van Kerschaver 2013, a14).

It is at least remarkable that the perspective and voice of advocacy groups and of the deaf community is entirely lacking in the strategic decisions on this issue. Fevlado, the federation of Flemish Deaf organizations and DOV, a deaf parent organization, reacted strongly:

> Deafness is not a life-threatening disease that requires immediate and urgent surgery. It is by no means defensible to impose technology on parents and deaf children. You suffer from the same fallacy as most of your colleagues in the medical profession: that deaf people are a walking pair of ears waiting for your salvation. […] Not that long ago, your own Algo test resulted in the word "fail" in case of hearing loss (nowadays this has been changed to "refer"). "Fail"! What a great start in children's lives. (De Meulder 2013, 3).

These contrasting views are illustrative for the unopposed technology optimism and technology centrism that seem to exclude multiple voices of the lifeworld. The firm belief in a technological solution for deafness and hearing impairments has run continuously in the period we have investigated and predated the first optimistic expectations of cochlear implantation. The construction of deafness as a flaw that should be cured immediately has resulted in the presentation of generalized screening and consequently the introduction of prosthetic devices as a major achievement of modern science. Individual responsibility of clients (parents and children) is stressed without questioning the impact of social structures and institutionalized policies.

Discussion

This study must be read as the story behind the pre-diagnostic stage of identifying children with hearing loss, not as a plea against neonatal hearing screening. Nowadays, few parents, professionals, or policymakers will refute the advantages of early identification and interventions in services for deaf children (Archbold 2010). Knowing early that your child is different (recognizing the otherness) and could be helped by assistive technology and/or by learning sign language is not a bad thing. It is the failure to acknowledge the complex interrelations involved that ought to be questioned. Conceptually, early identification of hearing loss should not be equated with early intervention and normalization. Yet, all the findings in this study point to this conflation and we believe there are reasons to question the complacency that exists in the current state of affairs, since the long-term effects of these early intervention practices and technical solutions are far from clear (Mauldin 2012; Kermit 2012).

In line with the work of De Winter (1986) and Batstra et al. (2012) this study confirms the classic critique of the medical view of childhood (Timimi 2002). The social consequences of labelling a child who differs from an average standard of health or normality may already be apparent during the screening stage (Grob 2008). Our findings support Batstra and colleagues' (2012) plea for cautious waiting and multistep care during the pre-diagnostic stage of childhood problems and also even earlier still, giving parents room to welcome their newborn.

In the case of screening for neonatal hearing loss in Flanders since the late 1970s, human judgement and agency seem to be further excluded. Preference is given to machine-generated measurements, which produce a clear conclusion not dependent on hearing the voices of parents and children (Grob 2008; Verhaeghe 2009). The test introduces a standardization intended to guarantee quick and efficient follow-up to medical and therapeutic services. A science-centred morality and technology optimism are placed at the forefront and presented as self-evident, underestimating the possible coercive effects on families with deaf children. Doubts and uncertainty can take over when parents are confronted with new intervention possibilities they are not familiar with. A diffuse pressure to intervene gives rise to therapeutic parental duties and to the popular discourse of deafness as a personal tragedy. This implies that parents are obliged to recognize the impairment and come to terms with it, have to act and not to reflect (Bosteels et al. 2012). Complex parental positions that contain compliance as well as resistance to normalizing discourses are not included in the national strategic decisions on preventive neonatal healthcare.

