FACULTY OF PSYCHOLOGY
AND EDUCATIONAL SCIENCES

The malleable child
A social-pedagogical study of early interventions in families with deaf children

Sigrid Bosteels

Supervisor: Prof.Dr. Michel Vandenbroeck
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A dissertation submitted to Ghent University in partial fulfilment of the requirements for the degree of Doctor of Social Work and Social Welfare Studies

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Dutch title

Het maakbare kind. Een sociaal pedagogische studie van vroegtijdige interventies in gezinnen met dove kinderen

Doctoral Advisory Committee

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Prof. dr. Rudi Roose,
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Acknowledgments

I always thought I was different, though without feeling special. Where did this feeling come from, and why was it so hard to understand, or to be understood? I grew up in a big family of four girls and one boy. More women than men. My mother was a nurse and my father a physiotherapist who held a master's degree in physical education. Body and soul, care and education. We lived in a big, century-old house, with paintings of angels on the ceiling of my parents' bedroom, and scenes of nature and deer on the walls of our play-room. There was a huge garden with a little slope in the middle, although with a reasonable view it looked like a little hill. I felt like I was in heaven! I knew this without having the words to explain it. There were flowers everywhere. I was surrounded by the smell of good food, the sound of Leonard Cohen, Nana Mouskouri, Bach and Vivaldi, the comfort of warmth and luxury but with a vibrant message that people should be modest and humble, spiritual and authentic, healthy and foolish, thinking and feeling, and especially never forgetting that things could be different. Then there were parties, holidays on a sailing yacht with all five children, quiet and peace while admiring the horizon, the sunset and feet in the water, laughter and happiness. My mother was always ready to help neighbors, friends, and family whenever they faced material or emotional threats. My father was the perfect listener for his patients and for his children (if he was at home) but he did not understand his wife. Few words but a lot of thoughts and feelings.

I consider my father as a great mind, my mother as the warmest heart. But together and in between, things didn't work out. Another divorce of sixties-parents, who were victims of their time and yet, passionate and beautiful people. In the course of life, both of them gave me images and lessons in how things could or should go as human beings without presenting big truths. Gender, politics, sexuality, wisdom and science, creativity and innovation, plays, colors, sounds and music, taste, odors and doubts, no topic was avoided but welcomed as challenges to the already known. Mother and father, who gave me the capabilities and the competences to be alive. Do we have to transcend our childhoods, or is there a moment in time when we stop and ask ourselves whether it was the best or worse of times?

Why would I write and speak about Otherness, about Difference? I believe I already had thoughts before I could speak; there were ideas without words. Curiosity for thoughts, feelings and minds is my greatest passion. During years of teaching philosophy to social workers, I always included biographical notes of great minds. I never believed that thoughts emerged apart from bodies, hearts and feelings. On occasion, I was astonished by the thinking of others. Some of them (especially philosophers) crossed my path in my reading, trying to understand their words. Others spoke to me or I just listened to arguments that were so remarkable they created a kind of shock in the brain. Very few amongst them make me laugh. I believe the most powerful tool, associated with the greatest intelligence, is humor. This cannot be taught. I think of it as a gift of nature or genes, although I doubt if this capacity can be localized somewhere in the body or the brain. But there were only two people who caused a constant stuttering in my being: my father and my mother.

All five children in our house believed in, ‘a healthy mind, in a healthy body’. So, health was all over the place but at the same time there was a kind of Burgundian way of being with escapades of ‘the good life’. The way our bodies and minds developed as young teenagers was too much to handle for our mother. We thought it had everything to do with her not wanting to grow old whilst we, developing as young, wild girls, had the whole world at our feet. One day, convinced that the good life was elsewhere, she left everything behind, including her husband and children. Before that, of course, there had been a period of strain, disagreements, fights, fear, nightly discussions and tears. But before all that, we grew up as happy and loved young children in a house full of joy, warmth, love, flowers and music. We evolved as complex, vulnerable, resistant and independent teenagers, seeking a way of coping with the accusations and suspicions of neighbors and family, with less and less money or financial security, and with the constant lack of a mother. I wonder if I would have been the same person if she had stayed. But this fact shaped my being, probably much more than anything else. Things that evolved afterwards were consequences of this critical incident. We would show the world that we were fine, that we could run a household, get good grades at school and understood what love was all about! I realize now that we became informal carers without knowing what this implies or what the consequences would be in our later lives. Gender and generation issues were often discussed in the evenings when everyone was gathered around the table. A special and precious daily moment with honesty and openness to every possible subject depending on who needed it the most. My father listened and only spoke if real questions were asked. Otherwise, he just observed the situation and enjoyed that moment before all practical things demanded his attention. I could say that after my mother had left, we became poor in socio-economic terms but rich in our socio-emotional development. A lot of freedom, independency, curiosity, creativity and humor surrounded the family despite all the challenges and the hardships of daily life.

But then, there was always that gut-feeling, that something was wrong, that we were not a normal family with normal children. My mother was emotionally very vulnerable and perhaps she was really tired of raising this big family by herself. As a child, before you become a parent yourself, you are incapable of understanding the drives and motivations that lead your parents to do stupid things. You just feel neglected or hurt and consider these life-events as a threat to your own well-being or liberty. In our case, we were often angry at the lack of motherly love and attention in our daily lives, although we compensated this between ourselves. It was an open house, with people constantly coming and going, a cozy refuge for anyone needing to be just him or herself. It continued to be one of my drives: just wanting to be myself - whoever or whatever this was. When I was fifteen years old I had to quit school, and manage the household.

For a year I did the laundry, cleaned, cooked and took care of the house and the other children. In fact, it wasn't even a punishment or a bad thing. It just happened because I was the one with a difficult attitude towards education, someone with a rather naughty mouth but no big problems in terms of grades etc. In the evenings, I went to follow classes in typewriting, French and German, and hung out with my friends. During that year, I really learned to know my father. It was a strange, new sensation for a young girl who didn't know who her father really was until his wife had left him. Before that, I think he did not really appreciate all the compliments I got from my mother and thought I was a rather spoiled child. My mother just adored me. There wasn't much I could do or say wrong. Because of all that attention my father believed it would be wise to make me responsible for the others instead of being the central point of attention in the household. It was only later that I discovered this, when my father mentioned it between other things. By that time, I was already in my forties, and had become a mother myself, though after seven years of trying and being turned upside down. I never had an impression of myself as someone who received too much attention compared to the other children. On the contrary, I felt misunderstood, misjudged, left alone and I was rather quiet and introvert. Things turned out differently. My mother became emotionally strong, whilst my father became physically vulnerable and emotionally stubborn.

And so too my own educational, emotional, physical and professional pathways shifted and changed, back and forth. To be understood, one should speak up or write it down. I am a cultural sociologist who taught philosophy for 17 years to social workers, a qualitative researcher in a nursing department, a coach in guiding students in applied psychology to search for the real questions, a divorced woman struggling with juridical and financial claims, a nail stylist with a fascination for hands, a time wrestler with a heart and mind for children, a mother and woman balancing in the borderlands of what is good or bad.

Lander and Minne, my children: the most precious gift without guidelines. I am so grateful for how they've evolved. They came late but always came first, beyond and above all the rest.

Michel Vandenbroeck, my promotor*:* Erudite, welcoming, quiet and structuring. He reminded me time and again to focus: that without structure I would endlessly yell in the desert. Thank you for accepting my complex way of being and for being so patient with my slow-science mentality. Every form of feedback and advice was helpful and inspiring. You managed to formulate it in such a way that it seldom felt like criticism. Or you just pushed me into action. You convinced me again and again that if I didn't write this down, nobody would, and all these insights would be like pearls for the pigs.

Geert Van Hove, my co-promotor: Humor and wisdom and a through believer in my right to exist together with all my differences. You never give up, no matter what kind of structural or formal formats are presented. You always know

perfectly how to maneuver in those realms. You listened to my words, feelings and doubts for many years and inspired me by sending the right texts at the right time. A good academic friend, you have taught me to read backwards while thinking ahead.

Ignaas Devisch: posed the right questions at the right time. Beautiful voice and challenging thoughts without any ambition to convince or telling the truth. Thank you for being that honest.

Rudi Roose and Ann Buysse: although there were limited occasions to discuss the different topics of this thesis, I was convinced of the indispensable value of the social work perspective and the psychological perspective that both of you provided.

Stuart Blume: my distant friend who is always attracting woman in agony. Parent of two deaf and creative sons without technological devices and a professor who never grows (or admits to growing) old. You were always there, travelling with me through words, thoughts and feeling, all those years. Thank you for invaluable feedback.

Elisabeth De Schauwer: we travelled together to New-York more than a decade ago when you were pregnant with your third child. You were in the middle of a PhD journey. I, was only at the beginning when I gave my first international presentation at the Disability Studies in Education Conference. I was impressed by your honesty, vulnerability, and true concern for the good life.

Howest, my employer: thank you for giving me the opportunity to accomplish this type of research without having any certainty that there would be deliverables at the end.

Oscar Brenifier: offended me once with a painful statement: ‘you exist too much!’. But in a way, you were right. We must never underestimate or neglect the vulnerability of people. We should exist, but in- between, beyond and connected to others.

Parents, children and Kind & Gezin: without your participation and openness to conversations, discussions, dialogues or silences, there wouldn’t be a story to tell.

Nietzsche (+) a different philosopher– resistant to established thoughts, walking hills and mountains, challenging us to admit that the mind should become like a child. Be, feel, think, act, destroy and rebuilt. Nothing new just accept things are the way they are meant to be.

My friends Leen, Jenny, Jef: Thank you for being there when my world was falling apart. You just stood by me without any judgement at a critical moment in time, and obliged me to finish this dissertation.

Danny: at the final stage of completion, at the end and at a new beginning, you were the only man who could break through defensive walls and convince me that it was all worthwhile and that we are on top and at the edge of the world. My heart starts to trust my mind.

My mother and father: thank you for allowing me to live my own life. Thank you for that big heart and great mind!

To all these people, thank you for inspiring me.

That is where it all came from. The malleable child.

Sigrid,

October 2018

Preface

At the final stage of finishing this thesis, the only public wisdom that continuously runs through my mind is that the proof of the pudding is in the eating.

Families with (deaf) children and professionals with an openness for change, development of a personal critical view on where to set our boundaries, improvements in care, people's real needs and societies' real challenges, are invited to select and rethink some of the proposed insights. They will not offer safe guidelines, and will hopefully challenge others to dig deeper into the shadow zones of what or who might be forgotten. For every sentence we write down, someone, somewhere in the world has already created an interesting view. A lifetime is short, and the working of our brain still an inadequately understood aspect of our humanity. As a result, we can only embrace temporary knowledge, thoughts, images, feelings and the ideas of others that direct our attention and our actions towards what is good, better or best.

This thesis will touch upon paradigmatic considerations and will question underlying presuppositions, assumptions and conceptual frameworks. We will make a case for what remains unsaid or present only in implicit argumentations. We will tickle like bees in a rose bed. Not because of a mere intellectual, entrepreneurial or creative drive, but because of a more general human desire to acknowledge a responsibility towards those whose voices risk being silenced.

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CHAPTER 1

Introduction

1.1 Background

In a general paradigm about the grammar of Social Work, the complex relations between the individual and society, between actors and systems and between practice and policy are subjected to multiple interpretations (Piessens, 2008). Piessens points to the importance of not considering such a model as a prescriptive protocol but as a contouring plan for social workers in which actual discussions, standards and legitimations about social interventions can be situated and investigated. Social scientists are concerned with tendencies of civilisation, normalisation and medicalisation in societies that put diversity on top of the collective agenda (Baart, 2002; De Swaan,1986; Devisch, 2008; De Winter, 1986; Fisher, 2007; Isarin, 2001; Macartney, 2008; Rapp & Ginsburg, 2001; Vandenbroeck, 1999, 2004; Van Hove & Goodley, 2005). Kunneman (2005), for instance, describes current questions in care, education and organisational settings in terms of an acceleration problem. An orientation on efficiency, clear-cut solutions and goal-rational thinking, which involves the risk for certain groups in society of not being counted in, of not having the capability to act and to participate or of not being able to keep up with the high-speed demands of society. Framed in terms of public interest, the ideal of the autonomous, independent and negotiating individual shows cracks and bumps (De Swaan, 1986), and an increasing demand for public interventions and professional assistance jeopardises the potential of a democratic citizenship (De Winter, 2007).

From this point of view, social pedagogical studies could benefit from slow research questions that generate insights in the paradox of contemporary welfare states and leave room for multidimensional interpretations (Van der Loo & Van Reijen, 1997). Roose (2003), for instance, considered these types of questions in a study on youth care in Belgium. A central point of interest in this work deals with the tension between overactive and too passive social interventions and a concern for professional engagement in relations between parents and children. This thesis aims to contribute to an investigation of early interventions in families with deaf children in the Flemish part of Belgium. We make the case for social and collective participation in society that can be stimulated through care and education in which additional efforts to support parents and children who differ from average standards of functioning are recommended. Furthermore, normative professional frameworks and interventions should remain open for discussion, change and democratic dialogues (De Winter 1986, Read, 2000; Roose, 2003; Moqvist, 2003; Lawy & Biesta, 2006; Lister, 2007). Research questions for this study originate from earlier research, which we conducted between 2005 and 2007, where care paths of congenitally deaf children that were screened with a new hearing test were investigated. The social factors that contributed to the parental decision-making process for cochlear implantation or traditional hearing aids in young children were questioned (Hardonk et al., 2010). It demonstrated that the impact of professional assistance and advice on parental perspectives in case of childhood deafness could not be underestimated and should be studied more carefully. In what follows, the balance between care and control will be a constant and fundamental orientation in a scientific and human search for the *good life*.

In 2005, we discussed the consequences of differing human conditions on care trajectories of families and the possibility of developing an interdisciplinary research project with a group of scholars of diverse academic backgrounds. As most of our colleagues were social scientists, our gaze was directed towards the socio-cultural determinants of care paths. Deafness was withdrawn because of clear selection arguments. First, the diagnosis of hearing loss in people is a certain and not contested activity, which is executed by medical professionals. In comparison to conditions such as autism spectrum disorders and attention deficit disorders, the selection of deafness as a research topic could not cause doubts in terms of the diagnostic procedure. Secondly, we opted for bilateral, congenital hearing loss without additional impairments. Thirdly, Kind & Gezin, the Flemish public child healthcare organisation welcomed our research interests and would support the selection procedure of the participants. This organisation was well-known and successful for its neonatal hearing screening programme in Flanders since 1998 and was one of the first regions in the world to accomplish this with almost full coverage of the Flemish population (Van Kerschaver & Stappaerts, 2008).

1.2 Why make the case for families with deaf children?

Deafness in young children is considered an important health problem that restricts interaction and participation in society (De Raeve, 2006; Verhaert et al. 2008). The situation of being *at risk* because of deficient hearing capacities has generated multiple early intervention programmes for young children (Govaerts et al., 2002; Leigh, 2008; Marschark, 2005; O'Neil et al. 2004). Speed, efficiency and a strong sense of technicality and rationality is surrounding the domain of early child interventions. Fewer studies demonstrate that the socio-historical context and the social pedagogical implications of this condition for children and families deserve explicit consideration (De Winter, 1986). Furthermore, health and social professionals could benefit from legitimacy questions in care for deaf children, since current practices are subject to public requests to safeguard a workable and affordable balance between formal and informal care. The myth of rationality as explored in a recent study of Devlieghere and Roose (2017) grasps valuable insights in social work practices that directs our attention towards welcoming creativity and ambiguity in human care instead of fighting it in the name of certainty and predictability. A valuable insight in search for the good life is the embracement of unpredictability and the wondering about *what if* questions. What if things turn out differently? Otherness and difference will pop-up frequently in this work.

Most parents-to-be hope for, and expect, a ‘normal’ baby: perfectly formed with all its organs, limbs, muscles and senses and equipped to follow a normal process of growth and development. Advances in prenatal genetic testing, embryo selection, and assisted reproductive technologies seem to bring the possibility of a ‘designer baby’ within reach: a child even more precisely tailored to its parents’ dreams (Rothschild, 2005). This possibility, of course, is one that does not find universal acclaim (e.g. Parens and Asch, 1999). Clearly, for most parents-to-be, the child they hope for will be able to see and to hear. Because hearing is taken to be the basis of language acquisition, it is considered important to establish the presence of normal hearing in a baby. In the richer countries of the world, including Western European welfare states such as Belgium and the Netherlands, all babies’ hearing has long been tested as a matter of routine, though the way in which testing is carried out, and when, has changed over the last few years. Where hearing is found to be deficient by reference to population norms and the child categorised as ‘deaf’ or ‘hard of hearing,’ some kind of prosthesis will almost certainly be prescribed. Here too, technological advances have led to new prosthetic options. Medicine, with its techniques of measurement, its categorisations and prosthetic devices, intervenes profoundly in the lives of deaf children and their families (Bosteels and Blume, 2014).

Current research tends to focus on the effects of technical interventions in young children on language, speech, cognitive development and learning abilities (see also, Hauser and Marschark, 2008). Although there is compelling evidence for the benefits of early intervention in cases of hearing loss, new technical interventions raise ethical, political, socio-cultural and pedagogical questions that still demand attention (Blume, 2010; Hintermair and Albertini 2004; Levy 2002; Young and Tattersall 2007).

1.3 Theoretical underpinnings and research questions

This enquiry goes beyond the topic of deafness as a social and a medical problem. It will be a multi-perspective attempt to interrupt decontextualised and instrumental views on early interventions in young children and on social constructions of the ‘good parent’ and the ‘good child’. Limited attention is spent on a socio-historical perspective in health- and healthcare-related problems, which colours the relations between children, parents and professionals (De Winter, 1986). In studies of medico-social practices, insufficient thoughts are dedicated to the risks of inadequate referral of people, such as processes of exclusion and to the sometimes invisible nature of specific caring needs in families with deaf children (Young, 2010). However, Kind &Gezin, the Flemish child healthcare organisation in Flanders, has achieved a prominent role in the hearing screening tests for neonates and exemplifies good policy work.

In the early detection and early intervention practices for families with deaf children, a medical and linear orientation in care is apparent and will be problematised in the field of disability studies (Desnerck et al., 2006; Fisher & Goodley, 2007; Gabel and Peeters,2004; McKeever & Miller, 2004). Social pedagogical studies that interrogate the consequences of these early interventions on social support services for families with deaf children are rather scarce. Yet, the tense negotiation between a necessity to intervene in the development of a young child and trust in the socialisation potential of parents is a typical social pedagogical concern (Bouverne-De Bie, 2002). With this in mind, we will constantly question the balance between care and control in the medicalised care practices with deaf children. Furthermore, questions about raising children to become critical social actors with rights and duties to participate and to develop a unique and dynamic identity will be an additional concern (IVRK, 1989; Lister, 2007; Lawy & Biesta, 2006; De Winter, 2007; Vandenbroeck, 1999, 2004). It is all about social and health interventions in young children, so this thesis is another way of investigating malleability and enhancement in human beings (see also, Eilers et al., 2014). Questioning agency in care for oneself, others and society offers possibilities to elicit tacit knowledge in the field of social pedagogy and contributes to an ethics of care (Tronto, 2010).

The central question for this thesis is: in what ways are early interventions in families with deaf children justified from different perspectives? It consists of four phases of investigation: Parent, Policy, Child and Society.

1. Parent perspective: in relation to their child and the environment
2. Policy perspective: a socio-historical view on the policy of a child healthcare organisation
3. Child perspective: the deaf and hard-of hearing child in relation to their parents and the environment
4. Social perspective: considerations on democratic care in relation to the deaf child's case

Our qualitative research approach will be based on in-depth questioning. We will not make a choice in favour of or against one specific treatment or intervention programme for deaf children. The interpretation of a unique combination of voices (parents, children, policy and society) offers a more comprehensive view on the current situation of families with deaf children in Belgium.

In the first phase of our study, the interpretation of parental experiences and perspectives on the deafness of a child will be guided by the continuous interplay between individual values and representations and social and contextual elements. Parents of deaf children may be subjected to a professional logic in which subtle and unbalanced interactions take place. At the same time, they can be seen as architects of change and progress by caring and acting on behalf of their children (Fisher and Goodley, 2007). By moving parents as nurturers and advocates to the centre of the disability debate, we encounter a paradox in negotiating parenthood. Opposing forces are at play in parenting, between saying to the child 'I love you as you are', whilst also expressing 'I would do anything to change you' (Landsman, 2003). Consequently, unidirectional interpretations that are based exclusively on professional judgments or moral claims, underestimating the pivotal role of parents as mediators, will be challenged. This part of the thesis contributes to studies of dynamic social constructs within experiences of transition to parenthood in cases of young children identified with a label (e.g. Goodley and Tregaskis, 2006; Goodley, 2007; Clavering et al., 2006; Van Hove et al., 2009).

In the second phase of the study, we examine and contextualise the practice of new born hearing screening, showing how these efforts at identification came into being historically, discursively and in policy. 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 generalise 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? 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 potentially at risk (see also, Armstrong 1995). Children with disabilities, diseases, and deficiencies are categorised 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). 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 medicalisation of childhood (Grob, 2008; Vandenbroeck, 2009; Vanheule, 2008; Verhaeghe, 2012). We will position this part of the thesis as a moderate, critical investigation of the non-medical, non-physical aspects of early interventions in the deaf child’s life.

