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ON DEAFNESS, OVERCOMING DEAFNESS, AND CAPABILITY

Wouter Rijke

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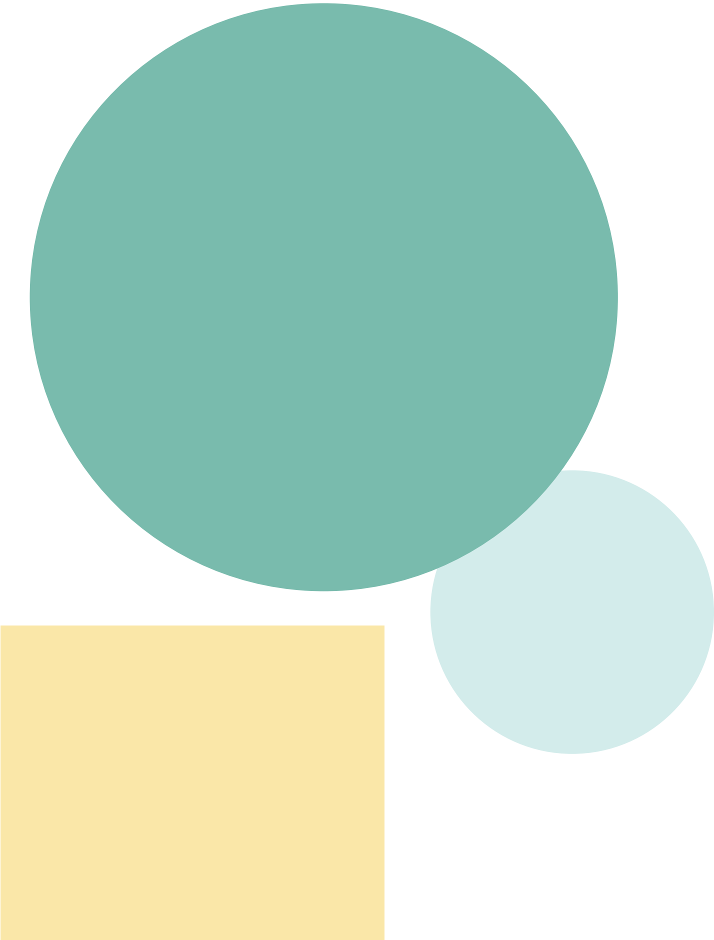

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GENERAL INTRODUCTION

Capability

In the absence of appropriate restorative or compensatory measures, deafness has the potential of having a devastating effect on human development and well-being, even though its impact will vary with the degree of hearing loss, age of onset, laterality, concurrence with other types of disability, progression, and context (Dammeyer, 2018). This observation raises two pressing questions: [1] what restorative or compensatory measures may be considered appropriate, and [2] how should the development and provision of such measures be organized within our societies?

Health Technology Assessment (HTA) plays a key role in helping to answer the first question, producing an empirical basis to address the second one (O'Rourke et al., 2020). However, in order to fulfil this role, HTA requires a normative framework, if only to know what facts actually matter (Van der Wilt & Oortwijn, 2022). In the current practice of HTA, a dominating framework is utilitarian in nature, giving rise to the calculation of the incremental cost-effectiveness ratio (ICER) of developed health care services. The framework rests on a number of assumptions. Firstly, it holds that if the task is to establish a person's well-being, one can best adopt some measurement procedure such as the Standard Gamble or the Time Trade-Off Method, the outcome of which will reveal the utility that this person associates with the relevant situation or condition in which he finds himself (e.g., a specific health state). Secondly, it holds that if the question is whether a particular service qualifies for public funding, this should be inferred from its contribution to the maximal production of aggregate utility in the relevant community. In the context of health care systems, this has been translated into the maximization of Quality Adjusted Life Years (QALYs) for a given budget. Notwithstanding its broad adoption in HTA, the utilitarian framework has been criticized for a variety of reasons (see, for example, Richardson 2000; Nussbaum 2000; Sen, 2000).