By the end of the year 2015, K&G will have screened one million babies, about one thousand of whom will have been diagnosed as deaf. According to the head of the medical department, all these children "are now saved" thanks to easy access to early professional and medical intervention. It is argued that the world we live in is totally different from that of thirty years ago because of the revolutionary possibility of cochlear implants. With this sophisticated hearing aid which is commonly implanted before the age of one year, deaf children have access to sound and to spoken language, can participate in mainstream education and can have a fulfilling and happy life among hearing people (Van Kerschaver 2013). Blume (2010) and Kermit (2010, 2012) however, have demonstrated that such a credulous stance does not contribute to a better understanding of the social, political, and cultural processes in which deaf children and their parents are engaged. It fits a Western Cartesian view of humanity and medicine in which diagnosis and treatment of diseased organs and systems are the main targets. Moreover, following the current state of the art on cochlear implantation (The Ear Foundation 2014*)*, executive professionals and parents are advised to implement the surgical procedure even earlier in infants aged only a few months. Cochlear implants are still not an instant repair for deafness. It is the major beneficial treatment that demands a period of close follow-up with varying results. Predictions and figures on outstanding outcomes in profoundly deaf children surpass expectations, leaving more modest assessments of uncertainty and variability underrepresented:

> When looking at outcomes in "real life" such as in the home and in educational settings, then the complex interaction of the many influences on progress increases the likelihood of variability in outcome. (Archbold 2010, 395)

The search for children at risk, as promoted by the WHO, has led to large-scale investments in early detection and prevention techniques, resulting in a classification system that is still growing and an increasing variety of diseases and disorders. Deviant cases, which are seen to pose a risk to public health and education are rewarded with more funding for research or professional training (Verhaeghe 2012). Sooner or later, every parent and child will encounter part of the health-driven ideology and will be pressured to fulfil their societal duty to contribute to "optimal development and health" for everyone (Conrad 2006; Crawford 1980; De Winter 1986; Devisch 2014; Tucker 1998).

In this case of screening deaf children at an early stage of development, it is not the physical fact of deafness which is considered the main problem but rather the socio-economic consequences of this condition for the child's future participation and integration in society. Early screening for hearing loss in young children is finding fertile ground in the development of new health technologies. It is argued by K&G that non-intervention would inevitably leave permanent traces on the child's identity or character. Not being able to interact in a predominantly hearing world is predicted to be the highest possible price to pay. A medical-technological discourse surrounds the justification of early screening for hearing loss, wrapped in a rationalized framework of neutral and scientific truth claims. Timmermans and Buchbinder (2012, 2013) look at the limitations of prevention and point to the extraordinary belief in the power of screening to save children's lives.

Since deafness cannot be viewed as a life-threatening condition, the public interest which is implicitly defended in this Flemish case is not the rescue of deaf children but instead the exclusion of otherness. This will be explored in further research in the context of deaf children's embodied experiences with human and technological interventions. One could say that the attempt to "cure" deafness in children is being made at the cost of "deafening" parents. Parents, as well as the professionals involved (especially nurses in this case) risk becoming passive players in a national, strategic plan which involves seeking out children who might be missed. Although access to healthcare, education, and rehabilitative care in Flanders can be considered very democratic compared to non-western countries, deaf children's voices are rarely heard (Kind en Gezin 2012). The few studies that do listen and consider deaf children emphasize the need to further explore identity issues and questions about social well-being (e.g. Isarin, 2008; Sheridan 2001). The emphasis on oral language acquisition and development of proper social skills, serves societal demands, assigning individual and parental responsibility in case of deviance from an optimal default position which assumes that we are only real if we speak and participate in a hearing world (Valente 2011). A decade of public recognition of Flemish sign language (2006) as a fully-fledged language has not broadened the bioethical discourse on ever-earlier interventions imposed on the social and physical condition of deaf children. Modern scientific assumptions and beliefs about the salvation of children (Vandenbroeck and Bouverne-De Bie 2006) have created a public view of well-performing, autonomous, integrated, and self-confident children who receive all necessary support. What is missing in the public debate on screening for hearing loss is a truthful exploration and inclusion of experiential knowledge in spaces of interaction of deaf children, their parents, and assisting service providers. Insights from the field of enhancement and disability studies (e.g. Eilers et al. 2014; Foster 2003; Kelly 2005; Vehmas 2012) could contribute to a better understanding of the embodied experiences. As Kermit (2012) argues, a central ethical idea is the notion of unconditional recognition of the deaf child as an authentic individual, a concept that could be investigated more thoroughly in relation to early testing and rehabilitation programs.