The aim of the third study is to explore deaf children’s perceptions of their deafness and give voice to their experiential knowledge in interaction with parents. In what ways do Flemish children’s narratives refer to deaf or hearing identities or to ‘something in between’? Present efforts to tailor public practices are said to correspond to the social, educational and communicative challenges facing deaf children in the 21st century (Archbold, 2010; Luterman, 2010). Modern scientific assumptions and beliefs about the salvation of children (Vandenbroeck and Bouverne-De Bie, 2006) and about the need to act fast to normalise the child have created a public view of well-performing, autonomous, integrated and self-confident children who receive the necessary support. However, there are grounds for questioning, and the different framing of current practices. These practices rest on a very narrow understanding of deafness to which evidence-based success stories of early medical and technological intervention are central. Evidence for the wider implications of deafness and for the attempt to explore what it means to be a deaf child or to parent a deaf child is more or less ignored (Tattersall and Young, 2006; Valente, 2011). By foregrounding the voices of children, we contribute with this part of the thesis to a micro-sociology of childhood with underpinning concepts of children’s agency and figurations of social relationships (Cunningham, 2006; Mayall, 2002). The voices of children are not separated from or set against adult voices but are included in a broad spectrum of mutual context-dependence of the achievements of children, parents and significant others.

In the last part of the study, we connect the private experiences of a family with a deaf teenager to the public domain of harmonising formal and informal care related ideas and choices. Disabling mechanisms in society are far from eradicated. Yet, the rights of children to participate and the call for greater autonomy of care receivers have been globally accepted (Goodley and Runswick-Cole, 2012). In line with the work of Joan Tronto (2013) in her quest for a caring democracy, we emphasise the need to examine hidden biases in care for deaf children. One way to accomplish this is to question the tension between autonomy and responsibility of care receivers and care givers. To illustrate this, we reflect on the case of a deaf girl whose care track is different from what is standardly prescribed as adequate or good care. What caring needs and caring means need to be addressed in this particular case? And how can this narrative be illustrative for a consideration of democratic moments in ongoing care processes for families with deaf children (Biesta et al., 2014)? Including voices of difference and otherness will be a prime concern in this part of the thesis and aims to contribute to an ongoing democratic dialogue about equal capabilities to care for deaf children and families.

1.4 Methodological considerations

A fundamental methodological concern is that this study is based on the narratives of *hearing* parents with deaf children. Consequently, the voices of deaf parents, of hearing children with deaf parents and of deaf children with multiple disabilities will be excluded from this work. Not because we consider these voices of lesser value but because of the consequences of pragmatic selection decisions. Arguments to justify this choice can be found in figures that reveal one to two children per 1000 births are born with a substantial degree of bilateral hearing loss and about 90 percent of these children are born to hearing families (De Raeve & Lichtert, 2012).

Problematising the neutrality and unidirectionality of contemporary evidence-based practices is a central orientation in this study. The investigation of justification grounds in early interventions in the lives of deaf children and their family will be based on qualitative research methods with engagements of a reflexive understanding. This method works with experiences, thoughts, feelings, doubts, uncertainties, implicit and explicit arguments when obvious and taken for granted assumptions do not speak for themselves. Structuring the methodological outlines for this work regularly created an experience of aporia. Our position in research and education has always been characterised by the incorporation and embracement of ambiguity and paradoxes, which allows us to imagine the world differently (Wang, 2005). In trying to capture the complexity of the different processes and levels of investigation, we are determined not to bend for mechanistic and deterministic perspectives of technical rationality (Webb, 2001). Referring to Lather's (2009) argument, we are convinced that this type of research questions is grounded in: 'messy spaces 'in between' where centres and margins are both situated and yet constantly changing intersections of interpretation, interruption and mutuality' (Lather, 2009:15).

As mentioned earlier, the main topic of investigation for this study was initiated by a research project that we conducted between 2005 and 2008 with the first generation of parents whose babies were evaluated with an innovative screening test of Kind & Gezin. The interview data from this project with parents influenced our gaze and directed our attention to significant questions that remained unanswered and demanded a persistent attitude of digging deeper into these parental insights. From this point on, different levels of methodological complexity were distinguished, which was negotiated within our guiding committee. In what follows, we summarise the different methodological decisions in relation to the four phases of investigation.

1.4.1 Understanding parental insights through a secondary data-analysis of in-depth interviews (2011-2012)

Parental experiences and perspectives on the deafness of a child were obtained from retrospective in-depth interviews with families of children with congenital hearing loss but no other impairments. Classification of the degree of hearing loss is arbitrary and is based on measurements of an average tone loss in comparison with normal hearing levels (Falvo, 2005). We will use the term 'deaf children' to refer to children with moderate to profound hearing loss. Recruitment of families took place via Kind & Gezin. Sixteen families with deaf children between five and seven years old were studied (born between 1999 and 2001). The database of Kind & Gezin did not permit identification of families with at least one deaf parent. Characteristics of the research population can be found in the second chapter. Between 2006 and 2007, two in-depth interviews were conducted with each family when their child transitioned from kindergarten to primary school, resulting in 32 interview transcripts. Parents were asked to recall their experiences and decisions since their child's birth (see Hardonk et al., 2010). The research protocol was approved by the Ethical Committee of the UZ Brussel, University Hospital (reference 2006/139). The secondary data analysis, which we conducted in 2011-2012, was based on a phenomenological, thematic analysis and considered the narratives as an incomplete map of a co-constructed reality with which to explore various temporal regions and paths, guided by the parents rather than by a rule-bound process (Sermijn et al., 2008; Kvale, 2006; Schwandt, 1999). Thematic analysis was directed by four interlinked phenomenological tools that created a sense of direction (Wouters, 2004): description of experiences without the urge to explain; variation of viewpoints to understand the obvious; experience of a general insight from the personal and specific; and articulation of the quality of meaning.

1.4.2 Collecting policy information on early hearing screening through archival research (2012-2013)

In order to understand the justification grounds for introducing early hearing tests in children, we conducted our research in the archives of the government child healthcare organisation Kind & Gezin. 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 this part of our study was made on the basis of a content analysis to include all documents containing information on how and why the national preventive child healthcare organisation in Flanders decided to organise national hearing screening. This final selection consisted of: reports from the medical advisory committee; recommendations concerning the hearing test; reports from the head and coordinator of the medical department; short notes in the journal *Het Kind* etc. More information on the data collection can be found in the third chapter. A combination of conventional and summative content analysis of the archival documents was carried out. This phase of the study proved to be an intensive approach focusing on the interpretation of the content or contextual meaning of a large quantity of text data. Through an inductive classification process, a feasible number of meaningful categories were described with the purpose of gaining insight in a phenomenon for which existing theory or research literature is limited (Hsieh and Shannon, 2005). The procedure of analytical induction implied that the researcher stayed as close as possible to the archival material in order to explore sensitising concepts derived from specific to more general patterns of thought (Bowen, 20006). First, using conventional content analysis, we explored the whole corpus of policy documents without preconceived categories or theoretical perspectives. Second, we applied a summative content analysis that worked through specific parts of the policy documents. Analysis of the specific context of the data associated with the usage of words or phrases provided us with an unobtrusive tool for demonstrating that textual evidence was consistent with the interpretation (Hsieh and Shannon 2005).

1.4.3 Connecting children's voices with parental and environmental factors through semi-structured interviews (2013-2014)

A further exploration of identity issues and questions about social wellbeing of deaf children was executed by conducting semi-structured interviews with children and parents in 2014. This part of the study contains a longitudinal dimension, since the interviews were executed 7 years after the first interview rounds with the same families. The families were contacted again and with their children's consent, five of them agreed to participate in this study. Two families had more than one deaf child. During this phase of interviews, the children (7) were 12 to 14 years old and transitioning form primary to secondary education. The children explicitly agreed to share their personal experiences. More characteristics on the children interviewed can be found in the fourth chapter of this work. Parents and children were visited at home and given a general presentation of the results of the earlier research phases, giving them the opportunity to ask questions about the previous phase of the project. Most interviews with children were conducted with at least one parent, which turned out to be an additional strength in the mutual conversations. Children and parents were comfortable in each other's presence and shared their views with no sense of being tested. Each session began by situating the interview in the framework of the larger study and recalling some basic aspects of the previous interview. The parents were then asked a general question about their experiences since then. The interview with the child started with general questions about their identity and how this related to their hearing impairment (Irwin, 2005). The experiences of children were catalogued according to a summative content analysis (Mayring, 2014) but showed insufficient and fragmented experiential meaning. A second analytical stage of deconstruction yielded a more complex, detailed description of the interactive meaning of children's and parent's perspectives. The analysis of deconstruction is marked by an attention strategy, which suggests forgetting about the idea that responsiveness can be directed. Trying to cling to specific frameworks almost certainly leads to a loss of sense (Wouters, 2004). Instead, inverting the stories and themes, confronting the two voices while forgetting about the initial questions and tailoring creative and critical concepts of human experiences, created the central ideas of the embodied experiences of deaf children.

1.4.4 A meta- and cross-analysis of a particular case related to social and public challenges (2015-2017)

In the last phase of this study, we intend to make sense of the complex relations between actors and systems, between the private and the public, between formal and informal care, between care and control in education, between including and excluding mechanisms for deaf children etc. This ambitious attempt was guided by the researcher’s conviction of the necessity to think globally but to act locally. Without zooming in on private, social practices of families with deaf children, questions of public engagement and participation become meaningless and vice versa. During the entire analysis of the different interview data we collected over the past ten years, the story of one deaf teenager remained something like a thorn in the side. A story that seemed to fit nowhere but kept creating a disturbing ache for the completion of this project. We decided to discuss and describe these aching insights gained out of three in-depth interviews with Sien and her family. We do not pretend to have had just one static method of secondary data analysis of Sien’s narrative. The analysis of the interviews with this family was initially guided by emergent listening and described by making use of the critical incident technique (CIT) (Chell, 2004). Emergent listening, as conceived by Davies (2014), is not a method but merely an ethical practice, idea and ideal of attending to difference. It is slow, ethical listening that challenges scholars to overcome safe reflexivity and to dwell in the space of openness to the world; the space and pause between one and another. The concept of emergent listening fits well with Tronto’s (2013) view on studying people’s interdependence through the ways we organise care practices, such as early interventions for deaf children. The basic principles of Critical Incident Analysis (Chell, 2004) came close to what we were intending to do: give voice to care receivers, conceptualise difference or otherness as central, keep reasonable distance from theoretical frameworks and identify gaps or hidden biases in the borders between formal and informal care for a deaf girl.

1.5 Outline of thesis

Drawing a structure in the search for missing or unheard voices is like an exercise in pragmatic thinking. I constantly realised that in trying to capture all complexity and ambiguity of a topic of investigation, it would almost certainly lead to chaos, loose and fragmented thoughts and, particularly, to a never-ending story that no one would hear or read. At a certain moment in time, you should decide that things come to an end or to new beginnings. We leave room for those who are challenged by these ideas and insights in order to continue on pathways that we draw out for each other, as gifts for change, new framings or openings to individual and social questions that keep academia going, even if we quit. The outline of this thesis was interrupted, coloured and guided by my personal and professional experiences throughout the past seven years. This dissertation presents a map of possibilities that draws on perspectives and different framings of knowledge that could be valuable for social scientists who are not satisfied with the way things are or with the acceptance of an optimal level of civilisation.

In chapter two, we give voice to those parents who initiated all subsequent and unanswered questions for this thesis. Some of them told me years ago that if I did not pose these questions, no one would hear their story, and scholars would only read fragments of technically and medically driven interventions in people’s lives. This would do harm to the multiple and possible readings of people’s experiences, if something at the beginning of our lives turns out to be different than expected. The rollercoaster of experiences tries to capture these parental experiences.

In chapter three, we do not question the value of early neonatal hearing tests in children. We do question the ways in which the implementation of these tests are justified in the policy of Kind & Gezin. It became the hardest part of the investigation, because we had to manage hundreds of socio-historical documents from which we could never be sure of grasping it’s complete meaning. This part especially describes our interpretation of the implicit reasoning behind the introduction of the hearing tests and its underlying constructions of childhood, deafness and preventive health.

Chapter four considers the voices of deaf children seven years after we talked to their parents. It comprehends a longitudinal dimension of care paths of seven children without claiming generalisability of the results. However, children as meaning makers are capable of formulating their own view on what constitutes or hinders their sense of self.

In chapter five, attempts are made to connect particularity to public thoughts of democratic care for deaf children and families. It describes the case of Sien, an entrepreneurial deaf girl with lust for life. This case turned out to be an extra trigger for our understandings of the many possible bridges between the individual and society and between seeds of resistance and possibilities for change in care and education.

In the concluding chapter six, we reflect on the main findings of these different voices and perspectives on early intervention in families with deaf children. We will question the arrangement of our discourses and the inviolability of professional expertise. It can be read as a multi-perspective concern for participative interventions in childhood (deafness).

1.6 References

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Verdrag inzake de rechten van het kind. Aangenomen door de algemene vergadering van de Verenigde Naties op 20 november 1989 (art.3, art.5, art.8, art.12, art.13, art.14, art.17, art.18, art.26).

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CHAPTER 2

The roller-coaster of experiences: becoming the parent of a deaf child[1]

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[1] Based on: Bosteels, S., Van Hove, G. & Vandenbroeck, M. (2012). The roller-coaster of experiences: becoming the parent of a deaf child. *Disability & Society* 27 (7):983–996.

2.1 Abstract

When early testing indicates a hearing loss, parents find themselves on a roller-coaster of experiences leaving little time or space for reflection. This study is based on interviews with families in the Flemish region of Belgium, one of the earliest in the world to introduce universal neonatal screening for hearing loss. Starting from a phenomenological approach, we explore parents' accounts of their experiences to uncover the meanings of early parenting of a child identified with a label. Soon after birth, these parents encounter a different world in which intertwined discourses construct parenthood with a deaf child. During the process of becoming a parent, representations of deafness as impairment were omnipresent. In contrast to a medical and technological perspective that insists on the need to intervene as fast as possible, it is argued that the private and social implications of rapid intervention require explicit consideration.

2.2 Introduction

In this paper, we focus on the experiences of parents whose children are diagnosed with a hearing loss at an early age. Fundamentally these experiences are about children at risk of discrimination and prejudice in society and about the various fields in which parents are enabled or disabled to care and act on behalf of their disabled children (Ferguson, 2001; McKeever and Miller, 2004). In the light of recent studies pointing to the ways in which parental perspectives contribute to the social fund of knowledge (e.g. Rapp and Ginsburg, 2001), parents can no longer be viewed merely as passive recipients of care and in need of social support (Van Hove, 2009). Dynamic social constructs in experiences of transition to parenthood in cases of young children identified with a label, are increasingly studied (e.g. Goodley and Tregaskis, 2006; Goodley, 2007; Clavering et al., 2006). By moving parents as nurturers and advocates to the center of the disability debate (Kelly, 2001) we encounter what Larson (1998) and Landsman (2003) describe as a paradox in negotiating parenthood. Opposing forces are at play in parenting, between loving the child and hoping to erase the impairment; between saying to the child: 'I love you as you are' whilst also expressing 'I would do anything to change you' (Landsman, 2003).

Interpreting early parental experiences and perspectives on the deafness of a child needs to be guided by the presupposition of a continuous interplay between individual values and representations and social and contextual elements.

Parents of deaf children may be subjected to a professional logic in which subtle and unbalanced interactions take place. At the same time, they can be seen as architects of change and progress by caring and acting on behalf of their children (Fisher and Goodley, 2007). Policy and societal structures influence the process of parenting through the standards or norms of compliance that they embody and enforce (Ramaekers and Suissa, 2012). Consequently, unidirectional interpretations that are based exclusively on professional judgments or moral claims, underestimating the pivotal role of parents as mediators need to be challenged (Fisher, 2007; Murray, 2000).

We locate our study in a phenomenological sociology of impairment that interrogates the production of disablism in society by looking at embodied experiences of impairment in the everyday world (Paterson and Hughes,1999). It demands that we leave the forefront of a story behind and work with the reverse side of it; to get lost in concreteness and get a grip on the abstract. The parents on whom we focus were the first generation whose children were screened with a new neonatal programme in the Flemish community of Belgium where hearing screening programmes are freely accessible to all, and enhancement initiatives and early intervention programmes are seen as exemplifying good practice (Van Kerschaver *et al.,* 2007). Several initiatives are being developed worldwide in order to meet the demands and hesitations of parents with a deaf child more effectively and to engage them in a collaborative partnership with professionals (e.g. Luterman, 2010). However, few authors critically examine parents' stories. Here we use them as a lens with which to uncover the meanings of parenting of a child identified with a label (Isarin, 2001; Read, 2000; Van Hove *et al.,* 2008). 'It provides the opportunity to examine spaces of social interaction that are both intimate and public in which impairment is produced and made meaningful' (Kelly, 2005).

2.3 Background

Flanders was one of the first regions in the world to introduce a new programme of universal neonatal hearing screening in 1998. Called the Algo-test, it is based on auditory brainstem response audiometry. Currently 95% of babies are screened between four and six weeks after birth. Every parent of a new-born baby has access to a consultation with the district nurse of the Flemish public childcare organisation Kind & Gezin (Child & Family). The results of this simple and non-invasive hearing test indicate either 'pass'(negative test result) or 'refer'(positive test result). A positive result implies that hearing is probably impaired and that subsequent testing is needed. A second test is typically performed no more than 48 hours after the first one and in the presence of a medical doctor. The objective of Kind & Gezin is to ensure a full diagnosis around the age of 3 months. In policy documents of the national childcare institution, the continued effort to improve this early healthcare practice is legitimated as follows:

> *Hearing impaired children miss sensory stimulation which is a prerequisite for speech development. This impairment has a fatal influence on the total development of the personality in all its social, emotional, intellectual and locomotive aspects. Furthermore, the absence of auditory impulses has a negative effect on the process of nurturing and on the parent-child relationship* (Van Kerschaver and Stappaerts, 2008).

The quote illustrates how deafness is constructed as a '*fatal*' impairment that can affect all aspects of the child and the assumption is that early intervention enables a far more effective support than was otherwise possible. In principle at least, these rehabilitation options could also include sign language instruction for the parents, and the beginning of a sign-based communication with the baby. Testing a baby at the age of four to six weeks, and the promised benefits of early intervention, such as the fitting of a prosthesis, clearly assumes a medical understanding of hearing loss. Yet, at the same time it ignores consequences for social, emotional and psychological responses of the parent. The quote also shows how the baby's lack of auditory impulses is considered to be a cause of alleged parenting problems.

Current research tends to concentrate on the effects of technical interventions in young children on language, speech, cognitive development and learning abilities (see also Hauser and Marschark, 2008). Although there is compelling evidence for the benefits of early intervention in cases of hearing loss, new technical interventions raise ethical, political, socio-cultural and pedagogical questions that still demand attention (Blume, 2010; Hintermair and Albertini, 2004; Levy, 2002; Young and Tattersall, 2007). Technology cannot always effectively counter the processes through which deaf people are excluded from the hearing world or the deaf world (Isarin, 2008; Sparrow, 2010). Fundamental choices have to be made on behalf of a very young child, based on information that highlights the success and triumph of medical intervention and downplays areas of uncertainty. Dependency on (hearing) technology tends to replace or distract the attention from human care.

2.4 Methods

Qualitative data were obtained from retrospective in-depth interviews with families of children with congenital hearing loss but no other impairments. Classification of the degree of hearing loss in dB is arbitrary and is based on measurements of an average tone loss in comparison to normal hearing levels (see also Falvo, 2005). In this study, we use the term 'deaf children' to refer to children with moderate to profound hearing loss. Recruitment of families took place via Kind & Gezin. All families, meeting our inclusion criteria, were contacted by Kind & Gezin. After approval, the researchers contacted the collaborating families. 16 families with deaf children between five and seven years old were studied (born between 1999-2001) [table I]. The database of Kind & Gezin did not permit identification of families with at least one deaf parent. Two in-depth interviews were conducted with each family. Parents were asked to recall their experiences and decisions since the birth of their child, while the interviewer asked additional questions based on the parents' accounts. Two interviewers were present at the families' private homes: one leading the conversation and the other filling out a life-grid scheme (a tool for facilitating and validating the chronology, dates, order of events and consistency of retrospectively collected information) (Hardonk *et al.,* 2009). The time between the first and second interview was between nine and 12 months. All interviews were audio-taped and transcribed. The research protocol was approved by the ethics committee of the 'UZ Brussel' university hospital (reference 2006/139). The phenomenological, thematic analysis considered the narratives as an incomplete map of a co-constructed reality with which to explore various temporal regions and paths, guided by the parents rather than by a rule-bound process (Sermijn, 2008; Kvale, 2006; Schwandt, 1999). A basic template of questions was expanded and compared by the researchers after 5 interviews had been completed. This enabled us to adjust the interview process where necessary. The resulting interpretative scheme was applied to all subsequent first round interviews. A first set of nodes, were generated with the help of Nvivo software served to reveal significant concepts and possible inconsistencies in the interviews (Bowen, 2006), that structured the second interview. We conducted thematic analysis with the aid of 4 interlinked phenomenological tools that created a sense of direction (Wouters, 2004): (1) description of experiences without the urge to explain, (2) variation of viewpoints to understand the obvious, (3) experience of a general insight from the personal and specific, (4) articulation of the quality of meaning. The coding process was inductive: meaningful entities, like knots in the web of parents' experiences, were explored (Van Manen, 1999).

Two clear themes, identified as key-moments in care, emerged: (1) the screening and diagnosis of the hearing loss of the child, (2) finding a proper school for the child. For the purpose of this paper we will concentrate on the description of the first key-moment and uncover the meanings of these early experiences for parents with a deaf child.