In the second half of the last century, drawing on a famous thought experiment ('the veil of ignorance'), Harvard philosopher John Rawls developed an alternative framework which he coined 'justice as fairness' (Rawls, 1971). Rather than focusing on subjective well-being -as in utilitarianism- Rawls proposed that a society's prime concern should be about the distribution of so-called primary goods. These would include liberties and rights, opportunities, income and wealth, and the social bases of self-respect. The argument was then pursued by Nobel laureate Amartya Sen. He agreed with most of Rawls's critique of utilitarianism, but held that Rawls was too much focused on resources, thus insufficiently acknowledging what people can actually do or achieve with the resources that they possess (Sen, 2009). Accordingly, Sen developed the capability approach (CA) to well-being (Sen, 1980).

While seeking to strike a balance between subjective (utilitarian) and objective (Rawlsian) approaches to well-being, the CA holds that a person's well-being depends on his resources, factors that determine whether this person can employ those resources to do or be something that is of value to him, and the freedom that he has to actually pursue such activities or modes of being (so-called functionings). The CA has attracted a tremendous amount of interest from a wide variety of domains (e.g. education, human development, and healthcare) world-wide, but a major source of ongoing concern has been its operationalization. To remain faithful to the concept, empirical research into capability would require that resources, conversion factors, functionings and their dynamic interactions become sufficiently apparent. Also, the focus is not so much on what people actually do or be, but whether they have the real opportunities to do and be the things they have reason to value. In other words, whether the things that people end up doing and being are forced upon them, or the result of more or less considered choices.

Another key issue relates to the question as to what sort of functionings are, in fact, of value such, that they should, in principle, be within reach of every member of a society, and how this should be established. For these and related reasons, the CA has by some been dismissed as an interesting, but unworkable idea (see Robeyns, 2005). In an interview with Ingrid Robeyns, responding to the critique of the impracticality of the CA, Sen recounted the parable of the man who had lost his keys during a walk in the night, looking for them in the light of a lamppost. Someone else comes along and offers help. 'You lost them somewhere over here, right?' 'No', says the man, 'but here, at least, I have some light.' The suggestion was clear: do you choose to examine things for which an accepted methodology is in place but that are of questionable relevance, or do you persevere in developing and testing methods for examining things that really matter? The present thesis was conducted in the latter vein. While accepting that no final answers or solutions would be forthcoming, we endeavoured to explore what light a CA might shed on 'how well people's lives with hearing impairment are currently going in our country'.

To be sure, we are not the first to explore the possibilities that the CA offers for researching well-being in the realm of health and health care. There are **existing capability measures** such as the ICECAP from the UK, which asks individuals to rate their capability in five domains using a four-point scale (Al-Janabi et al., 2012). However, the question is whether these measures provide enough insight into an individual's actual capabilities and what factors enable or inhibit them. The concern is that relying solely on numerical scores without understanding the context behind them may limit the usefulness of these measures in effecting change (Morris, 2009). While these capability measures aim to capture an objective assessment of an individual's abilities, they still contain subjectivity, as they rely on individuals' perceptions of their own capabilities. Therefore, it is important to consider the specificity and context of the questions asked in such measures. It is also important to note that these measures were designed for health economic evaluations, whereas we were attempting to gain insights into the underlying factors and mechanisms that appear to determine capabilities.

Deafness, hearing aids and cochlear implants

In a predominantly hearing society, not being able to hear has a significant impact on a person's life. The WHO (2023) defines hard-of-hearing individuals as those with a hearing loss of over 35 decibels in the better hearing ear, while individuals who hear close to nothing (over 80 decibels of hearing loss) are considered deaf. **Deaf and hard-of-hearing (DHH)** individuals face difficulties with oral communication, which depends on the ability to perceive speech. Those with moderate to severe hearing impairments or deafness from birth, who are not adequately rehabilitated, have limited ability to develop linguistically complex skills that are appropriate for their age (Holzinger et al., 2020). Although sign language can be valuable for those with severe to profound hearing loss, it is not commonly used in society. Secondary consequences of hearing loss, in addition to the loss or reduction of speech perception and production, impact an individual's well-being (depression, loneliness, decreased autonomy) and have societal effects (reduced social interaction and lower employment rates) (Bott & Saunders, 2021; Kramer, 2005; Kramer et al., 2006; Svinndal et al., 2018).