With ever-expanding newborn screening we are creating what Grob (2008, 1063) describes as:

> … an ever-larger group of parents who face at-birth diagnosis of a well or seemingly well infant. These parents also represent a new manifestation of how risk discourse can structure human experience—i.e. by altering the way parents come to know and to care for their newborn babies, and reframing the role health-care providers play in this process.

Although this study is limited to a specific case of neonatal screening for hearing loss, its relevance goes beyond the topic of deafness. It can contribute to conceptual development, for example in relation to uncertainty in terms of both felt experience and knowledge of the condition being screened for (Gillespie 2012; Timmermans and Buchbinder 2012; Verhaeghe 2009). Identical procedures and protocols of the newborn hearing test are now being implemented for screening of all Flemish babies for "lazy eyes." The well-known "pass or refer" terminology at the end of each consultation is intended to be the formal guarantee offered to parents, predicting a healthy trajectory with a newborn or indicating that this may be in jeopardy (or indicating the beginning of a much longer process of becoming). Similar considerations are now also being put forward in the case of neonatal screening for obesity in babies. It would be beneficial to further investigate “human voices” during the immediate postnatal period as policy moves ever further in the direction of rapid testing and intervention.

References

Archbold, S. 2010. Deaf education: Changed by cochlear implantation? PhD Thesis, Radboud University Nijmegen Medical Centre.

Armstrong, N. 1995. The rise of surveillance medicine. *Sociology of Health and Illness* 17(3): 393–404.

Armstrong, N., and H. Eborall. 2012. The sociology of medical screening: Past, present and future. *Sociology of Health and Illness* 34(2): 161–176.

Batstra, L., M. Hadders-Algra, E. Nieweg, D. Van Tol, S.J. Pijl, and A. Frances. 2012. Childhood emotional and behavioural problems: Reducing overdiagnosis without risking undertreatment. *Developmental Medicine and Child Neurology* 54(6): 492–494.

Blancke, L. 1977. Letter from the medical advisor of the NWK for the province of East Flanders, sent to all medical doctors of the consultation departments. Brussels: Kind en Gezin.

———. 1980. Letter from the medical advisor of the NWK for the province of East Flanders, sent to all Flemish childcare centres, 3 March. Brussels: Kind en Gezin.

Blume, S. 2010. *The artificial ear: Cochlear implants and the culture of deafness*. New Brunswick: Rutgers University Press.

Bosteels S., G.Van Hove, and M. Vandenbroeck. 2012. The rollercoaster of experiences: Becoming the parent of a deaf child. *Disability & Society* 27(7): 983–996.

Bowen, G.A. 2006. Grounded theory and sensitizing concepts. *International Journal of Qualitative Methods* 5(3): 12–23.

Clement, H. 1980. Letter from ENT department of the academic hospital of Vrije Universiteit Brussel, 2 July. Brussels: Kind en Gezin.

Chang, V., and N. Christakis. 2002. Medical modelling of obesity: A transition from action to experience in a 20th century American medical textbook. *Sociology of Health and Illness* 24(2): 151–177.

Conrad, P. 2006. Up, down and sideways. *Society–New Brunswick* 43(6): 19–20.

Crawford, R. 1980. Healthism and the medicalisation of everyday life. *International Journal of Health Services* 10(3): 365–388.

Davis, L.J. 1995. *Enforcing normalcy: Disability, deafness and the body.* London: Verso.

Declau F., A. Boudewyns, J. van den Ende, A. Peters, and P. van den Heyning. 2008. Etiologic and audiologic evaluations after Universal Neonatal Hearing Screening: Analysis of 170 neonates. *Pediatrics* 121(6): 1119–1126.

De Meulder, M. 2013. Doven zijn zijn geen mislukkelingen.[Deaf people are no losers] *De Standaard Online*, April 8. http://www.standaard.be/cnt/dmf20130407_00532242. Accessed April 8, 2013.