2.5 Results

2.5.1 Shock and awe: “I was in a different world”:

A common theme in experiences with testing and diagnostic procedures for impairment is that parents are often able to reconstruct these events in great detail as if it happened only yesterday (Bjarnason, 2008; Goodley and Tregaskis, 2006). Every parent we talked to took us back in time to a moment of confusion and uncertainty when suspicion of hearing loss of the child was communicated. The importance of how and when these messages were formulated and passed on to caregivers cannot be overestimated. First contacts with the preventive health nurses were presented almost word for word as having had substantial impact on family life. At first sight, the requirement to collaborate as a parent in carrying out the non-invasive hearing test were modest, since the only expectation was that the baby should be calm or asleep if possible. However, we noticed that the nurse’s presence left an almost indelible impression in parents’ memories. Nurses whose messages were experienced as empathic and helpful tried to ensure that parents understood the significance of their words:

> Mother of Sien: I have to say, the lady from Kind & Gezin, she was very kind. She knew exactly what to do and how to tell us very gently that ‘something seems to be not quite right.’ No, they said ‘it’s not normal that we get a ‘refer’ constantly, we definitely have to look into this’. But they never said, ‘the child is probably deaf.’
> Father: They never referred us really, did they?
> Mother: They did say that we had to keep an eye.
> Father: Follow up.
> Mother: Yes, that we needed to follow up.
> Father: For people that don’t know anything about this, and you are, you have to follow up. What exactly is follow up? Can you follow up at home or you should consult someone *else?*

Despite a positive test, repeated 4 times, Sien’s parents did not understand what the need to follow up on these results meant. Consequently, they waited for three years until their daughter went to kindergarten and the preschool-teachers noticed that there was something wrong with her speech. Due to the low prevalence of deafness, nurses are not often confronted with a positive test result. Moreover, not only are the babies’ younger than ever before but, during the first years of the screening, the nurses were unfamiliar with the new technical tools. Parents recalled that the testing frequently had to be repeated, and they found it difficult to cope with the sometimes-clumsy handling of technical equipment and with the waiting periods in between. The possibility or assumption that something was wrong turned the first months of parenthood into a tense and worrying time.

> Mother of Jolien: That was the first time the nurse of Kind & Gezin experienced this because the Algo-test hadn’t been around for very long, just a few months or less than a year. She says ‘There must be something wrong with the appliance […], I will visit you at home on Thursday and bring another one. Then here, with that other machine, again ‘refer’. She then spoke on the phone to someone from the company, did the test 3 times and by then I started to get worried, like, what’s going on here? And the next day again with another appliance, that was the 3rd one.

These parents were only just beginning to know their baby. Senses were acute and parents very susceptible to blurred communication. Even clear messages did not get through at all just because at times parents were not ready to get a grip on new information. Hesitant, blunt or vague answers from these professionals put a stamp on the attitudes of parents, which could lead to delays in follow-up or a denial of subsequent diagnosis. The success of the neonatal hearing programme, in terms of a quick and reliable result, depends on the cognitive and emotional comprehension of parents.

> Mother of Jonas: Until the contact person of Kind & Gezin said to me ‘look, it’s time you went to the doctor’. So, I did and she (the medical doctor) said straight in my face ‘yes, I suppose he is deaf’. That was it and I found it incredibly difficult to deal with. So, the way in which, it just isn’t done, I felt really awful about it for a long time. As a result, I could not face it, so I waited for six months (before having further tests done). In hindsight I don’t understand myself, don’t understand my reaction.

The frequency of consultations with care providers from Kind & Gezin is mostly limited to a few contacts during the first months with a baby. Nevertheless, if professionals transmitted worrying messages about the child, parents' confidence in professional support was strongly influenced by these initial experiences. After neonatal hearing screening, there is a whole range of supplementary auditory testing before the final diagnosis is made. Parents especially mentioned Brainstem Electric Response Audiometry (BERA) as being thorough and confrontational. Even if there is no real medical need, babies often had to be sedated to be able to perform a reliable test. In only one case a mother refused firmly because she considered her daughter as too small for such an examination. The consequence was that her child was diagnosed very late.

Parents reported that during these first months they were overwhelmed by new information and technical procedures which interfere with the intense feelings of early parenthood. They mostly had no prior knowledge of deafness and entered into a strange world of medical terminology, with the aid of which parental practice was soon held up for public scrutiny. A crucial incident or turning point is the moment when the hearing loss of the child is finally established. From one moment to the next a label turns people's world into an alien one.

> Mother of Jolien: At first it was a bomb, you cannot believe it, but then, you have to. I was completely out of it. Half of the time, coming home, I had to ask my husband 'what was it again they said about that, and that? During those first weeks, months really, I was in a different world, the shock.

Early diagnosis offers clarity but it also objectifies a child as a deaf child. At first a man and a woman become father and mother, shortly after that they become a family with a deaf child. The question of *who* this child is, becomes overshadowed by doubts and fear of *what is wrong* with the child (Isarin, 2001).

2.5.2 Negotiating parenthood: 'And then you have to explain':

In giving our children a name, we offer them entry into a social world, a world of communication.

> Mother of Bram: You're at home, you just had a baby and then … your child can't hear, you say its name and you realise, oh he cannot hear

> me. That's terrible; it may be stupid but those first three weeks I was just going on at the child while he couldn't hear me at all.

The fact that this mother's voice was not recognized created a sudden awareness of the lack of reciprocity between her and her child. The child missed something (hearing capacity) that parents cannot offer naturally, and means of interaction are under pressure. The first reactions of the baby to facial expression, light, touch and sound were interpreted differently due to the attention focused on the hearing loss. Asymmetry enters into the relationship between a hearing parent and a deaf child at the earliest stage of possible bonding. This confrontation challenged parents to question their identities as fathers or mothers. Especially mothers seemed to be struggling with an internal dialogue on how to look at their new-born baby.

> Mother of Jelle: yes, with pity really, something you shouldn't do, but I could not look at the child without crying. Yes… was it self-pity perhaps? It could have been self-pity, I don't know.

The emotional and personal search for emergent parenthood went along with a conflict between the hope to be heard and the fear of having to recognize the impairment. Parents tried out diverse sound exercises with their child, seeking to negate the reality of deafness.

> Mother of Jolien: You are doing all kinds of tests yourself, all the time. She would be asleep in her cot and you are making a noise in all kinds of ways to see if she jumps. Like with two pan lids; she did not jump as such but she did blink. But that was just because of the draught you are causing. At that moment you think, she has heard it really. You are fooling yourself in so many ways, you cannot accept it.

Being the parent of a deaf child is not only a private matter of parental coping strategies but is also embedded in a social environment. Parents negotiated their proper location and the value of their children in the family and in society.

> Mother of Dieter: We rejected the idea, we thought, no way. Probably it was the shock that made us react like that. We told everyone, 'they say our son is deaf, but that's not true, he can hear us all right'. Well, we convinced all our friends and family that it wasn't true.

The gaze of others confronted parents with the deafness of their child. They dealt with personal feelings of guilt and responsibility and at the same time they express aspirations of being seen as *good parents*.

> Mother of Jelle: I even had this problem that, when Jelle was little and in his buggy, I would remove his hearing aids when I went out. Well, I mean, nobody would then see, you know. My (ex) husband would say, ‘you can see them, but the child must be helped’. Or when it was summer I would no longer stop to have a drink at an outdoor café. Because one time Jelle began to scream and started to act up, only because I had not put his hearing aids in, and people gave me looks as if to say ‘what is wrong with that child?’ And my husband would then react and say ‘yes, well, we’ve got ourselves a noisy one here.’ While I wanted to go into my shell and felt awful.

Representations of good or bad parenthood evolved over time but were challenged by having to justify their role and capabilities of raising a deaf child.

> Mother of Lara: In the beginning it was very difficult, you have to come to terms with it yourself and then everybody descends on you with ‘how was it? how was it?’ And then you have to explain, yes, that was difficult.

The otherness of the child made every day experiences distinctive, but were mediated by the birth-order of the deaf child. If the firstborn was deaf (7 families), and the cause of deafness was related to hereditary factors, parents were often reluctant to extend the family and questions of guilt arose. If the deaf child was born within a family where older children were present (9 families), these siblings were part of the care trajectory and influenced time and space of parental activities. If one of these brothers or sisters was also deaf (3 families) then hands-on expertise with a clear view on the paths to follow was present.

2.5.3 Acting and being acted upon: ‘You end up being a therapist’:

One of the first fundamental questions was to understand the meaning of deafness and to integrate the available information into the parental role, which seemed quite difficult in the first year of life. Doubts and uncertainty took over when parents were confronted with new intervention possibilities they were not familiar with.

> Mother of Lara: And the strange thing was, the moment we stepped outside (the hospital), we felt we had to sit down for a bit and we were, like, what is happening? Then we saw a child come by with a, such a cochlear (implant),but at the time we didn't know what it was, with a round thing behind and a rucksack with a lot of stuff...and the child was using sign language. And we thought, will we have to learn that too? What kind of things are they... yes, it was really making us feel ill.

As soon as parents had a clearer view on possible actions, they began acquainting themselves with the auditory tools and technical equipment that entered their lives. If the use of hearing aids seemed to be unproblematic, the possible resistance of the baby was underestimated.

> Mother of Jolien: Jolien had hearing aids when she was six weeks old. She is the youngest ever, they know all over the world, that Jolien already had hearing aids. If I think back on it all now, but you have no idea. And that was that, at first every other week at least, every 10 days, for other ear pieces. Because those little ears grow very quickly. And as soon as there was any air between the ear pieces, they began to whistle. So, you couldn't cuddle your child, or pick her up properly because that hearing aid would always be whistling.

The use of traditional hearing aids is recommended to preserve stimulation of the auditory sense, and is meant to support development of speech and oral language. The assumption is that hearing parents prefer oral communication to silence and sign language.

> Father of Gella: I am constantly busy with her, even during the day, in teaching her as much language as possible, in fact with the silliest things. I wouldn't do this with a normal child. With a normal child, I wouldn't be that occupied, that's for sure.

The story of a fulfilling life without a hearing aid was absent and the natural ability of the child to learn sign language appeared seldom to be discussed. Parents started depending on the expertise of the Ear-Nose and Throat (ENT) specialists who guided them towards promising possibilities of altering the physical condition by cochlear implant surgery.

> Mother of Karlien: Because well, having the hearing aids didn't help, what are you to do? There is not a lot of choice. You can go on

> functioning with a deaf child or yes, it is one or the other. So no, I never hesitated, I thought the sooner the better. Although afterwards, when that noise started for the first time I did think, 'what have I done now?' Because we want her to be able to hear. We didn't ask her, 'what is it you want? Do you want to hear or not?' You can't ask the child, can you? Later on, one time, we might ask her.

During the early years of care, parents encountered diverse professionals operating largely in clinical settings. One important exception are the care-at-home professionals, mostly speech-language therapists, in Flanders members of multidisciplinary rehabilitation centres. Most mothers considered them as supportive for the opportunities they offered to have a break from the daily routine, to get a close-up observation of the child's development, to receive information about technical and administrative matters and to articulate insecurities.

> Mother of Lara: If we have any questions, or when it gets too much for us, all those people sometimes, nagging us with how come this and that? We can talk to her about all that. And sometimes we really need that. To have someone we can have a good old moan with, I always say. Father: She is our ambassador really, if you can call it that. Mother: Our Wailing Wall. Someone who at least knows what she is talking about, because you, as a parent, don't know (anything) really, you are just thrown to the wolves as it were.

Contact with these professionals take place in parents' private environments and so differs from interactions with other care providers that usually take place in more clinical and public surroundings. All the narratives point to a diffuse pressure to intervene as soon as possible. Although parents did not refer to much pressure from professionals, the invitation to act quickly and not to reflect was overwhelmingly present. The construction of parenting of a deaf child was initiated by emphasizing the individual responsibility of parents. By accepting the responsibility of their parental role, they would offer children optimal opportunities for social interaction and future integration into mainstream, hearing society.

> Mother of Gella: I believe we have a feeling we could not expect from the community to adapt to our child. Father: If a community has to adapt

> to this, then you have to adapt to everything, to all disabilities. To me this is practically not feasible.

All eyes were directed towards technical solutions for dealing with or minimizing the disablement of hearing loss. Parents may forget about the entire, healthy baby with a non-life-threatening condition and concentrate on what is missing or threatening. Deafness today is treated much as we treat chronic diseases and multiple voices are silenced. Professional interpretations and implicit normativity of categories permeate early family life.

> Mother of Jolien: We were told, ‘spend as much time as possible, expose her to noise’, so in our free time, yes, it became an obsession, we did nothing else. But you end up being a therapist, you’re no longer a mother or father.

2.6 Discussion

Our analysis emphasizes the velocity of the construction of parenthood with a deaf child. Through the early hearing screening and intervention programmes, parents were strapped into a roller-coaster of impressions with little time for reflection on existential questions. The confrontation with an essential difference and asymmetry in the parent-child relationship, determined enabling or disabling spaces for intimate and social interactions. Representations of deafness as impairment were omnipresent during the process of becoming a parent.

The majority of our respondents soon found themselves confronting the four intertwined discourses identified by Landsman (2003). (1) The popular discourse of deafness as a personal tragedy meaning that parents have to recognize the impairment and come to terms with it. This experience questioned their parental identity and was surrounded by feelings of doubt, guilt, hope and responsibility. (2) The discourse of medical and pediatric practices by which deafness is considered as a pathological condition of the individual. Parents were expected to treat deafness in ways that would normalize the child (see also Foster, 2003; Hyde and Power, 2005; Young and Tattersall, 2007). From the beginning, parenting was reduced to the establishment of speech and language development by following a prescribed path: auditory testing, use of hearing aids, and intensive rehabilitation. Obligatory encounters with nurses, ENT-specialists, care-at-home support etc., became part of daily family life. (3) Parents encountered heroic discourse of progress and technological advances that included promises of cure on condition of parent's hard work and children's perseverance. The growing attention for the globalized debate around cochlear implant surgery, together with an increasing tendency to consider profoundly deaf children with a prosthesis as enhanced and integrated children goes beyond the purpose of this paper (Blume, 2010; Bosteels, 2009). (4) The fourth discourse identified by Landsman deals with responsibilities of society, for example diminishing social and structural barriers for parents with deaf children. The parents' narratives touched upon the medicalization of deafness, expressed as intertwined voices that penetrated the parenting pathways. We do not see this as due to the effects of expert knowledge only. Rather, medicalization is the result of interactional processes in society involving different stakeholders. As medical categories increasingly infiltrate our social world, they function as directives for acting responsibly in the name of a healthier lifestyle (Conrad, 2006). This helps to create a culture in which all perceived defects are to be eliminated. These concerns are related to parents' hearing status and may be dealt with differently by deaf parents. Consequently, our analysis must be read as the story of hearing parents. As demonstrated in a similar study with a small sample of Flemish deaf parents, findings indicate that the child's deafness was not considered a personal tragedy and parents were seldom impressed or influenced by professional advice, by time-limits to early intervention options or by new possibilities of hearing assistive technology (Hardonk *et al.,*2011).

Although the distinction between the social and medical models of disability remains an important discursive resource in daily practice, we found evidence of parental positions that can be described as in-between: complex (eclectic) positions that include compliance as well as opposition to medical and normalizing discourses (see also Gabel and Peters, 2004). Within certain families examples can be found of critical reflection as regards personal thoughts of tragedy. Perhaps some parents are evolving towards 'philosophers of the present and becoming'. With this position Fisher and Goodley (2007) constructed bridges between individual and social model approaches relating to disability. As 'philosophers of the present and becoming', parents with deaf children can look at doubts and uncertainties in the light of chances and opportunities, can try to enjoy their child and parenthood now, avoid unrealistic expectations for the future, and be prepared to resist if they have to defend their rights or those of their children.

Our findings, based on Flemish parents' experiences, are particularly relevant since intervention in care for children with a hearing loss takes place earlier than almost anywhere in the world. Nowadays, few will refute the benefits of early identification and intervention in the services for children with a hearing loss (e.g. the work of Adrian Davis at the NHS new born hearing screening programme in England; Davis and Hind, 2003). Nevertheless, as Kunneman (2005) points out, legitimization in care is mainly focussed on acceleration, implying patterns of thought and behaviour based on efficiency and enhancement strategies. Screening for a growing range of (largely genetic) conditions is becoming more and more common. Whilst families might welcome information about such conditions, only partial knowledge is available on how these early interventions affect family life (Timmermans and Buchbinder, 2010). The importance of public storytelling (Rapp and Ginsburg, 2001) and narratives of family lives successfully led, are fundamental for bringing a shift from exclusion to inclusion to the fore. As Sparrow (2010) argues, this must be embedded in a broader social policy debate and will require ‘thinking hard about what sorts of experiences and achievements make a human life worthwhile.’ That is why we emphasize a need to encourage slowness in crafting appropriate intervention practices for families with deaf children. The challenge is to embrace unpredictability at the beginning of a young child’s life and to create space for reflexive professionalism (Vandenbroeck et al., 2009).

Table 1: characteristics of research population

Families contacted	
First announcement	69
Reminder	23
Respondents (households)	
After first announcement	15
After reminder	1
Parents participating in interview	
Mother	10
Mother and father	6
Included deaf children per family	
1	15
2	1
Gender of child	
Male	8
Female	9
Age of child at time of interview	
5	1
6	9
7	7
Hearing loss of child[2]	
Moderate (41-70dB)	4
Severe (71-90dB)	2
Profound (>91dB)	11
Type of hearing aids[3]	
Bilateral traditional hearing aids	8
Unilateral cochlear implants	3
Bilateral cochlear implants	6

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[2] For the purpose of this paper we use the term 'deaf children' to refer to children with a moderate to profound hearing loss.

[3] Traditional hearing aids and cochlear implants are both hearing aids but with the substantial difference that the former refers to assistive technology that does not require surgery.

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CHAPTER 3

Saving deaf children? Screening for hearing loss as a public interest case[4]

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3.1 Abstract

New-born screening programs for congenital disorders and chronic disease are expanding worldwide and children ‘at risk’ are identified with 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 reflexive professionalism should interrogate the ever earlier interference in children’s lives. The Flemish community of Belgium was among the first to generalise 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 organisation 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 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.

3.2 Introduction

The field of new born 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 (American Academy of Pediatrics 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 Organisation (WHO, founded in 1948) promoted primary healthcare worldwide, broadening the definition of health to include broader developmental and mental aspects of wellbeing. 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 (WHO 1999). Globally, groups at risk should be identified as early as possible and mass screening methods developed accordingly (WHO 1999). It is now acknowledged that the social and ethical implications must also be addressed (WHO 2003). 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 civilisation’ 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 categorised 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 normalising 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 medicalisation of childhood (Grob 2008, Vandenbroeck 2009, Vanheule 2008, Vanobbergen and Vansieleghem 2010, 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 social 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 health care providers (Grob 2008).

From a medicalized and normalising 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 socio- cultural and linguistic differences, and screening is the first step in potentially denying a deaf child’s birth right (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 (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?

3.3 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)

Preventive health care for families with young children in Flanders is in the hands of *Kind & Gezin,* K&G (Child and Family), the government organisation responsible for preventive neonatal health care 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 percent of all new borns. Ninety two percent 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 new born's life, 97 percent of the parents receive at least one home visit from the PHN and 88.3 percent 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 & Gezin 2013).

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

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 percent of these children are born to hearing families (Moores 2001). Compared to the other conditions for which new borns 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)

3.4 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 organisation *Kind & 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 organisation in Flanders decided to organise 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.

3.5 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).

3.5.1 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 & 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 & 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 percent 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 & Gezin 1978).

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 & 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 & 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 & 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 & Gezin 2008). The automated version of the hearing test was considered to be objective and experts claimed a validity score of almost 99 percent (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 & 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 en 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 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 & 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 & Gezin 2003). Workshops and information sessions were organised 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 multi-disciplinary cooperation between professionals and on parent participation during medical and paramedical care. The management reports from the college of medical advisors of Kind & 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’, ‘standardised’, 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 & 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).

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)

Optimising objective standards of measurement and minimising 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).

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 & Gezin 2013).

3.5.2 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, italics by authors).

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. K&G 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 & Gezin 1992). The theme of deafness as a serious defect that jeopardises 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 & Gezin 2008).

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 & Gezin 1996)

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 & 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 policy makers 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)

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). 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).

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 organisations and DOV, a deaf parent organisation, 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).

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 believes in cochlear implantation. The construction of deafness as a flaw that should be cured immediately has resulted in the presentation of generalised 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 institutionalised policies.

3.6 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 policy makers 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 normalisation. 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 (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's (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 new-born.

In the case of screening for neonatal hearing loss in Flanders since the late nineteen seventies, 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 standardisation 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 (Authors 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 1 million babies, about 1000 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 rationalised 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 intervention. 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 to become 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. The few studies that do listen and consider deaf children emphasize the need to further explore identity issues and questions about social wellbeing (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, 2012). A decade of public recognition of Flemish sign language (2006) as a fully-fledged language has not broadened the bio-ethical 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 new born screening we are creating what Grob (2008 p.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 new born 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 new-born 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 new-born 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.

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CHAPTER 4

Put your ears on! Deaf children's embodied experiences with human and technological interventions[5]

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4.1 Abstract

This paper considers the voices of deaf children and their parents in Belgium’s Flemish community. The study is part of a larger longitudinal project on early interventions in families with deaf children. We open up questions of identity and belonging for empirical examination by exploring the unrecognized borderlands of a particular childhood in a particular society which is guided by the quest for physical, social and mental health perfections. Qualitative data were obtained from interviews with parents and children with congenital hearing loss but no other impairments. It is argued that children as meaning makers enact difference or sameness as a means of participating in wider social encounters. Changing contexts and social encounters, together with expectations of how a deaf child is supposed to behave, add an element of contingency, of fluidity to children’s sense of self. Dominant discursive practices of a fixed all-or nothing position are challenged or rejected.

4.2 Introduction

How do congenitally deaf or hard of hearing children think of themselves: of their identity and their belonging? In this paper we set aside the institutionalized binary notions which, for over a century, have constituted conflicting ideas of good care for prelingual deaf children. From a professional and policy point of view, the possibility to hear and speak is categorically set as the standard for a normal, happy and healthy child. Accordingly, the absence of these capacities creates a generalized identity construction of the child as deaf or disabled, with the implied risk of diminished personhood (Bosteels and Blume, 2014). Listening to the voices of children themselves, and their parents, we open up questions of identity and belonging for empirical examination.