While there is no cure for deafness, hearing loss can be mitigated using various tools. In the Netherlands, two commonly used devices for hearing loss rehabilitation are **hearing aids** and **cochlear implants**. Hearing aids amplify sounds and are fitted at the ear canal level. In instances of severe or profound hearing loss, when traditional amplification methods do not offer sufficient access to spoken language, the appropriate course of action is to consider cochlear implantation for electrical stimulation. Cochlear implants consist of four parts: a speech processor, a headpiece, an implant-receiver, and an electrode array in the inner ear. The implant bypasses non-functional inner hair cells and electrically stimulates the cochlear nerve with a maximum of 22 intra-cochlear electrodes, resulting in improved speech recognition and verbal communication. Although a cochlear implant does not fully restore hearing, it does provide significantly improved speech recognition, spoken communication, and quality of life compared to conventional hearing aids (Bat-Chava et al., 2005; Boerrigter, 2021; Easwar et al., 2018; Huber, 2005).

Hearing impairment is a condition that may arise at any point in one's **lifespan**. While some individuals may experience hearing loss from birth or early childhood, others may develop it later in life, often associated with aging. It is reasonable to assume that individuals' priorities and values evolve over time. For instance, the goals that one aspires to in primary school differ from those in puberty, adolescence, and young adulthood (Campbell & McKendrick, 2017). Furthermore, as individuals reach their mid-twenties or approach retirement, their values may change once again. This transformation can be attributed to life transitions, such as entering the workforce, starting a family, or reaching retirement age. These transitions impose distinct demands on individuals, particularly when coping with hearing impairment. For instance, challenges may arise during early education, affecting learning and social development; during adolescence, peer group influences can be significant; and raising children with a hearing impairment as a parent can be particularly demanding.

A cochlear implant (CI) team, comprising otologic surgeons, audiologists, psychologists, linguists, and rehabilitationists, collaborates to enhance post-implant hearing abilities, specifically focusing on facilitating social-communicative spoken interactions. Clinical-researchers from the CI team at the Ear, Nose, and Throat (ENT) department of the Radboudumc/Pento have expressed interest in exploring the concept of capability. This interest stemmed from their clinical observations of children who still faced challenges in functioning in their daily life, despite having favorable outcomes in terms of audiological measures. They assumed that incorporating the concept of capability into their evaluations could provide valuable insights to optimize the rehabilitation.

Thesis outline

So, how do severely hearing-impaired individuals with hearing aids or cochlear implants fare in terms of their well-being? The **main goal** of this doctoral research was to explore how the capability approach could help us answer this question. This immediately raises several other questions: can existing capability instruments be employed for this purpose, or would it be more appropriate to develop a questionnaire specifically tailored to the target population? Alternatively, should a more qualitative approach be adopted? How should we determine what people should be able to do and be (the content of capability)? Considerations about causality also arise, among other issues. While we do not claim to have answers to all of these questions, this thesis sheds some light on the potential value of the capability approach in understanding the well-being of individuals with severe hearing impairments in our society.

Chapter 2 presents the findings of our scoping review on capability impact assessment. The review aimed to identify approaches to operationalizing the capability approach, assessing the impact of interventions on people's capability, and reporting those assessments effectively.

In **Chapter 3**, we attempt to measure capability by developing a questionnaire that compares the capability of children with cochlear implants to typical hearing children. We also use speech perception scores to triangulate the questionnaire outcomes.

However, we wanted to gain further insight into these children's situations. Specifically, we aimed to identify their specific challenges and needs. To achieve this, we recognized the need to engage with the children themselves. **Chapter 4** describes our mixed methods study where we interviewed children with cochlear implants within a comparable age range (8-12 years). In addition, we included children with hearing aids and typically hearing peers in this study.

From a methodological standpoint, the children in Chapters 3 and 4 were between the ages of 8 and 12, which may limit their ability to identify important factors that influence their lives. Parents also play a significant role in their lives. To address this, we considered interviewing older youth between the ages of 13 and 25 who are more focused on autonomy, self-development, and identity formation, and who have more agency in decision-making, making Amartya Sen's concept of freedom of choice more relevant. These interviews are covered in **Chapter 5**.