Devisch, I. 2008. An open future? The principle of autonomy within medical “codes of conduct” versus the heteronomy effects of predictive medicine. *Central European Journal of Medicine* 3(2): 141–148.

———. 2014. *Ziek van gezondheid. Voor elk probleem een pil*? [Sick of health. For every problem a pill?] Antwerp: De Bezige Bij.

De Winter, M. 1986. *Het voorspelbare kind. Vroegtijdige onderkenning van ontwikkelingsstoornissen (VTO) in wetenschappelijk en sociaal-historisch perspectief* [The predictable child. Early detection of developmental disorders in scientific and socio-historical perspective]. Lisse: Swets & Zeitlinger.

Eilers, M., K. Grüber, and C. Rehmann-Sutter, eds. 2014. *The human enhancement debate and disability. New bodies for a better life*. Hampshire: Palgrave Macmillan

Foster, S. 2003. Examining the fit between deafness and disability. In *Rethinking disability: The emergence of new definitions, concepts and communities*, edited by P. Devlieger, F. Rusch, and D. Pfeiffer, 111–129. Antwerp: Garant.

Gillespie, C. 2012. The experience of risk as “measured vulnerability”: Health screening and lay uses of numerical risk. *Sociology of Health and Illness* 34(2):194–207.

Grandori, M., and F. Lutman. 1998. European consensus statement 2000 on newborn hearing screening. Milan: Italy, May, 15–16.

Grob, R. 2008. Is my sick child healthy? Is my healthy child sick? Changing parental experiences of cystic fibrosis in the age of expanded newborn screening. *Social Science and Medicine* 67(7): 1056–1064.

Hsieh, H.F., and S.E.Shannon. 2005. Three approaches to qualitative content analysis. *Qualitative Health Research* 15(9): 1277–1288.

Isarin, Y. 2008. *Zo hoort het. Dove kinderen in het CI-tijdperk: een participatieonderzoek* [How it should be. Deaf children in the CI-era: A participation research]. Deventer: Uitgeverij Van Tricht.

Kelle, H. 2010. “Age-appropriate development” as measure and norm: An ethnographic study of the practical anthropology of routine paediatric checkups. *Childhood* 17(1): 9–25.

Kelly, S.E. 2005. “A different light.” Examining impairment through parent narratives of childhood disability. *Journal of Contemporary Ethnography*, 34(2): 180–205.

Kerschner, J. 2004. Neonatal hearing screening: To do or not to do. *Pediatric Clinics of North America* 51(3): 725–736.

Kermit, P. 2010. Choosing for the child with cochlear implants: A note of precaution. *Medicine, Health Care and Philosophy* 13(2): 157–167.

———. 2012. Enhancement technology and outcomes: What professionals and researchers can learn from those skeptical about cochlear implants. *Health Care Analysis* 20(4): 367–384.

Kind en Gezin. 1978. Report of the college of medical advisors of the NWK, November 25. Brussels: Kind en Gezin.

———. 1980. Report from the college of medical advisors, March 29. Brussels: Kind en Gezin.

———. 1987. De Ewing-test. Omstandigheden waarin de test wordt afgenomen in de RJK en kribben [The Ewing-test.

Circumstances for applying the test in the RJK and child daycare centres], May, 1–24. Brussels: Kind en Gezin.

———. 1992. Nota ter attentie van de heer L. Vandenberghe, Administrateur-generaal. Betreft: Ewingtest [Note to Mr. L.Vandenberghe, general administrator. Concerning: Ewing test], April 27. Research department. Brussels: Kind en Gezin.

———. 1993. Rapport van het interprovinciaal overleg over het Ewing-team [Report of the inter-provincial meeting concerning the Ewing-team], June 21. Brussels: Kind en Gezin.

———. 1996. Workshop on Ewing hearing screening. Resultaten van de gehoorscreening van de provincie Antwerpen [Results of the hearing screening of the province of Antwerp], March 13. Brussels: Kind en Gezin.