According to the World Health Organization’s terminology, deaf children are categorized as “children with disabilities,” and in need of prompt medical attention (WHO, 2010). National policies should therefore provide for early detection of hearing impairments and rapid intervention. This, it is suggested, is the best way of ensuring equal opportunities for deaf children in society (WHO,2015). In Western European countries, there is indeed a trend in diagnosing hearing loss in children as early as possible, and to intervene promptly in case any hearing loss is identified. Today, about 80% of western

European children found to have profound bilateral hearing loss undergo cochlear implant surgery before the age of three years (De Raeve and Hardeveld, 2013). Cochlear implantation is considered the most effective treatment for deaf children and is said to give them access to the world of sound and spoken language, and to prepare them to participate in mainstream education and society (Blume, 2010). Research has shown that early cochlear implant surgery is of great benefit to profoundly deaf children. As a consequence, parents are advised to have the operation carried out when their child is only a few months old (The Ear Foundation, 2014)

All of these recommendations have been adapted into policies and practices in Belgium's Flemish community, where the present study was conducted. The neonatal screening program is well established, and diagnosis of a hearing impairment is followed by rapid medical intervention (Kind & Gezin, 2012; De Raeve and Lichtert, 2012). Present efforts to tailor public practices are said to correspond to the social, educational and communicative challenges facing deaf children in the 21st century (Archbold, 2010; Luterman, 2010). Modern scientific assumptions and beliefs about the salvation of children (Vandenbroeck and Bouverne-De Bie, 2006) and about the need to act fast to normalize the child have created a public view of well-performing, autonomous, integrated and self-confident children who receive the necessary support (Bosteels et al., 2017). The emphasis on oral language acquisition and development of conventional social skills serves societal demands, assigning individual and parental responsibilities and prioritizing the need and the obligation to speak and to participate in a hearing world (Valente, 2012).

There are however grounds for questioning, and the different framing of current practices. These practices rest on a very narrow understanding of deafness, to which “evidence-based” success stories of early medical and technological intervention are central. Evidence for the wider implications of deafness, for its profound influence on children’s identities and on parental trust and sense of competence, is more or less ignored (Bosteels et al.,2012; Tattersall and Young, 2006; Valente, 2011; McIlroy and Storbeck, 2011).

The concept of deafness on which current practices are based is also a profoundly ahistorical one. For some scholars, current practices have to be seen against the history of oppression and neglect of the deaf, and the transformation in deaf consciousness which emerged in the 1970s, partly as a result of research on the sign languages of deaf people (Van Cleve, 2007; Lane et al., 1996). Within this newer perspective, some use the term “deaf” to refer to membership of a distinctive sign language-using community: a community of people with a different linguistic and socio-cultural heritage and identity from hearing people. The term “deaf” is then used to refer to people who consider themselves as hearing impaired and as experiencing consequent disabling effects in society (Bat-Chava, 2000; Kermit, 2009). Here, for reasons that will become clear, we avoid making this deaf/non-deaf distinction.

Kermit argues that two alleged antinomies distort discussion of the precise meaning of the deaf child's best interests (Kermit, 2012). One side tends to consider deaf children as needing repair and remediation by experts, both physically and socially. The medical (individual) model of disability is traditionally associated with this view, also supported by a hearing (speaking) majority. Within a social (constructionist) model of disability, deafness should be viewed as a function of the interaction between the individual and society. Remediation or repair of societal and structural barriers is the biggest challenge. A socio-cultural (deaf) perspective fits well within the second perspective on disability (Foster, 2003).

This is an ideological and essentializing debate, in which little attention is paid to everyday lived experiences in one society or another (Freely, 2016). The deaf child is then either a candidate for prosthetization, or a potential member of a distinctive community. Excluded is the attempt to explore what it means to be a deaf child, or to parent a deaf child. Although access to healthcare, education and rehabilitative care in Flanders, Belgium, can be considered very equitable, deaf children’s voices are mostly lacking or become decontextualized, as is the case more generally.

The few studies that do listen to and consider deaf and hard of hearing children emphasize the need to further explore identity issues and questions about social wellbeing (McIlroy and Storbeck, 2011; Isarin, 2008, Sheridan, 2001). As Wheeler demonstrated in a study with young cochlear implant users, identity is a flexible concept and young people do not position themselves in fixed or one-dimensional categories such as either deaf or hearing (Wheeler et al., 2007)

The aim of this study was to explore deaf children’s perceptions of their deafness, and give voice to their experiential knowledge in interaction with parents. In what ways do Flemish children’s narratives refer to deaf or hearing identities, or to “something in between”? By foregrounding children’s voices, we position this study within a micro-sociology of childhood with underpinning concepts of children’s agency and figurations of social relationships (Cunningham, 2006; Mayall, 2002). Children’s voices are then not separated from, or set against adult voices but are included in a broad spectrum of mutual context-dependence of children’s, parents' and significant other’s achievements (Vygotski, 1986). Consequently, the use of specific theoretical paradigms is considered as hindering the researchers’ open attitude of emergent listening which proves to be crucial in understanding meaning and experiences of participants.

We acknowledge Castro’s (2004) delineation of children’s subjectivities that:

> *… consist of ongoing processes decentred from the individual unit, the person as a whole, made to circulate among very diverse elements of the social world: symbols, language, norms, values, objects, tools and machines etc*. (Castro, 2004:473)

4.3 Methods

This study is part of a larger longitudinal project on early interventions in families with deaf children. In 2006–2007, 16 families with congenitally deaf or hard of hearing children (between 5 and 7 years old), living in Flanders (Belgium), and screened by a new hearing test, were included in the research. Flanders is a world pioneer in screening for hearing problems. The current hearing test is an adapted version of an existing Automated Auditory Brainstem Response Audiometry (AABR) test that is labeled the Algo test. This Algo test is administered by the preventive health nurse in all infant consultation schemes to babies at age four to six weeks from 1998 onwards ((Van Kerschaver and Stappaerts,1998). Since its introduction, more than 95 percent of all babies have undergone the Algo test. As a result of using these tests, 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 70 children are born deaf every year. About 90 percent of these children are born to hearing families [8]. Recruitment of families for this study was executed by Kind & Gezin, the child welfare organization of the Flemish community of Belgium (for additional information about the research population, see Table 1 and Table 2).

The first author conducted two interview rounds with the parents when their children transitioned from kindergarten to primary school. The parents were asked to recall their experiences and decisions since their child's birth (Van Kerschaver and Stappaerts, 1998). Seven years later, the families were contacted again and, with their children's consent, five of them agreed to participate in this study. Two families had more than one deaf or hard of hearing child. During this second phase of interviews (conducted in 2014), the children (n=7) were 12 to 14 years old and transitioning from primary to secondary education. None of the parents were deaf. The children explicitly agreed to share their personal experiences.

Before the first author visited each family, the interviews conducted 7 years previously were re-studied and structured in order to start with a general impression and tentative knowledge of the family history. Parents and children were visited at home and given a general presentation of the results of the earlier research phases, giving them the opportunity to ask questions about the previous phase of the project. Most interviews with children were conducted in the presence of at least one parent, which turned out to be an additional strength in the mutual conversations. Children and parents were comfortable in each other's presence and shared their views with no sense of being tested. Only Kobe and Marthe's mother invited the researcher to do the interview in the children's own bedrooms in their absence. The interviews lasted between 60 and 90 minutes. Interviews were audio-taped with the parent's and child's consent and were verbatim transcribed afterwards. All names are anonymized.

Table 1. Characteristics of the children interviewed in 2007

Families contacted	First announcement	69
	Reminder	23
Respondents (households)	After first announcement	15
	After reminder	1
Parents participating in interview	Mother	10
	Mother and father	6
Included deaf children per family	1	15
	2	1
Gender of child	Male	8
	Female	9
Age of child at time of interview	5	1
	6	9
	7	7
Hearing loss of child	Moderate (41-70dB)	4
	Severe (71-90dB)	2
	Profound (>91dB)	11
Type of hearing aids[6]	Bilateral traditional hearing aids	8
	Unilateral cochlear implants	3
	Bilateral cochlear implants	6

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[6] Traditional hearing aids and cochlear implants are both hearing aids but with the substantial difference that the former refers to assistive technology that does not require surgery.

The interviews were semi-structured, providing flexibility to adapt to the situation. We translated research questions into interview question that could provide thematic knowledge and also contribute dynamically to a natural conversation flow to generate spontaneous and rich descriptions (Moores, 2001). (for more information on the interview guide, see Table 3, and on the craft of qualitative research interviewing, see the work of Kvale and Brinkmann, 2009). Each session began by situating the interview in the framework of the larger study and recalling some basic aspects of the previous interview. The parents were then asked a general question about their experiences since then. The interview with the child started with general questions about their identity and how this related to their hearing impairment (Irwin and Johnson, 2005). An example of such a question is: “How will you present yourself when entering a new group of people? Do you consider yourself as different than other children? How?” The interview also included questions about how others reacted to the child (e.g. “How do other children react to your hearing aids?”) and questions about their possible belonging to different sociocultural worlds (e.g. “Do you know sign language? When/where do you use it? Would you like to have more contact with other deaf children?”).

Transcription and coding of the narratives was executed using NVIVO software and this supported the exploratory first steps in the analytical phase. Texts were written and read with background information about previous experiences with the same families in mind. An inductive coding process yielded a collection of themes which served as meaningful guides during the iterative, analytical phase. The themes emerging from this first interpretative process were: presentation of self, perception of hearing aids, use of frequency-modulated (FM) devices, experience without sound, description of deaf or hearing status, reactions from the environment, experiences at school, interventions of special educators, and thoughts about future deaf children.

Children’s experiences were catalogued according to a summative content analysis (Mayring, 2014) but showed insufficient and fragmented experiential meaning. A second analytical stage of deconstruction yielded a more complex, detailed description of the interactive meaning of children’s and parents' perspectives. The analysis of deconstruction is marked by an attention strategy, which suggests forgetting about the idea that responsiveness can be directed. Trying to cling to specific reference frameworks almost certainly leads to a loss of sense (Wouters, 2004). Instead, inverting the stories and themes, confronting the two voices while forgetting about the initial questions and tailoring creative and critical concepts of human experience, yielded two central ideas of the embodied experiences of deaf children. These two themes were about a temporal way of expressing who the children are and what they need. The two meta-themes were discussed with the second and third authors and used to structure this article and we emphasize that the purpose of this study is not to generalize findings for deaf, cochlear implant or hearing aid users. Rather, this study is an exploration of the unrecognized borderlands of a particular childhood in a particular society which is guided by the quest for physical, social and mental health perfection.

Table 2. Characteristics of the children interviewed in 2014

Child interviewed	Anna	Dieter	Dorien	Kobe	Marthe	Sien	Lara
		Siblings		Siblings			
Age at time of interview	13	14	12	14	13	13	13
Interview context	- Living room - Mother present	- Living room - Mother present	- Living room - Mother present	- Bedroom - private	- Bedroom - private	- Kitchen - Mother, father and sister present	- Living room - Mother and father present
Diagnosis as described by parent	Deaf	Hard of hearing	Hard of hearing	Deaf	Deaf	From severe hearing loss to deaf	Deaf
Type of hearing aids	Cochlear implants	Hearing aids	Hearing aids	Cochlear implants	Cochlear implants	Hearing aids/cochlear implants	Hearing aids
Age at time of first use of hearing aids	Both CI at 6 months	2 years	6 months	First CI at 18 months; second CI at 6 years	First CI at 8.5 months; second CI at 2.5 years	First HA at 3 years; first CI at 11 years; second CI at 12 years	6 months
Number of children in the family	3	2	2	4	4	3	1
Education (Primary/Secondary)	Mainstream/ Mainstream (socio-technical)	Special school for the deaf/ Mainstream (technical)	Special school for the deaf	Mainstream/ Mainstream	Mainstream/ Mainstream	Mainstream/ Mainstream (vocational)	Special school for children with learning disab. Mainstream (vocational)
Sign Language	No practical knowledge	Good practical knowledge – no longer used at home or at school	Good practical knowledge – used at school, not at home	Very good practical knowledge – no frequent use at home; no longer used at school	Very good practical knowledge – no frequent use at home; no longer used at school	Limited knowledge of basic signs	No knowledge

Child interviewed	Anna	Dieter	Dorien	Kobe	Marthe	Sien	Lara
		Siblings		Siblings			
Parents	Mother: cleaning lady; father: employee in elevator company	Mother: cleaning lady; father: no more contact. Divorced	Mother: cleaning lady; father: no more contact. Divorced	Mother: educated speech therapist/ audiologist working at home; father: independent creative	Mother: educated speech therapist/ audiologist working at home; father: independent creative	Mother: Early childhood worker at kindergarten; father: disabled by work accident	Mother: housewife; father: employee in public railway company

CI: cochlear implant; HA: hearing aid

4.4 Results

4.4.1 Who we are: identity, technology, contingency

The teenagers to whom we talked were rarely inclined to present themselves as deaf. When entering a new peer group (e.g. during the transition from primary school to secondary school), their deafness was only mentioned if others made remarks or asked questions about the condition.

> Marthe: I just tell them who I am but I never say “I am deaf,” actually. I never say it. Sometimes they really stare at my hearing aids. And if other children start asking questions such as “What is that by your ears?” or “Why do you often say excuse me?”, I will try to explain it as well as possible. Then I just say I am deaf, that it happened at birth and that I am not responsible for it.

Lara is diagnosed as hard of hearing and wears her hearing aids mostly covered by her long blond hair. She doesn’t like to talk much and hesitates during the interview, waiting for her mother to jump in with possible answers.

> Lara's mother: It is mostly the extra attention she receives, that unconscious attention she gets, from more people, isn’t it? (Lara hums, waits…) That is something she finds annoying, she doesn’t think it is much fun.
>
> Interviewer: Can you describe why this isn’t much fun?
>
> Lara: Well, there was something like, “What are you doing here? You shouldn’t be here, shouldn’t you go to another school?” I had that kind of feeling once, but now that is completely over. When I said, “I have hearing aids, I can hear but not that well,” I said that. Then they told me, “If someone bothers you, you should come to me” […] Like my best friend, I was playing with her one day and we bumped into two boys who were making comments like “Uh, what is that?” Then my best friend said:
>
> “Don’t you laugh at her or you can choose between the cemetery and the hospital.”

Not all children sought approval from their peers. Insecurity or shame about looking different is not something that bothered Sien. On the contrary, her new cochlear implants were presented as funny, unique accessories which made her all the more acceptable and special as a young teenage girl.

> Sien: I think it is fun, it is just a device. I tell them right from the start and they think it is nice and start asking questions. And I just say, “Well, I am deaf so you should pay more attention to me and speak clearly.” Then they understand it right away and start making it cool. […] I can feel it you know. Here, there is a hole and over there is a bump (laughing and showing the difference on her skull), you should feel it, there is a hole in my head.
>
> Sien's mother: She is constantly playing with it, you know, and uses it to her advantage, like “I have this and you don’t have it.” She exploits it to make it more beneficial, you know, which is really nice.

Except for Sien, being like other boys and girls is what preoccupies most children. The tangible situations in which they most often consider themselves as deaf are when they are in bed or in the bath – private, intimate places where hearing aids are left aside and sound is necessarily excluded. Since most Flemish deaf children with cochlear implants attend mainstream schools, they rarely have deaf peers to relate to and must adjust to situations where they are the only one with a different perception of sound. Visiting a public swimming pool, for example, was a challenging situation where they had to depend on lip reading, gestures and/or sign language to be able to participate and did not really feel safe. All the children we talked to characterised noisy environments such as the school playground as the most difficult place to interact and be just like others. These were places where there are no teachers, therapists or parents to evaluate or help if communication is difficult. Open spaces with a lot of background noise make it hard for deaf children to be included in interactions, heard or seen by others. In this often-neglected environment, no cognitive learning is going on yet it contains all the more micro situations of real life in which children like to participate. The use of a local dialect or the presence of larger groups of children chatting around them are also excluding factors for deaf children. Or as Marthe puts it:

> Then I don’t understand what they say and I repeatedly have to say, “Excuse me” and I really don’t like that.

The particular experience of the absence of sound felt boring for some and comforting for others. The children had an additional skill to manage the disturbance caused by noise and they used this in flexible ways according to their mood, feelings of self and interpretation of the situation.

> Sien: It is very quiet then because you don’t hear anything. You do “hear” the beating of your heart. But I turn them off [the hearing aids]

> if I am not feeling comfortable, when I have a headache and if I don’t want to listen.

In the morning, Kobe waits as long as possible before putting his hearing aids on, which causes distress for his mother. He compared his behaviour to his deaf sister's habits, who wears them for longer, puts them on earlier and is fascinated by the different sound of a voice, with or without hearing aids. In Kobe’s case, the hesitation to use his technical tools immediately had something to do with his sense of being by himself:

> Kobe: […] of course when I am asleep I don’t use them or if I want to read or study. Sometimes when I am using the vacuum cleaner I turn them off as well.
>
> Interviewer: You do these kinds of jobs in the house, nice. And what exactly is disturbing for you then?
>
> Kobe: It doesn’t disturb me but I would rather do these things quietly. Marthe puts her CI [cochlear implant] on immediately after she wakes up in the morning. I don’t do that and I postpone it as long as I can, but Mum doesn’t like that. Now, with my little brother J., I try to do it more often because he knows sign language but he doesn’t understand everything.
>
> Interviewer: … And why do you like your hearing aids being turned off?
>
> Kobe: … Yes, well, it is much quieter then and I don’t have to pay as much attention to my environment.

Most of the children wore their hearing aids all day long and the daily action of putting them on in the morning only differed in terms of the time taken to organize things before going to school. Components like batteries, FM tools or accessories for the cochlear implant were additional objects, making the organization of family routines more challenging for families with a deaf child. The task of checking if their children had all the items and tools they needed during the day was troubling for mothers:

> Mother of Kobe and Marthe: Well, yes, in the morning it is a real rush, everything is timed to get everyone out of the house in time. And with Kobe it is a fight sometimes, yes, to … get up in the morning, come down and put your ears on. And everything will go smoothly, well, for me I mean, because communication will be easier. In the morning you always have something in your hands, putting things on the table, making coffee, having J. (youngest child) in my hands and then…

> having to use my hands to communicate is not natural for me (laughing). So, with Kobe, I regularly have to struggle and ask "Please, during the week, put your ears on immediately and I will try to complain less."

Children were creative in adapting to their technological devices and often saw themselves as no different from everyone else. Nevertheless, they wanted people around them to be considerate about their condition. If they talked about it or presented themselves as hearing or deaf, they decided when, where and why they did so. Probably, because none of these children were born to deaf parents, the cultural divide of relating more to a deaf or a hearing world was absent from the interviews. In these cases, there is no reason to assume that the children are somewhere "in between worlds" because of their hearing impairment. They expressed no wish to have more contact with other deaf children or receive more information about deaf culture or the use of sign language. Since these children received an early diagnosis (before the age of one) and were prepared and trained to use their assistive technology from infancy, oral communication became part of the world they belong to and this was seen as the easiest way to connect with others.

> Marthe: There still is a difference between hearing and deaf children [positioning herself as hearing in this case], especially when it comes to making friends. With sign language, you can't always express what you mean and who you are. You can show other children a lot by the way you behave, telling them things etc., but with deaf children it isn't as fast. […] But there are a few advantages of being deaf you know [positioning herself as deaf in this case]. The funny thing, although in fact it is very impolite, is that when Mum is complaining, I can turn my hearing aids off. But I don't do it, I am too ashamed to. Apart from that, we sleep very well. And you can fool people by like turning it off and letting them tell you a whole story and when they have finished you just say, "I don't hear anything."

In trying to understand the children's perspective on deafness we asked for their opinions about a hypothetical situation of having a deaf baby in the future. This question turned out to be thought-provoking for some and very odd for others. Except for two children, who didn't know how to respond, the other five children had a common perception of a situation that would be regrettable but by no means a tragedy.

> Sien: I think it would be a pity, but not too much. I would teach them everything and I would contact someone who could do a cochlear

> implant, yes, because the sooner the better. Because they say then you will be used to it for later. I would immediately go to rehabilitation as well, so they can learn how to speak sooner and better. And I would say [meaning to her partner], that you shouldn’t feel sad about it, you should be happy instead.

We witnessed multiple voices in one child. One was the voice of a young citizen in society, confronting the barriers that deaf children still have to face. Another was the voice of a girl or boy trying to find out what love is all about. There was even a third voice, that of their parents, transmitting parents’ feelings of trust or grief.

4.4.2 Need and belonging: dependence and free space

When their children are confronted with judgments or questions about their sensory difference, or the way they talk or behave, parents often help out by interpreting the situation. The voice of the child is coloured and shaped by the words, sentiments, and interactions he or she encounters at home. Asking children whether they consider themselves simply as deaf or hearing offers them a dichotomized split that fails to reflect the complexity of the children’s sense of self. Parents add to this complexity by assigning specific qualities to their children’s behaviour.

Anna's mother, for example, contrasts her two deaf children in terms of the ways in which they adjust to particular situations, how they relate to others, and even how they fight. She describes her 19-year-old son C. as a “real deaf” person and Anna as a “hearing” child. Both the children are cochlear implant users and both have approximately the same degree of hearing loss:

> Anna's mother: For her, it is really hard if she cannot hear. She feels much more lost than her brother, who adapts more easily. In fact she is even more deaf than he is but she does more with her devices. She always looks for “hearing deaf” who are talking at the same level. On trips organized for parents with deaf children, she is one of the better “hearing” children. […] When they were younger, the way they fought drove you crazy, it was a kind of “deaf fighting.” They yelled at each other very loudly; they didn’t understand each other because they were not looking at each other’s lips, not realizing that they didn’t have their hearing aids on, then they became more and more frustrated, not recognizing that they couldn't hear each other. It was really hilarious.