Chapter 6 was the final empirical study conducted in this research project. It focused on adults who became deaf later in life and had varying degrees of hearing loss. The study had two objectives. Firstly, we aimed to investigate if there was a difference in capability between deaf adults with cochlear implants and those who were not as far along in the implantation process. Secondly, we aimed to compare two different measurement tools: utility and capability. This was done to determine if any differences could be identified between the two tools.

Chapter 7 provides a summary of the thesis results and discusses the most important implications and learned lessons from this thesis.

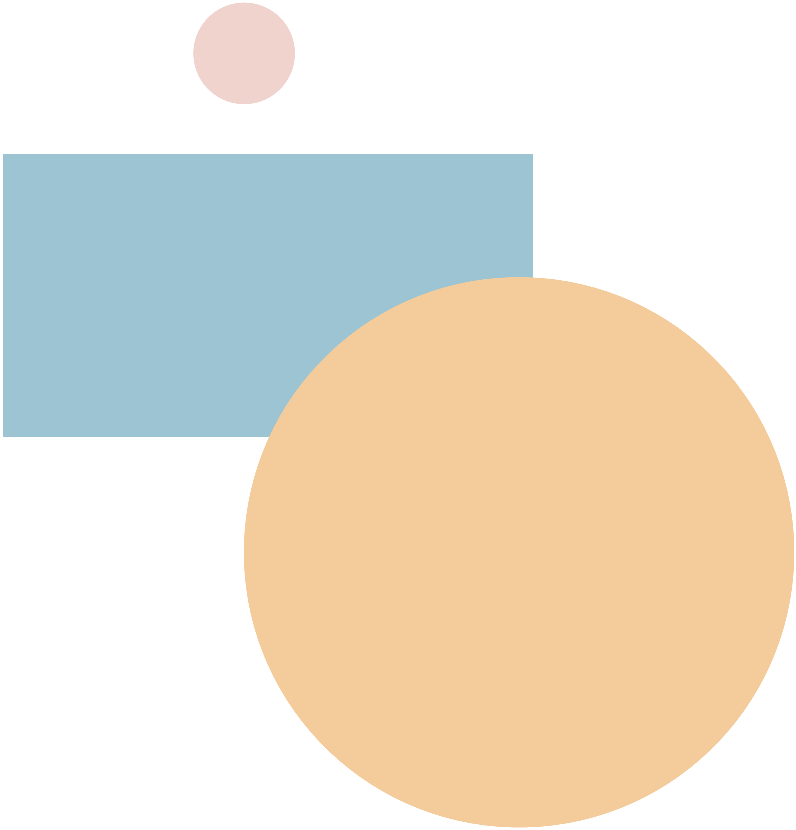
Chapter 8 contains a Dutch summary of the thesis.

The appendices include the acknowledgements, curriculum vitae, portfolio and a description of the research data management according to the FAIR guidelines.