———. 1997a. Algo gehooronderzoek informatiemap. Aandachtspunten bij gehoorscreening (A.A.B.R.). Tips voor de regioverpleegkundige bij de Algotest [Algo hearing research information. Points of attention for the preventive health nurse with the Algo-test]. Brussels: Kind en Gezin.

———. 1997b. Veralgemeende Algo-gehoorscreening bij zuigelingen. Een geïntegreerd project voor preventie van gehoorhandicap in Vlaanderen [General Algo-hearing screening in infants. An integrated project for prevention of hearing impairment in Flanders], December 5. Cel studie en Strategie, Brussels: Kind en Gezin.

———. 1997c. Jaarverslag Ewing 1997, Verslaggeving Ewing-gehoorscreeningsprogramma 1994–1996 [Annual report Ewing 1997, Report of the Ewing hearing screening programme 1994–1996]. Brussels: Kind en Gezin.

———. 2003. Vijf jaar ervaring met universele vroegtijdige gehoorscreening. Organisatie van de Algo-screening in Vlaanderen. [Report of presentation for medical doctors working in the K&G consultation schemes], April 9. Brussels: Kind en Gezin.

———. 2008. Hearing screening report of 2008. Universal hearing screening in Flanders. Coverage, test results and results of referred babies. Brussels: Kind en Gezin.

———. 2012. Jaarverslag 2009–2011. Universele gehoorscreening in Vlaanderen. Doelgroepbereik, testresultaten en resultaten van de verwijzingen [Annual report 2009–2011. Universal hearing screening in Flanders. Population, test results and results after referral]. Brussels: Kind en Gezin.

———. 2013. Jaarverslag 2012 [Annual report 2012]. Brussels: Kind en Gezin.

Kuyper, P. 1985. Ontwerp van een voordracht gehouden voor kinderartsen [Design of speech held for pediatricians], April 19. Eén kind, twee oren, drie patiënten [One child, two ears, three patients]. Brussels: Kind en Gezin.

Lane, H., and B. Bahan. 1998. Ethics of cochlear implantation in young children. A review and reply from a Deaf-World perspective. *Otolaryngology Head and Neck Surgery* 119(4): 297–313.

Martens, L. 1997. Gehoorscreening bij zuigelingen. De introductie van de Algo test. Speech of the Flemish Minister of Health, Family and Welfare at the press conference of the introduction of Algo hearing screening, December 5. Brussels: Kind en Gezin.

Matthijs, L., G. Loots, K. Mouvet, et al. 2012. Setting the stage: First information parents receive after UNHS detection of their baby's hearing loss. *Journal of Deaf Studies and Deaf Education* 17(4): 387–401.

Mauldin, L. 2012. Parents of deaf children with cochlear implants: A study of technology and community. *Sociology of Health & Illness* 34(4): 529–543.

Mayring, P. 2004. Qualitative content analysis. In *A companion to qualitative research*, edited by U. Flick, E. Von Kardorff, and I. Steinke, 266–270. London: Sage.

Moores, D. 2001. *Educating the deaf: Psychology, principles and practices*. Boston: Houghton Mifflin.

Nash, E. and A. Nash 1982. *Deafness in society*. Aldershot, Hants: Lexington Books.

Newborn Screening Authoring Committee. 2008. Newborn screening expands: Recommendations for paediatricians and medical homes—Implications for the system. *Pediatrics* 121(1): 192–217.

Proot-Cocquyt , H. 1978. Verantwoording tot aanwerving van Logopedisten in het N.W.K. Hoger Rijksinstituut voor paramedische beroepen [Argumentation for recruitment of speech therapists at the N.W.K of the Higher National Institute for paramedical professions], February 16. Brussels: Kind en Gezin.

Sheridan, M. 2001. *Inner lives of deaf children*. Washington: Gallaudet University Press.