Even in families that are convinced of the benefits of using sign language and have experiential knowledge of having more than one deaf child, things weren’t always that clear or similar to families with hearing children. The mother of Kobe and Marthe describes the difference as follows:

> I have the feeling, how should I put it, that they are more on a little island, a little bit trapped in their cocoon; auditory, emotionally too, but certainly on a social level. By this, I don’t mean that deaf people aren’t social, not at all, but […] There seems to be a kind of subtlety about seeking contact with others, knowing how to react. And yes, other children, you should teach them how to share and be thoughtful of others too, but I have a feeling that it is much more fine-tuned in comparison to them [meaning her deaf children], it is less obvious, not that easy…

The family of Kobe and Marthe can be considered a well-off professional family, well-educated and well connected. This is not the case for the mother of Dieter and Dorien, who is struggling much more to receive recognition for her role as a supportive mother dealing with a social environment, including her family, who have not always been respectful towards her children:

> They see it as something really simple, like,” OK, they are deaf, they wear hearing aids” and otherwise nothing is wrong, when there is so much more to it. […] My father always says, “It’s a lot better now isn’t it?” I say, “Nothing is better, it’s exactly the same.” There’s a kind of taboo and you get the feeling that you’re always trying to cope by yourself when everyone continues to think like that. Always denying things, not wanting to see it as just the way it is.

Dieter and Dorien appeared more dependent on their mothers’ voice to articulate their thoughts and feelings about the hearing impairment. They covered their hearing aids and were susceptible to critical remarks or questions about their condition. Professional or parental support seemed to be more appreciated and more frequently requested than in the other families. All the parents were occupied with their children’s future in society but the ways in which they expressed these concerns differed significantly. The mother of Dieter and Dorien was more anxious about her children’s future, their safety and ability to function independently in society. As long as her children's hearing ability was not declining, she said she felt OK. Kobe and Marthe’s mother was more self-assured about her children's opportunities if only “They put their ears on”; but critical of the public policy on child healthcare in Flanders because interventions are narrowed to a medical narrative that never fits the real-life experiences of particular families.

Critiques and questions about the future development of deaf children are easily linked to the parents' responsibility.

> Anna's mother: I think parents sometimes have too much information and are still hoping to get a hearing child back. When I see new parents like this I think “Man, just have some patience.” You know, they get the diagnosis “Your child is deaf” and want to turn them into a hearing child. Tomorrow. It’s technically possible, right? Give it time, take time to deal with it, make space, find out for yourself what it means to be deaf.

The way this responsibility is formulated by Anna's mother gives the impression of a secure and self-confident position in raising her children. According to the way she put it, deafness became “a hidden disability,” making it all the more important that parents try to communicate all necessary information when deaf children are participating in public spaces. This is very different from Dieter and Dorien’s mother, who was more confused, articulating feelings of guilt and a sense of being burdened with responsibility.

> Dieter and Dorien's mother: One day, I told a friend, that it is somehow a double feeling. On the one hand, I still don’t know where it comes from, and on the other hand, I know it can’t get any worse. I kind of have peace about that.

Interviewer: Suppose you knew the cause of their hearing impairment, would it be different?

> Dieter and Dorien's mother: Yes, because I would know the cause, I think that is important for them as well. Later, if they have a family of their own. One day they will become self-conscious about their deafness and I would be able to answer their questions because a mother is supposed to know everything, isn’t she? In the beginning I said, “I have created a deaf family…”

Some children require more intensive professional or parental involvement, as is the case with Dieter, who is afraid to talk about the technical aids he needs during class. At the beginning of secondary school, his mother had to intervene:

> Dieter's mother: During that first year, he had a special educator. He was so nervous, really anxious that he wouldn’t be accepted because

> of his hearing aids. He was so worried that he became ill and had to stay at home. So, I talked to her and explained that he was too ashamed to ask the teacher to use the FM tools. We told them they would get things that had to be hung around their neck. So, she decided to talk in front of the whole classroom (Dieter was absent) and explained that Dieter was hard of hearing and needed different tools and that the teachers should pay attention to it. After that he seemed more at ease.

The presence of others who are not friends or family members was just one of the unquestioned interventions that demanded flexibility and perseverance from both children and parents. Professionals sometimes gave advice guided by personal beliefs or opinions about a “generalized” deaf child. Even if children expressed their thoughts about not wanting further assistance or guidance with schoolwork or other tasks, they still received implicit messages or predictions of future problems. For example, Kobe received two hours of support a week from a special educator but doubted if this was really helpful.

> Kobe: The special educator told me that children who don’t know me would start talking louder to me. She said they would sometimes do that and it would be more difficult for me to deal with the rest of society. But that is not the case with me; other children will not behave in deviant ways […] In fact, she doesn’t do that much. Sometimes we make a plan or prepare a presentation for busy weekends, or I ask a question if there are things I don’t quite understand. It is OK, but if I didn't have that, it wouldn’t be a disaster.

Wearing hearing aids makes deaf children appear slightly different from other children, and in private situations, they adapt to this in flexible ways. At school, however, they preferred not to be special and the presence of assistive technology and professionals was considered as mostly intrusive or too visible to others. Especially the FM system, an assistive listening device which improves sound clarity and eliminates background noise, makes concentration for deaf children easier but at the same time it restricts their ability to escape from duties. It demands constant attention to the teachers’ voice and limits their engagement with the whole class situation, in which other children have more freedom to decide to listen or not. Whereas parents had been decisive and compliant with professional advice on always using this tool during primary education, their teenagers in secondary school started negotiating about where and when they wanted to use it. Most of them were bothered by it and they searched for ways to either eliminate it or would forget about handing it to the teacher or find other excuses.

> Anna's mother: […] They often forget that she is deaf. The thing we experience at school at the moment is that she doesn’t like using her FM tool. Last year it was obvious that she needed it, especially for French and writing exercises, she really needs it. And we pushed and pushed just like we did with her brother C. and told Anna ‘Please, tell the teacher to use that FM.” But recently we discovered that she practically never uses it. […] So, this year we are giving her the benefit of the doubt. Who are we to decide that she should use it? Maybe, in comparison to her brother, she is doing better than before with her hearing aids, who knows. […] For her, it is extremely important to belong to the group, and with the FM, the social element is eliminated and she can’t hear what the others say.

Dependence on technology is an important part of care for deaf children in society today. It becomes increasingly integrated into the child’s sense of self (Hole, 2007). For the deaf/hearing impaired children in this study, their distinctive reference to sound and to the human voice is shaped by these artificial aids. Apart from the financial cost of these items, which in Belgium is commonly covered by the health insurance system, there is a large amount of human and technological intervention to be added to deaf children’s list of duties. From birth, they are invited and urged to use the hearing aids constantly, practice oral language, have surgery for a prosthesis (sometimes more than once), and rehabilitate through speech training, social skills and balance exercises etc. These children are prepared for an experience of childhood determined and influenced by additional obligations and a sense of hard work rather than simply growing up like any other child. By the time they arrive in secondary school, it seems that they need more free space to decide and act for themselves.

4.5 Discussion

Essentialist notions of deafness and hearing underpin both medical-technological interventions in the lives of deaf children and their families, and the views of those who oppose these practices in the name of the deaf community (Bat-Chava, 2000; Hole, 2007; Hintermair, 2008). In this study, we have sought to go beyond these notions, allowing deaf and hearing impaired children, and their parents, to speak for themselves. How do these children see themselves? Unsurprisingly, the answer is complex and contingent. Their heteroglossic voices constitute unfinalized identity negotiations that are resistant to theoretical categorization. In line with the work of Kermit (2009, 2012) and McIlroy (2011), the recognition of intertwined discourses in social-pedagogical practices for deaf children opens up new perspectives on appropriate care for deaf children and families, and indicates the limitations of relying exclusively on medical notions of “evidence” (Hoogsteyns and van der Horst, 2013).

This account of five families with deaf children can be read as a journey through the challenges involved in trying to live an authentic life as an adolescent in Flemish society. For some children, this means that silence is appreciated and intrusive questions are avoided. For others, the absence of sound is scary whilst questions about a different appearance with technological aids are welcomed. Some deaf children like to be looked at and listened to, whereas others do not. While most people today make use of communications devices such as cell phones, deaf children have a more intimate relationship with their hearing technology (Kirk, 2010). In playful ways they demonstrate agency by choosing to connect to or disconnect from external sounds and stimuli. Or, as formulated by one of the mothers, the question of “putting your ears on” serves as a parental request to relate to the child, regardless of assumptions about spoken or signed languages. We should not interpret the child’s relationship to his or her technological aids or to his or her parents or caring professionals in terms of overcoming physical impairment or transforming the child’s nature. Rather we can say that these children enact difference or sameness, as they feel appropriate, as a means of participating in wider social encounters. The barriers that they may come across are located both in their (developing) bodies and in their social and cultural life worlds. So, swimming pools or playgrounds challenge their strategies of participation.

Children resist a unitary identity as deaf or hearing (Hintermair, 2008). But it is not sufficient to simply add a third stable “in between” identity, as Bat-Chava (2000) proposes. Rather, changing context and social encounters, together with expectations of how a deaf child is supposed to behave, add an element of contingency, of fluidity, to children’s sense of self (McIlroy and Storbeck, 2011; Hintermair, 2008). Consequently, this position will change over time and context, and in many cases deaf and hearing statuses may coexist.

Freedom to decide when and where to belong is what connects (deaf) children. For some, perhaps especially those coming from vulnerable families, choices may be reliant on parents' and professionals' assistance and guidance. For others, freedom of choice means searching for unique, educational paths that resist default positions. In seeing deaf children as meaning-makers, capable of forming their own views on what constitutes a (deaf) identity, dominant discursive practices of a fixed all-or-nothing position (e.g. screened and diagnosed, deaf and disabled, implanted and cured, speaking and integrated, hearing and normal, signing and different etc.) are challenged or rejected. In the negotiated borderlands of children's embodied experiences, silent questions arise about spaces of emancipation that interrupt unified scientific conceptions of the deaf child's best interests. What if we could start by conceptualizing dependency as a human gift instead of a regrettable weakness? (Reindal, 1999). What if we could make responsibility a shared choice rather than an individual burden? In the current debate on legitimate interventions in the deaf child's life world, these questions remain "Oh, so quiet" (Tronto, 2013; Lang and Reisfeld, 1995).

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CHAPTER 5

The power of voice and noise. Balancing in borderlands between formal and informal care for a deaf girl[7]

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5.1 Abstract

In this paper, we develop an understanding of formal and informal care-related ideas and choices of a family with a deaf teenager. A central point of interest is the tension between autonomy and responsibility of care receivers and care givers. This has led us to shift and dwell in the realm of private experiences and public issues. In doing so, we mainly concentrate on the ways in which this deaf girl makes her voice heard in interactions with significant others. Drawing on Tronto's work on a caring democracy and Davies' conceptualisation of emergent listening, we further explore pathways of making sense of difference. We argue that the concepts of authentic voices and disturbing noises in care and education for deaf children could be considered in an ongoing democratic dialogue.

5.2 Introduction

This study highlights the power of human voices in the allocation of formal and informal care for deaf children and their parents. In case of childhood deafness, autonomy and participation in care-related decisions have been merely reduced to pre-structured compliance with medical, technological and pedagogical advice. Flemish child healthcare policy contributes to the global effort of preventing congenital disorders by initiating early detection and intervention strategies to safeguard equal opportunities for deaf children in society (WHO, 2010; Kind & Gezin, 2012). Consequently, children are subjected to diagnostic tests shortly after birth, embarking on a journey of scientific certainty and objective predictions of future development (Authors' own, 2015, 2017). Yet, people do react and resist to prescribed labels of a disabled state of being. For example, the formal recognition of Flemish sign language in 2006 has not created a fundamental change to the deaf community's fear of being eradicated as a linguistic and cultural minority group. Medical progress in cochlear implant surgery and technology optimism are considered the main gateways to individual success, altering an impaired condition into a normal and healthy state of being, although there is still not an instant repair for deafness (Kermit, 2012). The Flemish deaf child became an object of public intervention, a problem allegedly solved on the condition of parents' responsible engagement in care and children's perseverance in the medical, educational and rehabilitative process. Private living rooms are filled with technological equipment and administrative regulations and are visited, interrupted and supported by professional assistance. Real opportunities to include sign language classes for parents with a deaf child are limited and are rarely advised. Classrooms, as the public locus of learning and integrating, are central environmental settings where teachers wear microphones to assist the deaf child and where additional special educators are present to include the deaf child and/or other children. Playgrounds are the diffuse fields or intermediate spots of peer-related interactions where a deaf or hard of hearing child is much more challenged to participate compared to other children; where distress for being excluded or being unheard becomes tangible (Authors' own, 2018). Interactions between parents at the school gate are real physical and emotional borders of 'in and out'. Parents often feel judged and evaluated by public wisdom and thoughts of not belonging or not having the right to include the deaf child among the other hearing pupils. The continuous quest for oral language acquisition and development of proper social skills is very demanding for family life. Intermediate care providers, such as nurses, speech therapists, care at home professionals and educators, balance between institutional demands and individual expectations, values and uncertainties. Society is challenged to create gateways to educate children to become critical, social actors with rights and duties to participate and to develop a unique and dynamic identity. In cases of childhood deafness, these challenges deserve more attention.

In this paper, we analyse formal and informal care-related ideas and choices of a family with a deaf teenager named Sien. In line with Tronto's (2013) ideas about the future of a caring democracy, we underline the need to critically examine hidden biases in care or in Tronto's terms, the consequences of privileged irresponsibility. This concept could be described as the opposite of shared responsibility. Care givers, professionals or policy makers discharge their obligation and engagement to think and act on behalf of the ones in need of assistance or guidance. Arguments used to defend their position are then based on false reasoning of bureaucratic restrictions or defended by excluding mechanisms of professional expertise. Privileged irresponsibility's are a direct threat to democratic societies that are confronted with fading trust in politics and a declining social participation of citizens. The democratic deficit suggests that people become less involved in the political debate on care and have doubts about the relevance of choosing for active citizenship through education (Biesta, 2007; De Winter, 2005). Drawing on Tronto's (2013) work on democratising care and Davies' (2014) conceptualisation of emergent listening, we explore new ways of making sense of difference in the case of one Flemish family with a deaf girl. Difference or otherness is at the heart of the debate on early interventions in the lives of deaf children. Yet, policy continues to rely on grand narratives that speak of certainty, objective measurement and the quest for normalcy and standardisation (Authors' own, 2016). We believe with Goodley and Runswick-Cole (2012) that disabling mechanisms in society are far from eradicated, at the same time acknowledging that children's rights to participate and the call for greater autonomy of care receivers have been globally accepted. Tronto (2013) points to the importance of tracking and eliminating bureaucratic blockages in the way we organise our social practises. Throughout this endeavour, the power of voices of care receivers becomes crucial.

A central point of interest in this text is the tension between autonomy and responsibility of care receivers and care givers. In doing so, we shift and dwell in the realm of private troubles and public issues. In studying Tronto's ethics of care, we were challenged by the statement that the conceptual split between the private and the public sphere is outdated and in need of serious rethinking. The private permeates public life; public rules and decisions influence the private sphere. To make this more tangible, we should therefore investigate pathways of deaf children and their parents in both fields. Their story invites us to think beyond paradigmatic contexts and dual notions of good or bad care.

To illustrate this, we critically reflect on the case of Sien whose care track is different from what is standardly prescribed as adequate or good care. We mainly concentrate on the way in which she makes her voice heard in interactions with significant others, such as family, friends, educators and professional assistants. This position presupposes a normative suggestion of considering democratic moments in social processes and care practises (Biesta et.al., 2014). Throughout this attempt, we aim to keep open doors for the democratic experiment and to invite policy makers, professionals and educators to rethink the ways in which we strive for social inclusion for children and adolescents.

5.3 Case description and methodological considerations

This study is part of a longitudinal encounter with Flemish families whose children were diagnosed as deaf or hard of hearing at an early age. During the entire analysis of interview data that were collected between 2010 and 2017, Sien's case remained something like a thorn in the side. A story that seemed to fit nowhere but kept creating a disturbing ache for the completion of the project.

We decided to discuss and describe these aching insights gained out of three in-depth interviews with this family (14.12.2006,15.06.2007 and 18.12.2013). First, during the initial phase of selection of respondents based on excluding criteria determined by the research group and the Flemish child healthcare organisation Kind & Gezin[8], Sien and her family did not meet the proposed criteria, because her degree of hearing loss seemed to be too low. The first author had already contacted the families before this initial selection problem occurred. Merely out of doubt about these objective inclusion criteria, she decided to interview this family anyway. A telephone call with the mother of Sien revealed that they were eager to talk with someone who was willing to listen to 'the whole story'. Between the first and the second interview, Sien's mother became pregnant with a third child and feared the early hearing test of Kind & Gezin. Doubts and feelings of guilt arose because of the difficult and complex care track Sien went through. By 2013, Sien became completely deaf and was fitted with a cochlear implant by the age of 11 years old. During the last interview, the third child seemed to pass the hearing test just fine, and Sien was in the middle of an educational problem in secondary school because of the supposed consequences of her disabled hearing.

The analysis of the three semi-structured interviews with Sien and her family was initially guided by emergent listening and described by making use of the critical incident technique (CIT) (see also Flanagan, 1954). Emergent listening as conceived by Davis (2014) is not a method but merely an ethical practise, idea and ideal of attending to difference. It is slow, ethical listening that challenges scholars to overcome safe reflexivity and to dwell in the space of openness to the world; the space and pause between one and another. It works with the self that emerges in the encounter of listening beyond already known categories and knowledge: the 'listening-as-usual'. Following Nancy's (2007) delineation of listening and Deleuze's (Pearson, 1999) thoughts on the self, Davies (2014) emphasises the need to listen with all senses and to consider ourselves as moving, dynamic and always involving the potential of transformation or creative evolution. But most of all, it presupposes a willingness to suspend judgment based on existing knowledge. The concept of emergent listening fits well with Tronto's (2013) view on studying people's interdependence through the way we organise our care institutions, such as early interventions for families with deaf

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[8] Preventive health care for families with young children in Flanders is in the hands of Kind & Gezin, (Child & Family), the government organisation responsible for preventive neonatal health care and infant and toddler consultation schemes. At present, Kind & Gezin offers home visits and infant consultations in 342 local centres in the Flemish community of Belgium. They introduced general screening for hearing loss in infants in 1999.

children. The only appropriate way to do this is through widely diverse democratic dialogues of agreeing and disagreeing.

As Tamboukou (2013) analysed Foucault’s resistance towards one clear-cut methodological approach of research data, we do not pretend to have had just one static method for the secondary data analysis of Sien’s narrative. Yet, the basic principles of Critical Incident Analysis came close to what we were intending to do: give voice to care receivers, conceptualise difference or otherness as central, keep reasonable distance from theoretical frameworks and identify gaps or hidden biases in the borders between formal and informal care for a deaf girl. By means of a critical incident analysis, we sought insight into how and why Sien and her family engaged in certain care activities. CIT is an effective and explorative tool in qualitative research methods that facilitates the investigation of significant occurrences, such as events, incidents and processes. The purpose is to gain insight into the experiences of the individuals taking into account cognitive, affective and behavioural elements (Chell, 2004).

In the Results section, we describe these critical incidents that we identified through multiple readings of Sien’s story (see also Goodly & Runswick-Cole, 2012).

5.4 Results

5.4.1 Resistance to prescribed tests and a definitive diagnosis

Shortly after her birth, the hearing test of Kind & Gezin showed that Sien might have hearing problems but certainty was not guaranteed. Her parents were referred to an ear, nose and throat specialist (ENT) at a local hospital for an supplementary test, preferably fully anaesthetised, but her mother refused to let her baby to be anaesthetised for a hearing test. Ultimately, the test was executed without narcosis, but the results were inconclusive. As a consequence, there were doubts but no real diagnosis. The parents were convinced that their baby hears. Sien grew up like any other child and disappeared from the monitoring track for deaf and hearing-impaired children as organised by Kind & Gezin. No further steps were taken to shed light on this matter, but her parents continued to hesitate while not expressing their concerns.

5.4.2 From hearing impairment towards deafness

At the age of three, Sien entered preschool. Her parents were informed that there were some problems with Sien's hearing and communicative development compared to pupils her same age. Feelings of guilt arose and from then onwards her parents followed the suggested care track. This time, the BERA test was actually performed and indicated that their daughter was hearing impaired and could be supported with hearing aids. Years of intensive rehabilitation and home-based early intervention followed, and Sien was submerged in oral language courses with Dutch as her mother tongue. Her parents supported her within and outside the family and meticulously followed all professional recommendations. Her mother had an especially troubled conscience because of the late interventions and the consequences for the further development of Sien. Moreover, she found it hard to come to terms with the label 'child with a disability' and the visibility of the hearing aids on the small face of her daughter. She kept hoping that the problem could be solved with an implant, but this was impossible; Sien did not meet the medical conditions. Her residual hearing was sufficient to continue to rely on hearing aids instead of a severe operation. Her father turned his daughter into a project and built a special computer to support her as much as possible. He was annoyed about the way the care system for hearing impaired children was organised and entered discussions at the school gate. Many parents had to deal with the remark that their child did not belong in the ordinary school. Also, they could not believe that the financial costs for extra colours for the hearing aids were not refunded. Standardly, people received brown ear pieces, which of course did not meet the preferences of a female teenager. Even Sien's brother made remarks at the beginning of the fitting with hearing aids about those 'dirty brown' ones. During her primary school years, Sien's parents made use of the limited support for integrated education that was allocated to them (two hours of support every two weeks, which was open for negotiation), but the parents asked for more support. Sien received training and coaching, performed well at school and was described as an easy and happy child with a strong will. During primary school years, her hearing gradually got worse and by the fifth year she was completely deaf, which meant that she was at last eligible for a cochlear implant (CI). The whole admission procedure for recognition, execution and refunding was started. Again, this involved an overload of medical and psychosocial tests and the fulfilment of administrative obligations. Her parents appreciated the support from the rehabilitation centre, and the family participated in activities and information sessions for families with deaf and hearing impaired children. The parents showed much respect and recognition for medical and professional expertise. Sien did not obtain an official diploma for her primary school career, because she was excused from the French courses and did not follow the sixth year. Consequently, she was referred to vocational education, which envisages specific job training instead of more generic skills. The diagnosis of deafness and the CI changed the attention from the environment to the package of multidisciplinary support. Sien and her family were more frequently invited to participate in research projects, the financial resources grew and the support for integrated education increased from two hours to four hours each week. The parents were grateful for the extra attention and support. By the end of primary school, Sien received, apart from the ordinary school work, eight hours of professional support a week.

5.4.3 A private message during childhood: you are unique!

Sien belongs to a family with three children, of which she is the second. The two other children are hearing. They have many animals (dogs, birds, rodents etc.), which are considered as members of the family. The family lives in a small row house and are rather poorly off. The mother works as a child care worker in a local preschool. The father is disabled because of an industrial accident. Since the diagnosis of impaired hearing, the parents told their other two children that Sien was not ‘abnormal’ or ‘disabled’. On the contrary, she was a unique person, because she had something extra which other children lack. The CI has reinforced this attitude and is almost treated as a gift. Sien is proud of it and makes her CI visible by all kinds of accessories and uses it to her advantage. She immediately tells peers that she is deaf and that they should show some consideration for her and talk more clearly. She likes it when they ask questions about her condition and enjoys the special attention she receives. When she does not feel like listening or when she has a headache, she switches her devices off. At school, on the other hand, she does not want to be treated in a special manner but wants to integrate in her peer group and be like all other pupils. She considers the hours of support for integrated education as ‘more of the same’. She especially hates when she is taken out of the classroom, when she must practise on her own with an external coach and when her friends ask questions about this. Increasingly, Sien uses her own voice to make clear that it is too much of a good thing and especially asks to let her do more things by herself.

5.4.4 A public message for the future: is she safe for children?!

The transition from primary to secondary school was accompanied by radical changes in her personal condition. Communicating with others became more difficult because of her increasing hearing loss, listening to music became harder and her hearing devices had to be replaced more frequently. Sometimes she had the impression she heard better, but on other occasions, she seemed to hear less. Her mother discussed elaborately the disbelief of the E.N.T. doctors concerning the varying experiences of Sien. Her gratitude was immense when she found a doctor who believed her story and gave her more information about her medical condition called ‘auditory neuropathy’. The operation for the CI, which took place during the fifth year of primary school, was a shocking experience that put pressure on the whole family and the school career of Sien. She had to repeat this fifth year but did not follow the sixth year. Learning a foreign language, such as French, in a school environment is difficult for deaf children. Alternative tracks are being traced to meet the minimal standards. Also, Sien’s results for French were not taken into account for her final results. Her parents regretted that she had not obtained her primary school degree, but this was also due to the medical-technological intervention being delayed until when Sien became 12 years old. Because of the intensive training during her childhood (in a professional context as well as in the family), Sien speaks Dutch fluently and developed a rich vocabulary. Moreover, when she was about 12 years old, she seemed to have made herself familiar with the West-Flemish dialect and has taught herself some basic knowledge of Flemish sign language, which she uses as an extra asset for social contact with hearing peers. She reads a lot, which in her opinion can only lead to a more elaborate vocabulary. Having a deaf child would not make her sad (‘you should be happy’), but she would immediately appeal to a rehabilitation centre (‘to learn to speak better’). This teenage girl follows her parent’s choices, but she protests the way education is organised and is against the fact that others make decisions instead of her. The 13-year-old Sien clearly wants to become a child care worker, and she is happy with the transition to vocational education. She gets good results in school but wishes to have less coaching. Often it is said that she will struggle with a ‘caring role’, but she does not agree. From time to time, she lends a hand in the preschool where her mother works. Because of this, she acquired a taste for caring for children. She also helps her father with his hobby, organising shows with birds of prey (e.g., during meeting days for deaf children, in a health care centre for elderly people and so on). In close consultation with the school, the coach for integrated education looks for a trainee post where Sien can work within a couple of years.

Again, they are told that this is going to be extremely difficult because organisations will hesitate while being confronted with Sien’s ‘handicap’. According to her coach, working with children is almost excluded, because the educational system assumes that the safety of the children cannot be guaranteed. On the other hand, care for elderly people could be taken into consideration, but Sien is not interested at all in this kind of work. Her parents strive for a balance between care for their child, the expectations of school and the demands of a potential labour market.

5.5 Conclusion

This narrative raises questions about the balance between formal and informal care-related ideas and choices in the private and public domain of care for deaf children. The importance of giving voice to care receivers became clear in earlier phases of the project (Authors own, 2012; 2018) and was confirmed once more in this in-depth study. It deals with the private, the intimate, the personal and the public politics of a *healthy and inclusive society.* In this paper, we intended to connect the concrete and private experiences of a family to the public duties in care and education in (Flemish) society. This attempt is not without risk since descriptions of particularity or subjective implication can seem futile. On the other hand, accounts of social responsibility can raise doubts and critiques about the abstract or unfeasible nature. Yet, both accounts are contingent and should be considered if we are willing to take up responsibilities in good care and education and redistribution of rights for deaf children and families.

In the following overview, we summarise the central ideas of Sien’s case. Throughout the analysis of the different sides of her care track, we constructed the concepts of authentic voices and disturbing noises in care and education for a deaf child. Authentic voice can be considered as an enabling power for good care and education, whereas disturbing noise risks to create disabling effects. This conceptualisation of voice and noise should not be read as dichotomised categories but as evolving life occurrences containing the potentiality to either limit or motivate people's participation in care.

Authentic voices	**Disturbing noises**
Resistance to procedure of early hearing test	Disappears out of formal care and follow-up
Insecurity and feelings of guilt	Problem of speech and language development are mentioned at school
Recognition and appreciation of medical and pedagogical expertise	Train and practise! Formal care enters lifeworld
Negotiation about content and amount of educational support. Investment in more of the same?	Claims on free space and play time
Search for unique personal development and capability to care	Prediction and implicit messages of possible failure in education and at future labour market

Referring again to Tronto’s (2013) account of eliminating bureaucratic blockages in the way we organise our social practises, we underline the need to trace hidden biases in care. Throughout this endeavour, the engagement of voices of care givers becomes crucial. In this story, the institutional thresholds that limit the coordination and harmonisation of people’s care needs becomes clear. We do not proclaim that actual care for (Flemish) deaf children is not equal to good care. Nevertheless, we question the consequences of specific choices in the care tracks of deaf children that are not aligned with pre-structured and protocoled care paths. Social policy remains to rely on ableist principles, but the arguments to defend these strategies are often masked in public messages of autonomy, personal strengths, resilience and individual responsibility. Not intervening or resistance towards the prescribed care, rehabilitation or educational standards becomes equated with not being responsible as a parent or child or not willing to take responsibility in the private sphere (Authors own, 2012). Sien’s case suggests that the disturbing noises limit future possibilities of adolescents and may not increase young citizens’ engagement in democratic policy. Signs of cooperation for improving our democratic institutions can be found in significant moments of particular resistance.

We summarise three significant moments of Sien's story and relate these to some main ideas of Tronto's caring democracy (2013). In our interpretation, this is a normative choice for an ethical and relational position of shared responsibility of both care givers and care receivers. Tackling a lack of shared responsibility in formal and informal care could be a vital key for bridging gaps in fragmented care activities.

The first moment is the initial refusal of Sien's parents to having their baby anesthetised. This could be interpreted as moments of using parental freedom and responsibility in the context of informal care. However, the consequence of this choice is that they excluded themselves out of formal care and rehabilitation. A question that remains unanswered is that whether professionals should have informed this family more accurately or could have been more convincing in pointing to the importance and value of the early hearing screening? Initially, there was no parental recognition of a possible developmental problem, which implies that there was no demand for professional care. According to the policy of Kind & Gezin, a positive result on the hearing test implies that soon after a clear diagnosis, hearing aids will be adjusted and an intensive process of rehabilitation and audiological training will start. For most (hearing) parents with a baby with hearing loss, this is a very intense period of insecurity and hard work. It puts pressure on parenthood and turns the first interactions with a new born into a vulnerable and uncertain endeavour (Authors' own, 2012). On the other hand, Sien evolves like any other child during the first three years of her life and freedom is safeguarded. This phase points to the importance of continuing the democratic dialogue of aligning caring needs and caring means (Tronto, 2013). It illustrates a relational tension between the readiness for care receiving and the possible resistance towards intrusive interventions, even without questioning responsibility issues.

The second critical incident that challenges the balance of care is when problems of insufficient language development are signalled by the Sien's school. Her parents are distressed by these messages, and they feel guilty about the late detection of the hearing loss and apparent consequences of these choices. Pedagogical and medical reasoning enters family life and Sien's parents invest in consequent follow-up of professional advice. They train, practise inside and outside the house, with and without the assistance of special educators, care at home professionals and speech therapists. This doesn't differ too much from other families with a deaf or hard of hearing child. Formal care enters family life without a real question for assistance. Deaf children today are often capable of reading before they enter preschool! Playtime, however, risks to be forgotten or neglected, and these children work before they even have the chance to play and learn. Freedom of choice and the amount of support and assistance in class is dependent on the initial diagnosis and is less intensive for hard of hearing children in comparison to deaf children. Hard of hearing children who are integrated in regular education receive two hours of support from a special educator a week. Deaf children can ask for four hours of support a week. In what seems a fair distribution of resources, mechanisms of the market come into play. These are not always aligned with the social-pedagogical implications of medical and technological interventions in deaf children. In the case of Sien, there was a period of parental demands for more hours of support when the diagnosis of hearing loss was set. Once she became completely deaf and received a CI, the supplementary hours of support were automatically assigned. This was accepted with gratitude from the parent's point of view, although in Sien's perception, this wasn't always useful and especially too much to handle or felt like an overdose of work. We are obliged to interrogate the reasonable distribution of available resources in education for deaf and hard of hearing children. Educational policy is not always efficient in recognising the real needs of care receivers and their translation into adequate care and education. In this phase, the importance of reducing power differentials and their effects on people becomes visible (Tronto, 2013). A commitment to genuine equality of voice in care relations should not be translated in prescriptions of standardised protocols.

A third significant moment can be found in the authentic voice of Sien. She demonstrates vibrant signs about the way she wants to construct her personal development. In the current debate on the mechanisms at play in transitions of community care and informal care, more emphasis is put on care receivers' own strengths and on a truthful cooperation and communication between formal and informal caregivers (Kelders et al., 2016). Considering Sien's voice, we question the neglect of her demand to become more independent of professional support and her ability to negotiate about the proper amount of supplementary assistance she needs in school. We could say that participation of this deaf teenager in co-constructing and possible modification of the formal care track is limited. A package of multidisciplinary support is offered to deaf children and they must take this as it is. It implies a constant violence of the necessary free space of young people. The formal labelling of the 'disabled child' continued to haunt this family and was confirmed by professional messages about possible failure in school and on the future labour market. An extra eight hours to invest in 'more of the same' cannot necessarily be considered as good care or good education. Neither is the implicit message of endangering the safety of toddlers because of Sien's hearing difference supportive for the hope in a just, equal and inclusive society. Sien is very respectful towards her parents and by no means would she like to undermine the opportunities and chances her parents created. Because of the CI, the world became a brighter place, she could hear music, social relationships with friends and family became richer and she presented herself as a young confident girl, an entrepreneurial spirit with lust for life. During the procedure to become eligible for a CI, she laughed with the strange psycho-social intake questions and instead tried to comfort her mother who was very insecure about the upcoming operation. According to the ways we interpret Tronto's main ideas (2013), these signs of interdependent care activities provide additional evidence for the relational, transgenerational and vulnerable nature of human care. At the same time, it contains a social political dimension of care, which permeates everyday life through enhancing or restricting mechanisms of participation.

A comprehensive and sustainable view on a caring democracy presupposes a true concern for education with an explicit emphasis on the complexity of values, norms and ideals that people adhere to. If we are willing to contribute to this pursuit, we must generate additional efforts on the level of a participative and inclusive social policy. Scepticism and social inequality persist if we do not align caring needs with caring means, and executive professionals will continue to yell in the desert and will beg for more freedom to act. We conclude with a slightly modified statement of Hanna Arendt's (1954) maxim:

> *Education and care are the points at which we decide whether we love the world enough to assume shared responsibility for it*.

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CHAPTER 6

Conclusion

The central aim of this study was to investigate the different ways in which early intervention practices for families with deaf children are justified. Starting from the indispensable value of parents' narratives, we soon recognized the ambiguous nature of the common grounds for the early screening practices in primary health care. Moreover, the (often unintended) side effects of this pre-diagnostic act in deaf babies was seldom explored and the impact of these merely technical and medical procedures on family life were not extensively documented (with the noticeable exception of the work of Timmermans, Buchbinder and Grob, e.g. 2010,2013,2018). We were urged to question the arrangement of our discourses and the inviolability of professional expertise (Davis, 2013). Screening *is* intervening and triggers a whole set of possible interdependencies across parents' and children's lifespan. In what follows, results and reflections on the different phases of our study can be read as a multi-perspective concern for participative interventions in early childhood (deafness).

6.1 Parents: acknowledge intertwined voices

We were straight forward in our assertion of the importance of including the voices of parents who experienced the consequences of rapid and medicalised investigation of their child. While doing so, we distanced this study from ongoing discussions about a non-life-threatening condition in children who are categorized as belonging to a group of children with disabilities or to a linguistic cultural minority. We still have not determined in what paradigmatic or conceptual framework these children can be situated. Determining the barriers and connections between their need for support and organisational and societal demands in health and normalcy, kept this search going. This type of investigation is not an obvious one. The *why-questions* that are included in this study easily generate suspicion or doubts that we are *against* technological innovation, efficiency in social and medical interventions and in enhancement strategies. We do position our work in a moderate-critical framework of resistance to truth-claims which lead to categorising, labelling or determining how people *should* live and act and in what ways they should comply with unfounded norms and rules. The implicit normativity of categorisation permeates family lives of deaf children and this is what we illuminated. The tension between genetic determinism on the one hand and the influence of environmental factors, as well as faith or destiny on the other, is a much discussed and analysed topic in the social and pedagogical sciences (Koops et al., 2010). Most human conditions are multifactorial: the result of interaction of (and between) genes and environmental influences. The risk of having an illness-related predisposition is often translated into a certainty that the negative consequences of this condition will certainly prevail as this is the case for congenital deafness in children. Risk is not the same as certainty so, adjustments in lifestyle and behaviour could alter the chance that unwanted effects will occur. Discipline and perseverance play an important role in this balancing exercise. Parents with deaf children are confronted with difficult choices and this immediately from the start of their baby's life and at the beginning of parenthood with a new-born. Social constructions of *the good parent* and of *the good child* put pressure on the decision-making process in health and education and direct parents towards complying with a prescribed path of sameness in children's abilities and in parents' equal capacities of raising a child.

In this study, we demonstrated the tension between institutional demands and expectations and individual experiences of parents in different formal and informal settings. It became clear that parents were actively and passively involved in the construction of their parental role which was linked to the situation of having a baby whose condition differs from an average and preferable state of health. Yet, once the objective standards were set in terms of diagnosis and possible treatment, the prerequisites for receiving further support and guidance of the child were formulated in terms of individual responsibilities and actions. Those who did not conform to the proposed interventions, were likely to be forgotten, not listened to or denied follow-up and advice. By the current possibilities of altering deaf children's hearing condition, parents were rushed and pushed towards invasive medical and pedagogical treatment that was meant to restore perceived deficiencies in their babies. A sudden awareness of the lack of reciprocity in the relationship between the child and the parent at the earliest stage of possible bonding was something which was much underestimated in the professional recommendations. Objectification of their child as a deaf child turned on a conflicting shift between the hope to be heard as a parent and the fear of having to recognize an impaired state of being. An overwhelming amount of information and new technological possibilities interrupted the feelings of becoming a parent. The velocity of the construction of parenthood with a deaf child resulted in disabling spaces hindering intimate and social interactions but most of all, a prominent lack of time to sit back and to reflect on existential questions. In the case of raising a deaf child, one of the most apparent lacunas seem to be the absence of a bridging person with specific communication qualities or a professional who could be present at times when parents have to deal with overwhelming (medical and pedagogical) information or troubled feelings and experiences. Making these individual needs in human care visible and explicit is not only an act of connecting to the concrete lifeworld of people. It would exemplify flexibility and willingness of professional interventions to diminish physical, organisational, social, emotional, cultural and psychological barriers that parents may experience in the course of their attempts to become a good parent for their child. Unexpected questions and ambiguity in lived lives from parents with deaf children point especially to the unintended effects of time pressure and of unpredictable outcomes in social pedagogical practices (Archbold, 2013). Making these practices transparent on a relational and on a structural level is what could bridge the gaps between social and medical workers and of all the in-between professions and would certainly be more respectful to the intertwined voices of parents with specific vulnerabilities in relation to their deaf child (Vandekinderen et al., 2018). Parents of deaf children are crucial informal carers who are engaged in a complex and ongoing educational process which consists of much more than an instant follow up on proposed treatment or cure of their child.

6.2 Policy: risk discourse and the exclusion of otherness

Because neonatal hearing screening now impacts so rapidly on constructions of parenting and on the educational process, we had to go back in time to understand the socio-historical meaning of these national preventive strategies of the child health care organisation in Flanders. Since the late nineteen seventies, Kind & Gezin has clearly invested a lot of means and efforts in managing and organising the hearing test at the national level. Legitimacy for these populations screening strategies of congenital disorders in children could be found in guidelines issued by the World Health Organisation (WHO). The health of its children is taken to be essential for a healthy and flourishing society at whatever stage of development the society has achieved. Investment in their healthy growth and development is therefore described as a proper, indeed a mandatory concern for all welfare states. Population screening programmes are translated into national policies in order to prevent congenital disorders which are considered as having serious consequences both for the individual and for society. Kind & Gezin was amongst the first to experiment with and generalise screening for deafness in neonates. They translated the WHO-recommendations for identification of congenital hearing loss and 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 (WHO report 1999, Grandori & Lutman, 1998). Furthermore, since approximately one to two children per 1000 births are born with a substantial degree of bilateral hearing loss, this is considered one of the commonest congenital disorders (Declau et al.2008, Kerschner 2004; Van Kerschaver et al.2007). The seriousness of the condition being screened for remains an important argument for the national health care policy and for its' continuous investment in early detection techniques. The risk described in the WHO reports are meticulously interpreted as a green card for quick and efficient action in primary healthcare. What then is this specific health problem in deaf children? The in-between-the line- interpretations of hundreds of documents of Kind & Gezin demonstrated that it was not the physical fact of deafness as such that was considered the most endangering for children's development. Rather, the main problem was the socio-economic consequences of this condition for both parent's and children's integration in society according to general standards of normalcy and wellbeing. It is argued that non-intervention would inevitably leave permanent traces on the child's identity and on parental competence and trust in raising a deaf child. The pervasive emphasis on oral language acquisition by deaf children and their consequent development of 'proper' social skills seems to take for granted that complete personhood implies speech and participation in a hearing world (Valente, 2011). Scope for human judgement and agency seem to be further reduced by limitless faith in technological possibilities, by a science-centred morality, presented as self-evident. All of this ignores or greatly, underestimates the possible coercive effects on families with deaf children. With ever-expanding new born screening possibilities we are creating what Grob (2008) describes as an ever-larger group of parents who are confronted with at-birth diagnosis of a seemingly healthy child and with examples of how risk discourse can structure human experience while excluding otherness.

The terminology used in the policy documents of Kind & Gezin fluctuated and changed over time, although the arguments for legitimizing the ever-earlier interference in the deaf child's life remained the same. Moreover, re-evaluation of the justification grounds for early hearing screening in the light of evolving technological and medical options were not considered. The earlier we can intervene, the better (at 4 to 6 weeks instead of at the age of 9 months). Objective measurement by machine generated knowledge is preferred above human and subjective interpretation ('refer' or 'pass' protocols instead of a nuanced communication of possibly impaired hearing). Medicalized and quick solutions exceed expectations. Outcomes with profoundly deaf children are so remarkable that bio-ethical or social pedagogical concerns are tacitly pushed back. These 'secondary concerns' can be left to other professions or referral organisations which should assume responsibility for the relational and socio-emotional aspects for the child's development. One could say that the attempts at 'curing' deafness in children came at the expense of 'deafening' multiple voices in parents' and children's' experiences. Labelling, categorisation and stigmatising terminology go hand in hand with truth claims. Predictions of probable social exclusion of deaf children, if they are not prepared to accept intensive testing and treatment, became generalized to a single all-encompassing judgement. The presupposition is that correcting deficiencies of individual human beings makes better citizens for society. It is at least remarkable (perhaps shocking) that the perspective and voice of advocacy groups and of the deaf community is entirely lacking in the policy decisions on this issue. Parents as well as the professionals involved risk becoming passive players in national strategic plans which involve actively seeking out children that might be missed. Illustrative for this tension are the words of Demeulder (2013) who wrote to the head of the medical department of the child healthcare organisation: […] 'Not that long ago, your own Algo test resulted in the word "fail" (nowadays this has been changed to "refer"). "Fail"! What a great start in children's lives' (De Meulder, 2013,3).