Stappaerts, L. 1998. Organisatie van de Algo-gehoorscreening in de regio's. AABR-screening voor gehoordeficiëntie in Vlaanderen [Organization of the regional Algo-hearing screening in Flanders], January 28. Brussels: Kind en Gezin.

The Ear Foundation. 2014. Implantable devices 2014: The state of the art. Paper presented at The Ear Foundation Annual conference, November 7, in Nottingham, United Kingdom.

Timimi, S. 2002. *Pathological child psychiatry and the medicalisation of childhood*. New York: Routledge.

Timmermans, S., and M. Buchbinder. 2012. Expanded newborn screening: Articulating the ontology of diseases with bridging work in the clinic. *Sociology of Health & Illness* 34(2): 208–220.

———. 2013. *Saving babies? The consequences of newborn genetic screening*. Chicago: University of Chicago Press.

Tucker, B.P. 1998. Deaf culture, cochlear implants, and elective disability. *Hastings Center Report* 28(4): 6–14.

Valente, J.M. 2011. Cyborgization: Deaf education for young children in the cochlear implantation era. *Qualitative Inquiry* 17(7): 639–652.

Van Cleve, J.V. 2007. *The deaf history reader*.Washington: Gallaudet University Press.

Van Kerschaver, E. 2013. Hij redde Vlaamse kinderen van doofheid [He saved Flemish children from deafness]. *De Standaard Online*, April 2. http://www.standaard.be/cnt/dmf20130401_00525885. Accessed April 6, 2013.

Van Kerschaver, E., A.N. Boudewijns, L. Stappaerts, F.L. Wuyts, and P.H. Van den Heyning. 2007.Organisation of a universal newborn hearing screening programme in Flanders. *B-ENT* 3(4): 185–190.

Van Kerschaver, E., and L. Stappaerts. 1998. De Algo-gehoorscreening. Managementrapport van het opstartjaar 1998. Procesbeschrijving en jaarresultaten van Vlaanderen en de Vlaamse regio's [The Algo-hearing screening. Management report 1998. Process description and annual results for Flanders and the Flemish regions]. Brussels: Kind en Gezin.

Vandenbroeck, M. 2009. In verzekerde bewaring. Honderdvijftig jaar kinderen, ouders en kinderopvang [In secured custody. One hundred and fifty years of children, parents and child care]. Tweede volledige bijgewerkte druk [Second]. Amsterdam: SWP.

Vandenbroeck, M., and M. Bouverne-De Bie. 2006. Children's agency and educational norms: A tensed negotiation. *Childhood* 13(1): 127–143.

Vanheule, S. 2008. Gedragsstoornissen en hun behandeling: Een methodologische doorlichting. [Behavioural disorders and their treatment]. In *Troubles de conduits/Gedragsstoornis* [Behavioural disorders], edited by N. Laceur and Y. Vanderveken, 23–26. Tubize: Quarto/iNWiT.

Vehmas, S. 2012.What can philosophy tell us about disability. In *Routledge Handbook on Disability Studies*, edited by N. Watson, N, A. Roulstone, and C. Thomas, 298–309. London: Routledge.

Verhaeghe, P. 2009. Het einde van de psychotherapie [The end of psychotherapy]. Amsterdam: De Bezige Bij.

———. 2012. Identiteit [Identity]. Amsterdam: De Bezige Bij.

White, K. 2003. Universal newborn hearing screening: Challenges and opportunities. *Vijftig jaar de Nederlandse Stichting voor het Dove en Slechthorende Kind* [Fifty years of the Dutch institution for deaf and hard of hearing children]. Utrecht, The Netherlands.

World Health Organization. 1999. Primary health care approaches for prevention and control of congenital and genetic disorders, Report of WHO meeting in Cairo, December 2000. Cairo, Egypt.

———. 2013. Quality and safety in genetic testing: An emerging concern. http://www.who.int/genomics/policy/quality_safety/en/index.html. Accessed March 12, 2013.