The social problem is situated in the failure of the child healthcare policy to acknowledge the complex interrelations involved or to bridge the gaps between professional and parental discretion. This thesis could contribute to conceptual development, for example in relation to the importance of current uncertainties in terms of both felt experience and knowledge of the condition being screened for (Gillespie 2012; Timmermans and Buchbinder 2012; Verhaeghe 2009). Furthermore, in current reports of the WHO, more and more attention is dedicated to social inequality in access to primary healthcare and to critical concerns for a globalised market of welfare and happiness (Chan, 2008). Since identical procedures and protocols of the new born hearing test are now being duplicated in screening of all Flemish babies for lazy eyes, and neonatal screening for obesity in babies is under consideration, there is surely a need for further investigation of the scope for human voices at the crossroad of health and lifeworld.

6.3 Children: to connect and to disconnect as unfinalized expressions of agency

Freedom to decide when and where to belong is wat connects (deaf) children. If they present themselves as hearing or deaf, they decide when, where and why they do so. Deaf children resist unitary and essentialist identity constructions which positions them in areas they do not recognize or feel familiar with in their lives. They depend on assistance or guidance from technical, professional or parental involvement if this brings them closer to participation in wider social encounters. We should not interpret children's relationships to their technological aids and to their parents or caring professionals in terms solely of overcoming physical impairments or transforming the child's fundamental nature. From birth, these children became familiar with technological accessories which support their capability to interact with others. Without these artificial aids, they remain in a world of silence; leaving aside any value-laden judgement of this embodied experience. Being like other boys and girls is what preoccupies most children. Since most deaf children are born to hearing parents, parents lack the acquaintance with a culture of deafness, or with other linguistic modalities, which would enable them to recognize possible added value to their life course. Moreover, because of children's intensive training and practice into the world of oral language and speech, they became integrated in regular education in which there is no room for exuberant deviance from a prescribed path of cognitive learning and educational development. Once they leave these spaces of predefined expectations, their sensory difference becomes more apparent. Playgrounds, swimming pools, separated classrooms and noisy environments are challenging for their ability to participate in social interactions with peers. Then they must explain or pay additional attention to their different perception of sound. Mostly they are creative in adapting to their technological devices. Asking to position themselves in one world or another only suggests a dichotomized split that fails to reflect the complexity of the children's sense of self. Parents add to this complexity by assigning specific qualities to their children's behaviour. They colour and shape children's voices by the words, expectations, doubts, sentiments and interactions used at home. Because from birth they were obliged to train, practice and rehabilitate, their experience of childhood is determined by these additional obligations and by a sense of it being hard work. By the time they arrive in secondary school, it seems that they need more free space to act and decide for themselves. They then express their agency in flexible ways by choosing to connect or to disconnect from external stimuli and sounds, by enacting sameness or difference as means of participating in changing social situations. It is an ongoing endeavour within developing bodies and an evolving social and cultural lifeworld.

In this study, we have not evaluated efficacy and efficiency of the early hearing screening or the value of technological assistive devices such as sophisticated hearing aids or the success stories of early cochlear implantation in children.

Other scholars in different disciplines have already carried out valuable large-scale investigations which provide us with comprehensive data on outcomes of early implanted deaf children (Archbold, 2010; De Raeve and Wouters, 2013; De Raeve and Hardeveld, 2013; Marschark and Hauser, 2008). These (mostly quantitative) results should be discussed together with insights coming from specific case studies such as our in-depth study of a sample of (hearing) families and deaf children. This open research method illuminates much that remains concealed or implicitly hidden underneath evidence-based interventions that are presented as the only just solution to the problems deaf children face. A multi-perspective and interdisciplinary approach to appropriate care for deaf children and families shows the limitations of relying exclusively on medical notions of evidence (Hoogsteyns and Van der Horst, 2013). We have been balancing in the borders between parental and professional influences, between uniform medical and social pedagogical practices and deaf children's interpretation of the situation. It is within and in between these boundaries that social problems often remain underexplored. Critiques and questions about deaf children's development are easily linked to parents' responsibilities and pedagogical efforts, and rarely to the limitations or negative consequences of early intervention and technological progress. *Speed parenting* and *speed learning* could be a summative statement for the experiences of parents and children within this Flemish case. The whole theme is related to the initial and fundamental question of how we (should) perceive the specificity of the deaf child at birth. Is this a disabled child, an incomplete child who is missing some necessary parts, or is it a child with a different birth right, a child with a different cultural and linguistic status? In the Flemish context, it became clear that the popular perspective of a personal tragedy prevails (Landsman, 2003). This sets in motion a series of enhancement strategies which become incorporated in parents' sense of (in)competence and children's experience of childhood. The problem is situated in the unquestioned evidence that *early* always implies *better*. This malleable child is offered the best possible treatment to comply to educational and social standards. The right and freedom to disconnect from the external pressure to conform is limit and makes real participation in care processes an underdeveloped objective.

Malleability of human beings also implies an ethical consideration of why, how and where we set the boundaries of early intervention services. The more possibilities in society to enhance the human body and mind, the more it becomes necessary to reflect on the accountability and responsibility of decision making in care. Where malleability exists, the question arises if those who make these options available and accessible should be held accountable for intervening, or for the limited choice between options which is typically offered. Especially in relation to parents and the postnatal choices on behalf of their child's health and wellbeing, this problem becomes even more complicated. Malleability implies decision making and should be based on comprehensive information and advice so parents can justify their choices to themselves and others, as having been freely made. What becomes interpreted as possible mistakes or wrong choices is also dependent on societal conceptions and political judgements, which of course evolve over time and differ from place to place (Sieburgh, 2010). The power of the majority can then appear as a preferable standard. Thus, so far as decision making in care for families with deaf children is concerned an apparent argument for choosing a single option which necessary excludes all other possibilities (e.g. deaf and disabled, hearing and normal, signing and different, speaking and integrated, screened and diagnosed, implanted and cured etc.) is rendered self-evident. Assuring freedom of choice for the individual is also a responsibility of the medical, paramedical and social professions. It would be beneficial if parents with deaf children were to receive more comprehensive information and a more eclectic view on ways towards the good life.

6.4 Society: shared responsibility in private and public spheres

During the last fifteen years, the importance of informal care is increasingly emphasized in most European welfare states and is subject to changes and shifts in the relations between care givers and care receivers and in policies intervening in those relationships (Eurocarers, 2017). The ways in which these contingent practices work ought to be justified and interrogated based on reciprocal democratic dialogues (Vandekinderen et.al.,2018). In the current debate on the mechanisms at play in transitions of community care and informal care, more emphasis is put on care receivers' own strengths and on a truthful cooperation and communication between formal and informal caregivers (Kelders et al., 2016). Within this view the importance of reducing power differentials and their effects on people becomes visible (Tronto,2013). Throughout this study we noticed signs of interdependent care activities which provide additional evidence for the relational, transgenerational and vulnerable nature of human care. At the same time, it demonstrated a social-political dimension of care that permeates the everyday through enhancing or restraining mechanisms of participation. Policies are not always efficient in identifying real needs and resources of care receivers and their translation into adequate care and education. People are not always capable of recognising restrictions to their caring role and may become too demanding or too passive in their expectations for public and professional support in the market of health and wellbeing. Intermediate care providers such as medical and paramedical professionals, care at home services, social workers, psychologists and educators, act and reflect within those spheres where the private and the public intersect. In early interventions for families with deaf children the intersectional harmonisation at stake can only be realised if the outdated debate on the private and the public split becomes resolved. These conceptual credos tend to maintain the *them* and *us* narratives which can only serve to discharge responsibilities to act in different contexts. Democratic and caring deficits go hand in hand (Biesta, 2007; Tronto, 2013, Van Laere, 2017). In societies in which increasing specialisation and technological progress seem to be the rule and in which diversity becomes the new *normal* (at least in promising words), bridging the gaps and boundaries between disciplines (especially between health-related and social-pedagogical professions) and between expert-knowledge-claims becomes even more of a challenge to guarantee equal distribution of social goods and responsibilities for individuals, groups and organisations (Davis, 2013; Fineman, 2010, Vandekinderen et.al., 2018).

Without underrating the accessibility to care for deaf children in Belgium, this thesis also underlines the need to consider and rethink mechanisms of the market that influence interrelations in deaf childhood. As demonstrated by Elias (1987) decades ago, blind mechanisms permeate public and private lives and construct figurations of social relations. These figurations are typified as waves and shifts in conditions of greater or lesser autonomy or *Selbstzwang,* as opposed to external pressure or *Fremdzwang* for individuals, groups and societies and which represent historical movements and assertions of civilisation (Elias, 1987). In the case of families with deaf children, medical, social and pedagogical interventions are currently preoccupied with the limitless and instant potential of science and technology. They offer public images of the deaf child overcoming his or her deficiencies by nature; equipped with the necessary tools and services to become an active, autonomous and integrated citizen of society. Underneath and across these stepping-stones towards the best of all worlds, complex social processes restructure the work of parenting. New figurations of interdependency between the child, the family and the environment are constructed, which the screening, diagnostic and habilitative acts only serve to initiate (Charmaz,1991). Making these acts and mechanisms explicit could reveal something of a more general interest in western societies. Policies and professional organisations tend to intervene more profoundly and earlier in health, welfare and education of children, while efforts are justified by declaring the creation of optimal conditions for an independent, resilient and social life (De Winter, 2007). Yet, the ideal of the public deaf child is intermingled with dynamics of a consumer market which is no longer seen as threatening for independent child development but celebrated as an expression of freedom. Living rooms became filled with: technological hearing equipment, more sophisticated, colourful and smaller earpieces, different brands of batteries and implants, allocation and reimbursement forms for one or two ears, school documents for more or less hours of inclusive support, etc. These instrumental guidelines are presented and managed in medical and educational surroundings and appeal to parental involvement, insisting that they invest in the best possible care for their deaf children. The negotiating family as gatekeeper and breeding ground for individual and civic/civilized values is equally engaged in business-oriented prerogatives which makes the educational role of parents with deaf children challenging and multi-layered.

Individuals, organisations and societies should be thoughtful of caring and educational practices that tend to erase or diminish shared responsibilities, reducing them to unidimensional rationality, bureaucratic protocols and predictable scientific certainty (see also, De Vlieghere & Roose, 2017). The way in which we *should* or *could* live our lives is subject to ethical, social, historical, cultural and political considerations of what makes a human life meaningful as tentatively described here for families with deaf children. Possibilities exceed expectations and scarcely point to limits of human brains and technological advancement. Ears, eyes, noses, brains, bones, skins, hearts, genes etc. are malleable by partial interventions that could alter the undesirable effects of not complying to a mean standard of healthy and flourishing human functioning. The way in which we deal with the (often) unpredictable and uncertain consequences of fracturing our bodily and social discretion illuminates human strengths and vulnerabilities.

6.5 An epilogue

Envisaging a future of imperfection is seldom appealing to actors navigating between the temptations of human enhancement and the attraction of existential slowness (Sloterdijk, 2011). How good it might be to remain silent sometimes and to disconnect from disturbing noises? Not having to hear, to speak, to argue or to convince; to only observe, share and witness what life amidst others can offer? In the case of intervening in deaf children's lives these questions are typically ethical in nature and could be complemented with insights from social pedagogical studies and disability studies. As Shakespeare (2014) states: 'It is not entirely clear what normal functioning actually is. If a species norm is used as a normative criterium to distinguish morally acceptable interventions, discriminatory use of the normal/abnormal frame could thus be reinforced' (Shakespeare, 2014, 13). Yet, these accepted norms are prepared, moulded and lived through in concrete social pedagogical acts of people and are institutionalised and temporarily fixed as frameworks for dancing on the thin line between care and control.

With a global goal of reducing child mortality and identifying infants with treatable congenital diseases such as hearing-loss, the World Health Organisation underlines the benefits of early screening programmes whilst also inviting nation states to consider the bio-psycho-social character of human functioning (WHO, 2018). However, in recent outlines on the impact of hearing loss in children we were astonished by the terminology still used to determine a kind of lifelong sentence for the non-screened and non-treated child:

> *'A child who struggles to hear may also struggle to speak, underachieve at school and end up socially isolated […] But this doesn't have to happen. We have a range of tools to help prevent, detect and treat childhood hearing loss […] Hearing screening programmes can dramatically improve the lives of children […] such as programmes to ensure that those in need of specialized care receive the interventions they need to be able to communicate, receive education and gain employment later in life.'* (WHO, 2018:1-2, italics add by author)

We were familiar with these causal deductions as we have found more or less identical ones in the documents of the national child healthcare organisation in Flanders of almost fifty years ago. Nevertheless, in finalising this dissertation we have been alarmed once more by these recent public reiterations of claims which only generate additional questions concerning (unintended) consequences of screening and subsequent follow up for non-life-threatening childhood conditions for which there is no straightforward or inclusive plan of action (e.g. autism, attention deficit disorders, obesity in children, cognitive malfunctioning etc.). This is by no means to misjudge the undeniable benefits of new born screening as a fruitful public health strategy, which can save lives and prevent severe disabilities as for example in the case of children with phenylketonuria (PKU) (Kelly et.al., 2016). Yet, even in this case of screening for PKU in the early years, risks caused by over-diagnoses and over-treatment are not diminished. For example, it is now acknowledged that some children with milder forms of the disease were put on a restrictive diet that was later recognized as unnecessary and potentially dangerous (Ross, 2010). In the case of conditions which are situated between health and lifestyle such as obesity in children, lines become blurred. Grob (2018) attends to the possible unanticipated consequences for children, parents and families in cases of true-positive screens for rare genetic conditions. As Tseng (2017) argued, governance in early childhood development is typified by medicalisation mechanisms that merely became risk-creation strategies. One of these strategies is that child development becomes publicly problematised and subject to individual surveillance. This implies that children are no longer considered as either normal or disabled. They end-up on a risk continuum in which adults and experts invest by persistent medical and social interventions (Tseng, 2017). Or, the number of patients (and thus also citizens) *in waiting* is rising dramatically, as Timmermans and Buchbinder (2010) put it.

In the light of these understandings, this study offers a striking example of these mechanisms and an invitation for further investigation. What is the value and what the applicability of the international classification of functioning, disability and health (ICF) (WHO, 2018) if environmental and socio-cultural influences are still reduced to trivial properties of individuals and societies at risk? Should we think globally to act locally or should it be the other way round? Is there a case to be made for reconsidering the distinctive claims of the different branches of knowledge as they bear on children’s development? Conceptual and scientific progress comes from focussing on upper and lower ends of the distribution of human characteristics. Inspiring questions in social-pedagogical research point to diverse pathways towards a human and temporary answer; thus, knowledge as perspective. ‘More than we already have done, still must be done’; appears to be an engaging statement of Sloterdijk (2011:261) quoting Seneca. The will to move on and the continuous drive to resist to indifference and ignorance will be our final remark.

6.6 References

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Nederlandstalige samenvatting

Het maakbare kind. Een sociaalpedagogische studie van vroegtijdige interventies in gezinnen met dove kinderen.

Sigrid Bosteels – oktober 2018.

Dit proefschrift wil een bijdrage leveren aan sociaalpedagogische studies waarin het spanningsveld tussen zorg en controle in gezinnen met een specifieke kwetsbaarheid wordt bestudeerd. We analyseren een case van doofheid bij jonge kinderen; een niet levensbedreigende conditie die vandaag wordt beschouwd als een ernstig en chronisch gezondheidsprobleem. Screening, snelheid, efficiëntie en een sterke gerichtheid op medisch-technologische innovatie en doel-rationeel handelen, doordringt het domein van vroege interventies bij (dove) kinderen. Minder aandacht gaat uit naar de sociaalhistorische context en de sociaalpedagogische implicaties van deze specifieke conditie voor kinderen en de gezinnen waarin zij opgroeien. We problematiseren de neutraliteit en unidimensionaliteit van actuele evidence-based praktijken. Het onderzoek brengt een meervoudig perspectief op vroegtijdige interventies bij kinderen waarbij de stem van rechtstreeks betrokkenen wordt gehoord en waarbij sociale constructies over de 'goede' ouder en het 'goede' kind in vraag worden gesteld. We miskennen de waarde van vroegdetectie en interventie bij dove kinderen niet. Wel nemen we in deze studie een kritische positie in ten aanzien van waarheidsclaims die kunnen leiden tot categorisering, labeling en directieven die voorschrijven hoe kinderen en ouders zich in een samenleving horen te gedragen.

Ouders

Het eerste deel van dit proefschrift geeft een stem aan de ouders die kort na de geboorte van een kind de boodschap kregen dat er mogelijk iets mis was met het gehoor van hun baby. De meervoudige interpretatie van hun ervaringen doorbreekt en bevraagt de succesverhalen van medisch en technologisch ingrijpen. Opvallend is de snelheid van het medisch-technisch interveniëren waardoor ouders, in relatie tot hun pasgeboren baby, in een roller-coaster van ervaringen belanden en tezelfdertijd de rol van co-therapeut moeten vervullen én van een aanwezige ouder. Dit kan belemmerend werken voor de intieme en sociale interactie, beperkt de ruimte voor existentiële vragen en zet het prille ouderschap van bij de start onder grote druk. Een overweldigende hoeveelheid informatie en een checklist van ingrijpende handelingsdirectieven om de conditie

van de baby te *herstellen*, stuurt elke interventie in de richting van het opnemen van individuele verantwoordelijkheid van ouders. Niet of aarzelend ingrijpen en het niet erkennen van de actuele mogelijkheden via: testing, gebruik van gehoorapparaten en cochleaire implantaten, multidisciplinaire revalidatie en een strikte training in spraakontwikkeling, kunnen ervaren worden als een oordeel over onverantwoord ouderlijk gedrag en als het hypothekeren van de toekomst van het kind. Objectiverende maatstaven die de blik en het handelen van ouders sturen in de richting van normatieve claims over normaliteit en conformiteit, hebben verstrekkende gevolgen voor een opvoedingsproces met een jong kind dat niet beantwoordt aan een gemiddelde norm van ‘normaal’ menselijk functioneren. Een opvallend hiaat in het traject dat ouders met een doof kind doorlopen, is het meestal ontbreken van een brugfiguur of een communicatieve professional die expertgrenzen overstijgt en aandacht heeft voor twijfel, onzekerheid en flexibiliteit in het proces van ouder-worden van een kind dat *anders* is dan verwacht.

Beleid

In een volgend hoofdstuk wordt aan de hand van archiefonderzoek, de introductie van de vroege gehoortest van Kind & Gezin onder de loep genomen. We beschrijven daarin de legitimeringen voor het invoeren van de test en we analyseren de onderliggende constructies over kind-zijn, doofheid en ouderschap. Neonatale screeningprogramma’s voor congenitale aandoeningen nemen wereldwijd toe en zijn gericht op het zo spoedig mogelijk identificeren van kinderen met een verhoogd risico op afwijkingen. Deze praktijken zijn niet neutraal en genereren bijkomende sociale en ethische vragen. Sinds het einde van de jaren zeventig werden in Vlaanderen door Kind & Gezin zeer grote inspanningen geleverd om de vroege gehoortest te standaardiseren en beschikbaar te stellen voor elke pasgeborene. Het organiseren van deze veralgemeende, preventieve gezondheidsstrategie en de continue investering van Kind & Gezin in vroege detectietechnieken, kunnen beschouwd worden als een consequente vertaling van de aanbevelingen vanuit de Wereldgezondheidsorganisatie. Een ernstige vorm van bilateraal gehoorverlies treft immers 1 tot 2 kinderen per 1000 geboortes en wordt beschouwd als een fundamenteel gezondheidsprobleem dat een efficiënte en effectieve screening op populatieniveau verantwoordt. De interpretatie van de archiefdocumenten van Kind & Gezin wijst uit dat het niet zozeer het fysisch defect is dat als problematisch wordt omschreven, dan wel de socio-economische consequenties van deze aandoening voor het kind en de ouders. Niet interveniëren wordt geassocieerd met het beschadigen van de identiteitsontwikkeling van het kind en met het vroegtijdig hypothekeren van een opvoedingsproces. Een alles overheersende klemtoon op spraakontwikkeling en een continu training van sociale vaardigheden bij dove kinderen, zouden een toegangsticket bieden voor integratie en volwaardige participatie in de (horende) samenleving. Het individuele beoordelingsvermogen en de handelingsbekwaamheid van ouders worden van bij de start in vraag gesteld en vervangen door een grenzeloos vertrouwen in medische en technologische mogelijkheden. De objectieve maatstaven en protocollen die bij de organisatie van de gehoortest ontwikkeld worden, nemen de plaats in van menselijke tussenkomst en interpretatie. We kunnen de vraag stellen of de inspanningen die actueel geleverd worden om een *defect* gehoor zo vroeg mogelijk op te sporen en te behandelen niet leiden tot het *verdoven* van de stem van ouders en kinderen. Het publieke belang dat impliciet wordt verdedigd bij het organiseren van de neonatale gehoorscreening in Vlaanderen is niet zozeer de kans om doofheid bij jonge kinderen te *genezen* maar eerder het normatief uitsluiten van verschil. Het sociale probleem situeert zich in het miskennen van complexe, intermenselijke relaties die een rol spelen in het zorgtraject met een doof kind. Zowel ouders als intermediaire professionelen dreigen passieve spelers te worden in een algemeen plan dat gericht is op de strikte opsporing en preventie van allerlei risico's bij jonge kinderen. De screeningsmethodes worden vandaag uitgebreid en ingezet voor andere bedreigingen zoals een lui-oog of obesitas bij kinderen, risico's die zich steeds meer situeren op de grens tussen gezondheid en levensstijl. Hierdoor ontstaat een steeds grotere groep ouders die kort na de geboorte, als gevolg van een pre-diagnostisch oordeel, geconfronteerd worden met onzekerheid, angst en twijfel over een schijnbaar gezonde baby. De vraag rijst of deze interventies geen toename van patiënten en burgers in *afwachting* doet ontstaan.

Kinderen

In een derde fase van ons onderzoek, gaven we ook een stem aan de kinderen zelf. Dit deel voegt een longitudinale component toe aan onze studie waarbij de betekenis en interpretatie over identiteit en zelfbepaling aan bod komen. Hoe presenteren dove en slechthorende kinderen zichzelf? Kort na de geboorte werden zij vertrouwd met het gebruik van technische hulpmiddelen zoals hoorapparaten en cochleaire implantaten en maakte dit integraal deel uit van wie ze zijn en wat ze verder worden. Van bij de prille start werden ze meegenomen in een intensief trainings- en revalidatietraject van taal- en spraakontwikkeling waardoor optimale interactie met de omgeving mogelijk wordt gemaakt. De jonge tieners waarmee wij in dialoog gingen, verzetten zich tegen essentialistische identiteitsconstructies. Zij gebruikten een creatieve en flexibele manier om met technische hulpmiddelen om te gaan en stelden zichzelf voor als doof of als horend afhankelijk van de context waarin ze zich bewegen. Daarbij kozen zij zelf wanneer, waar en waarom ze verwezen naar hun specifieke conditie die verschilt van horende kinderen. De expressie van gelijkenis of verschil was slechts een manier om in relatie te gaan. Voor sommigen was stilte geruststellend en werden indringende vragen over hun apparaten vermeden. Voor anderen kon de afwezigheid van geluid beangstigend zijn en werden vragen over hun beperkingen en mogelijkheden gewaardeerd. Wat hen onderling verbond, was de wens om gewoon zoals alle andere jongens en meisjes te zijn. In geen enkel geval drukten de kinderen een wens uit om meer in contact te komen met andere dove kinderen. Noch werden signalen gegeven die erop wijzen dat zij zich ergens in een soort tussenwereld zouden bevinden. Zij praten zoals anderen en het communiceren met gebaren maakt slechts een zeer beperkt deel uit van hun wereld. Een verlangen naar meer vrijheid en ruimte om zelf te beslissen waar, wanneer en bij wie zij horen, werd wel geuit. Het intensieve begeleidingstraject dat dove kinderen doorlopen, werd tegen het einde van de lagere school vaak ervaren als belastend en er werd meer getwijfeld over het nut van de extra ondersteuning op school. De complexiteit van ervaringen die dove kinderen uitdrukten, werd mee gevoed en gekleurd door de stem van ouders. In een gezin waar doofheid werd beschouwd als een persoonlijke tragedie, daar werden ervaringen van handicap en herstelgerichtheid gedeeld met kinderen. In een gezin waar doofheid gezien werd als een sensorieel verschil, een beleving van anders-zijn, daar werden ervaringen van flexibiliteit en onvoorspelbaarheid in een opvoedingsproces met een doof kind binnengebracht. Deze posities zijn niet statisch en veranderen onder invloed van medisch-technologische mogelijkheden en de manier hoe hierover in interactie wordt gegaan met ouders en kinderen. Door dove kinderen te beschouwen als betekenisgevers die in staat zijn een eigen mening te formuleren over wat bijdraagt aan hun welzijn en ontwikkeling, worden dominante wetenschappelijke discours over een voor-gedefinieerde status in vraag gesteld. Is dit een kind met een beperking, een onvolledig kind dat noodzakelijke functies mist, een kind met een verschillend geboorterecht, een kind met een andere culturele en linguïstische status, …? Zowel processen van in- als uitsluiting typeren de leefwereld van het dove kind en doorbreken vooral een uniform beeld van het gehandicapte kind dat ‘gered’ werd door tussenkomst van wetenschappelijke en technologische kennis en toepassingen. Het publieke beeld van het geïntegreerde dove kind dat zijn beperkingen heeft overwonnen, wordt vandaag verder gepopulariseerd en verspreid als een expressie van democratische zorg in de samenleving. Wij blijven deze tendensen in vraag stellen vanuit de erkenning van menselijke kwetsbaarheid, de betekenis van meerlagige identiteiten en het aanvaarden van onvoorspelbaarheid in zorgtrajecten.

Samenleving

In het laatste hoofdstuk verbinden we het particuliere verhaal van een doof meisje met het publieke discours over democratische zorg in een samenleving. Concrete en private ervaringen van een gezin met een doof kind worden verbonden met maatschappelijke verantwoordelijkheden in zorg en onderwijs. Deze fase schetst extra uitdagingen voor onderzoek naar mogelijke verbindingen tussen formele en informele zorg. Het gaat hierbij om betekenissen over het private, het intieme, het persoonlijke van een ondernemende en levenslustige dove tiener én over een publiek beleid dat mee vormgeeft aan een gezonde en inclusieve maatschappij. Beide invalshoeken moeten in rekening gebracht worden wanneer uitspraken gedaan worden over participatie en engagement van jongeren in een samenleving. Het verhaal van Sien is uniek in die zin dat haar zorgtraject enerzijds zeer sterk afwijkt van wat standaard wordt omschreven als het prototype van een succesvolle screening, medische interventie en sociaal-pedagogische begeleiding. Anderzijds, is het parcours dat zij doorloopt een voorbeeld van groot vertrouwen in technologie en professionele expertise en wordt dankbaar gebruik gemaakt van elke vorm van ondersteuning. Haar ouders balanceren tussen het verlenen van zorg en aandacht voor de *authentieke stem* van hun dochter en het omgaan met *storende ruis* die het opvoedingsproces en de schoolcarrière van Sien binnensluipt. Het belang van authentieke stemmen en/of storende ruis in zorgparcours worden niet als dichotome categorieën tegenover elkaar geplaatst. Wel bieden deze concepten een handvat om betere verbindingen tot stand te brengen tussen zorgverleners en zorgontvangers in sociaal-pedagogische praktijken. De noodzaak om bureaucratische en institutionele drempels in zorg en opvoeding van dove kinderen te elimineren wordt daarmee onderschreven. Het verhaal van Sien toont aan dat impliciete voorspellingen over mogelijk falen als gevolg van haar doofheid, de toekomstkansen in onderwijs en op de arbeidsmarkt bij voorbaat hypothekeren. Ondanks de eigenzinnige en flexibele houding van Sien zelf, haar zeer vloeiend en levendig taalgebruik en haar voorzichtige tekenen van verzet tegen een te hoge begeleidingsdruk, lijken de geboden kansen tot echte participatie vooral in de onderwijscontext onvoldoende te worden benut. Wil men jongeren engageren als betrokken burgers die mee vormgeven aan democratische zorginstituties dan staat er nog heel wat te gebeuren.

Het huidige debat over vermaatschappelijking van de zorg, legt steeds meer klemtoon op de eigen kracht van individuen en op de noodzaak om informele en formele zorg beter op elkaar af te stemmen. Toegepast op een zorg- en opvoedingstraject met dove kinderen impliceert dit dat ook barrières tussen het private en het publieke belang worden opgeheven. Intermediaire zorgverleners zoals medische en paramedische professionals, thuisbegeleiders, sociaal werkers, psychologen en onderwijskundigen, handelen in schemerzones waar het private, het publieke doorkruist en vice versa. Bij vroegtijdige interventies in gezinnen met dove kinderen lijkt net een vorm van intersectionele harmonisering wenselijk te zijn. Ongewenste effecten van een te snelle, gestandaardiseerde tussenkomst in revalidatie en opvoedingsprocessen met dove kinderen, een te sterke klemtoon op techniciteit en rationaliteit, een overheersend deficit-denken, belemmeren het opnemen van gedeelde verantwoordelijkheid in zorgtrajecten. Complexe sociale relaties structureren het opvoedingsproces met een doof kind en creëren nieuwe figuraties van interdependentie tussen ouders, kinderen en de omgeving. Screening, diagnostiek, behandelen, trainen en revalideren zijn invasieve interventies die een richting bepalen in het zorgparcours met een doof kind. Handleidingen voor de goede ouder en het goede kind bestaan niet. In Westerse welvaartstaten zoals België, worden wel beleidsdirectieven geformuleerd over wat een optimale vorm van participatie en burgerschap in de samenleving inhoudt. De manier hoe kinderen en ouders hiermee omgaan en hoe zij op een authentieke wijze vormgeven aan de zorg voor zichzelf en voor elkaar, wordt vandaag onderschat of onvoldoende gevaloriseerd. Maakbaarheid impliceert net daarom ook steeds een ethische overweging over waarom, hoe en waar grenzen worden gesteld aan vroegtijdige interventies in de kindertijd.

English summary

The malleable child. A social pedagogical study of early interventions in families with deaf children.

Sigrid Bosteels - October 2018

This dissertation contributes to social pedagogical studies in which the tension between care and control in families with specific vulnerabilities is being studied. We analyse the case of deafness in young children, a non-life-threatening condition which is considered a serious and chronic health problem. Screening, speed, efficiency and an overall focus on rapid medico-technical treatment and goal-rational thinking permeates the domain of early interventions in (deaf) children. Only partial attention is dedicated to the sociohistorical and the social pedagogical meaning of this condition for children and for the families in which they grow up. We will problematise the neutrality and the unidimensional perspective of current evidence-based practices. Our study can be read as a multi-perspective analysis of early interventions in childhood (deafness) in which different voices are heard and social constructions of the *good parent* and the *good child* are interrogated.

Parents

The first part of the study considers the perspective of parents who are confronted with an early message of their baby's possible hearing deficiency. The interpretation of their stories demonstrates that the time pressure of medical and technological interventions generates a roller-coaster of experiences. Early experiences of becoming the parent of a new born coincides with feelings of becoming a co-therapist. These mechanisms tend to endanger intimate and social interactions and limits the possibility to pause and reflect on existential questions. The overwhelming amount of information and new technological possibilities interrupt the feeling of becoming a parent. The current options of altering deaf children's hearing condition, rush and push parents towards an invasive medical and pedagogical treatment that is meant to restore perceived defeciencies in their babies. Once the objective standards were set in terms of diagnosis and possible treatment, the prerequisites for receiving further support and guidance of the child were formulated in terms of individual responsibilities and actions. Those who did not conform to the proposed interventions, were likely to be forgotten or were denied follow-up and advice. Parents' perceptions and actions were troubled and coloured by normative and scientific claims of

objectivity and normalcy. An apparent lacuna in the process of becoming the parent of a deaf child is the absence of an intermediary and bridging person or professional communicator. Someone who is willing to transcend established expert barriers and who is present at times when parents have to deal with doubts and feelings of insecurity. Parents of deaf children are crucial informal carers who are engaged in a complex and ongoing process which consists of much more than an instant follow up on a proposed treatment or cure of their child.

Policy

In the next chapter, we use a critical lens to study the archive of the government healthcare organisation in Flanders in order to uncover underlying constructions in childhood, deafness and preventive health. New born screening programmes for congenital disorders and chronic diseases are expanding worldwide and children *at risk* are being identified by nationwide tracking-systems at the earliest possible stage. These practices are never neutral and raise important ethical and social questions. An emergent concern is that reflexive professionalism should interrogate the ever earlier interference in children’s lives. The Flemish community in Belgium was among the first to generalise screening for hearing loss in young children. Since the late nineteen seventies, the organisation ‘Kind & Gezin’ invested in the standardisation and implementation of the early hearing test since deafness in babies was considered a serious health problem internationally as well as locally. Since approximately one to two children out of 1000 births are born with a substantial degree of hearing loss, this was considered one of the most common congenital disorders. The organisation of this preventive health strategy and the continuous investment in early detection techniques are consequent translations of the recommendations by the World Health Organisation. The interpretation of hundreds of documents by Kind & Gezin demonstrated that it was not the physical fact of deafness as such that was considered the most endangering for children’s development. Rather, the main problem was the socio-economic consequences of this condition for both parents’ and children’s integration in society according to general standards of normalcy and wellbeing. It is argued that non-intervention would inevitably leave permanent traces on the child’s identity and on parental competence and trust in raising a deaf child. The scope for human judgement and agency seem to be further reduced by limitless faith in technological possibilities. All of this ignores or greatly underestimates the possible coercive effects on families with deaf children. Objective measurement by machine generated knowledge is preferred above human and subjective interpretation (‘refer’ or ‘pass’ protocols instead of a nuanced communication of possible impaired hearing). One could say that the attempts at *curing* deafness in children came at the expense of *deafening* multiple voices in parents' and children's experiences. The presupposition is that correcting deficiencies of individual human beings makes a better citizen for society. Complex parental positions that contain compliance as well as resistance to normalising discourses are not included in the national strategic decisions on preventive neonatal healthcare. The social problem is situated in the failure of the child healthcare policy to acknowledge the complex interrelations involved or to bridge the gaps between professional and parental discretion. Parents as well as the professionals involved risk becoming passive players in national strategic plans which involve actively seeking out children that might miss out. Since identical procedures and protocols of the newborn hearing test are now being duplicated for the screening of all Flemish babies with lazy eyes, and neonatal screening for obesity is under consideration, there is surely a need for further investigation of the scope for human voices at the crossroad of health and lifeworld. With ever-expanding new born screening possibilities we are creating an ever-larger group of parents who are confronted with at-birth diagnosis of a seemingly healthy child and with examples of how risk discourse can structure human experience while excluding otherness.

Children

The third phase of this study considers the voices of deaf children seven years after we talked to their parents. Children as meaning makers are capable of formulating their own view on wat constitutes or hinders their sense of self. They depend on assistance or guidance from technical, professional or parental involvement if this brings them closer to participation in wider social encounters. We should not interpret children's relationships to their technological aids and to their parents or caring professionals in terms solely of overcoming physical impairments or transforming the child's fundamental nature. From birth, these children became familiar with technological accessories which support their capability to interact with others. Without these artificial aids, they remain in a world of silence; leaving aside any value-laden judgement of this embodied experience. Being like other boys and girls is what preoccupies most children. Since most deaf children are born to hearing parents, parents lack the acquaintance with a culture of deafness, or with other linguistic modalities, which would enable them to recognize possible added value to their life course. Asking to position themselves in one world or another only suggests a dichotomized split that fails to reflect the complexity of the children's sense of self. Parents add to this complexity by assigning specific qualities to their children's behaviour. They colour and shape children's voices by the words, expectations, doubts, sentiments and interactions used at home. Because from birth they were obliged to train, practice and rehabilitate, their experience of childhood is determined by these additional obligations and by a sense of it being hard work. By the time they arrive in secondary school, it seems that they need more free space to act and decide for themselves. They then express their agency in flexible ways by choosing to connect or to disconnect from external stimuli and sounds, by enacting sameness or difference as means of participating in changing social situations. It is an ongoing endeavour within developing bodies and an evolving social and cultural lifeworld.

Speed parenting and *speed learning* could be a summative statement for the experiences of parents and children within this Flemish case. The whole theme is related to the initial and fundamental question of how we (should) perceive the specificity of the deaf child at birth. Is this a disabled child, an incomplete child who is missing some necessary parts, or is it a child with a different birth right, a child with a different cultural and linguistic status? In the Flemish context, it became clear that the popular perspective of a personal tragedy prevails. This sets in motion a series of enhancement strategies which become incorporated in parents' sense of (in)competence and children's experience of childhood. The problem is situated in the unquestioned evidence that *early* always implies *better*. This malleable child is offered the best possible treatment to comply to educational and social standards. The right and freedom to disconnect from the external pressure to conform is limited and makes real participation in care processes an underdeveloped objective.

Society

In the last chapter of this dissertation attempt are made to connect particularity to public thoughts of democratic care for deaf children and families. This in-depth study deals with the private, the intimate, the personal and the public politics of a *healthy and inclusive society*. We describe the case of a deaf teenager whose care track is different from what is standardly described as adequate or good care. In this story, the institutional thresholds that limit the coordination and harmonisation of people's care needs became clear. We do not proclaim that actual care for (Flemish) deaf children is not equal to good care. Nevertheless, we question the consequences of specific choices in the care tracks of deaf children that are not aligned with pre-structured and protocoled care paths. Social policy coninues to rely on ableist principles, but the arguments to defend these strategies are often masked in public messages of autonomy, personal strengths, resilience and individual responsibility. We constructed the concepts of authentic voices and disturbing noises in care and education for a deaf child. An authentic voice can be considered as an enabling power for good care and education, whereas a disturbing noise risks to create disabling effects. This conceptualisation of voice and noise should not be read as dichotomised categories but as evolving life occurrences containing the potentiality to either limit or motivate people's participation in care.

In the current debate on the mechanisms at play in transitions of community care and informal care, more emphasis is put on care receivers' own strengths and on a truthful cooperation and communication between formal and informal caregivers. People are not always capable of recognising restrictions to their caring role and may become too demanding or too passive in their expectations for public and professional support in the market of health and wellbeing. Intermediate care providers such as medical and paramedical professionals, care at home services, social workers, psychologists and educators, act and reflect within those spheres where the private and the public intersect. In early interventions for families with deaf children the intersectional harmonisation at stake can only be realised if the outdated debate on the private and the public split becomes resolved. These conceptual credos tend to maintain the *them* and *us* narratives which can only serve to discharge responsibilities to act in different contexts. In the case of families with deaf children, medical, social and pedagogical interventions are currently preoccupied with the limitless and instant potential of science and technology. They offer public images of the deaf child overcoming his or her deficiencies by nature; equipped with the necessary tools and services to become an active, autonomous and integrated citizen of society. Underneath and across these stepping-stones towards the best of all worlds, complex social processes restructure the work of parenting. New figurations of interdependency between the child, the family and the environment are constructed, which the screening, diagnostic and habilitative acts only serve to initiate.

Individuals, organisations and societies should be thoughtful of caring and educational practices that tend to erase or diminish shared responsibilities, reducing them to unidimensional rationality, bureaucratic protocols and predictable scientific certainty. The way in which we *should* or *could* live our lives is subject to ethical, social, historical, cultural and political considerations of what makes a human life meaningful as tentatively described here for families with deaf children. Possibilities exceed expectations and scarcely point to limits of the human brain and technological advancement. Ears, eyes, noses, brains, bones, skins, hearts, genes etc. are malleable by partial interventions that could alter the undesirable effects of not complying to a mean standard of healthy and flourishing human functioning. The way in which we deal with the (often) unpredictable and uncertain consequences of fracturing our bodily and social discretion illuminates human strengths and vulnerabilities.

Date storage fact sheet

The malleable child. A social-pedagogical study of early interventions in families with deaf children

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2. Information about the datasets to which this sheet applies
==
* Reference of the publication in which the datasets are reported:

2.1. Bosteels, S., Van Hove, G. & Vandenbroeck, M. (2012). The roller-coaster of experience: becoming the parent of a deaf child. *Disability & Society* 27 (7):983-996
2.2. Bosteels, S., Vandenbroeck, M. & Van Hove, G. (2017). Saving deaf children? Screening for hearing loss as a public interest case. *Journal of Bioethical Inquiry*, 14 (1):109-121
2.3. Bosteels, S. Vandenbroeck, M. & Van Hove, G. (2018). Put your ears on! Deaf children's embodied experiences with human and technological interventions. *Advances in pediatric research,* 5. Open access: http://biblio.ugent.be/publication/8550728/file/8550729.pdf

2.4. Bosteels, S., Van Hove, G. & Vandenbroeck, M. The power of voice and noise. Balancing in borderlands between formal and informal care for a deaf girl. Submitted in: *Journal of Inclusive Education. Under review.*

* Which datasets in that publication does this sheet apply to?:

2.1. Interviewdata (32 in-depth interviews) collected between 2006 and 2007: audiofiles + transcripts
2.2. Archive documents (about 500 pages) collected at Kind & Gezin in 2012: paper documents
2.3. Interviewdata (7 semi-structured interviews with children, 5 interviews with parents) collected in 2014: audiofiles + transcripts
2.4. Interviewdata (3 in depth- interviews with one family) collected 14.122006/15.06.2007/18.12.2013: audiofiles + transcripts

3. Information about the files that have been stored
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3a. Raw data

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* Have the raw data been stored by the main researcher? [X] YES / [ ] NO
If NO, please justify:

* On which platform are the raw data stored?
  - [X] researcher PC
  - [X] research group file server
  - [X] other (specify): 2.2. Archive documents only available in print

* Who has direct access to the raw data (i.e., without intervention of another person)?
  - [X] main researcher
  - [X] responsible ZAP
  - [ ] all members of the research group
  - [ ] all members of UGent
  - [ ] other (specify): ...

3b. Other files

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* Which other files have been stored?
  - [X] file(s) describing the transition from raw data to reported results. Specify:

2.1. - Evaluation form for every conducted interview

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            - Checklist for every interview with schematic
            notes on consistency of content
            - Verbatim transcripts in print
      2.2.  - Chronologically organized documents from
1970-2013
      2.3.  - Evaluation form for every conducted
interview
            - Verbatim transcripts in print
      2.4.  Verbatim transcripts in print

  - [X ] file(s) containing processed data. Specify: ...
      2.1.  NVIVO coding reports
      2.2. Manual coding schemes on archival documents
      2.3. Manual coding schemes on interview transcripts
      2.4. Manual coding schemes on interview transcripts
  - [ ] file(s) containing analyses. Specify: ...
  - [ X] files(s) containing information about informed
consent
      - Informed consent of every parent participating in
the study
  - [ X] a file specifying legal and ethical provisions:
      -   Research protocol was approved by the Ethical
      Committee of the UZ Brussel, University Hospital
      (reference 2006/139)
  - [ ] file(s) that describe the content of the stored
files and how this content should be interpreted. Specify:
...
  - [ ] other files. Specify: ...

* On which platform are these other files stored?
  - [X ] individual PC
  - [X] research group file server
  - [ ] other: ...

* Who has direct access to these other files (i.e.,
without intervention of another person)?
  - [X ] main researcher
  - [X ] responsible ZAP
  - [ ] all members of the research group
  - [ ] all members of UGent
  - [ ] other (specify): ...



4. Reproduction
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* Have the results been reproduced independently? [X ] YES
/ [ ] NO
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* If yes, by whom (add if multiple):
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