References

1. Al-Janabi, H., Flynn, T. N., & Coast, J. (2012). Development of a self-report measure of capability wellbeing for adults: the ICECAP-A. *Quality of Life Research 21*(1), 167-176. https://doi.org/10.1007/s11136-011-9927-2
2. Bat-Chava, Y., Martin, D., & Kosciw, J. G. (2005). Longitudinal improvements in communication and socialization of deaf children with cochlear implants and hearing aids: evidence from parental reports. *Journal of Child Psychology and Psychiatry, and Allied Disciplines*, *46*(12), 1287-1296. https://doi.org/10.1111/j.1469-7610.2005.01426.x
3. Boerrigter, M. S. (2021). *Long-term psychosocial and executive function outcomes in children and adolescents with cochlear implants* (Publication Number 978-94-6421-311-9) [Doctoral dissertation, Radboud University]. Nijmegen.
4. Bott, A., & Saunders, G. (2021). A scoping review of studies investigating hearing loss, social isolation and/or loneliness in adults. *International Journal of Audiology*, *60*(sup2), 30-46. https://doi.org/10.1080/14992027.2021.1915506
5. Campbell, L. A., & McKendrick, J. H. (2017). Beyond aspirations: deploying the capability approach to tackle the under-representation in higher education of young people from deprived communities. *Studies in Continuing Education*, *39*(2), 120-137. https://doi.org/10.1080/0158037x.2017.1293630
6. Dammeyer, J. (2018). Mental Health and Psychosocial Well-Being in Deaf and Hard-of-Hearing Students. In H. Knoors & M. Marschark (Eds.), *Evidence-Based Practices in Deaf Education*. Oxford University Press. https://doi.org/10.1093/oso/9780190880545.003.0021
7. Easwar, V., Sanfilippo, J., Papsin, B., & Gordon, K. (2018). Impact of Consistency in Daily Device Use on Speech Perception Abilities in Children with Cochlear Implants: Datalogging Evidence. *Journal of the American Academy of Audiology*, *29*(9), 835-846. https://doi.org/10.3766/jaaa.17051
8. Holzinger, D., Dall, M., Sanduvete-Chaves, S., Saldaña, D., Chacón-Moscoso, S., & Fellinger, J. (2020). The Impact of Family Environment on Language Development of Children With Cochlear Implants: A Systematic Review and Meta-Analysis. *Ear and Hearing*, *Publish Ahead of Print*. https://doi.org/10.1097/aud.0000000000000852
9. Huber, M. (2005). Health-related quality of life of Austrian children and adolescents with cochlear implants. *International Journal of Pediatric Otorhinolaryngology*, *69*(8), 1089-1101. https://doi.org/10.1016/j.ijporl.2005.02.018
10. Kramer, S. E. (2005). The psychosocial impact of hearing loss among eldery. In D. Stephens & L. Jones (Eds.), *The impact of genetic hearing impairment* (pp. 137-164). Whur Publishers.
11. Kramer, S. E., Kapteyn, T. S., & Houtgast, T. (2006). Occupational performance: comparing normally-hearing and hearing-impaired employees using the Amsterdam Checklist for Hearing and Work. *International Journal of Audiology*, *45*(9), 503-512. https://doi.org/10.1080/14992020600754583
12. Morris, C. (2009). Measuring participation in childhood disability: how does the capability approach improve our understanding? *Developmental Medicine and Child Neurology*, *51*(2), 92-94. https://doi.org/10.1111/j.1469-8749.2008.03248.x
13. Nussbaum, M. C. (2000). The Costs of Tragedy: Some Moral Limits of Cost-Benefit Analysis. *The Journal of Legal Studies*, *29*(2), 1005-1036. https://EconPapers.repec.org/RePEc:ucp:jlstud:v:29:y:2000:i:2:p:1005-36
14. O'Rourke, B., Oortwijn, W., & Schuller, T. (2020). The new definition of health technology assessment: A milestone in international collaboration. *International Journal of Technology Assessment in Health Care*, *36*(3), 187-190. https://doi.org/10.1017/s0266462320000215
15. Rawls, J. (1971). *A theory of justice*. The Belknap Press of Harvard University Press Cambridge, Massachusetts.

16. Richardson, H. S. (2000). The Stupidity of the Cost-Benefit Standard. *The Journal of Legal Studies*, *29*(2), 971-1003. https://EconPapers.repec.org/RePEc:ucp:jlstud:v:29:y:2000:i:2:p:971-1003
17. Robeyns, I. (2005). The Capability Approach: a theoretical survey [Article]. *Journal of Human Development*, *6*(1), 93-117. https://doi.org/10.1080/146498805200034266
18. Sen, A. (1980). Equality of What? In S. McMurrin (Ed.), *Tanner Lectures on Human Values, Volume 1*. Cambridge University Press.
19. Sen, A. (2000). The Discipline of Cost-Benefit Analysis. *The Journal of Legal Studies*, *29*(2), 931-952. https://EconPapers.repec.org/RePEc:ucp:jlstud:v:29:y:2000:i:2:p:931-52
20. Sen, A. (2009). *The idea of justice*. Allen Lane.
21. Svinndal, E. V., Solheim, J., Rise, M. B., & Jensen, C. (2018). Hearing loss and work participation: a cross-sectional study in Norway. *International Journal of Audiology*, *57*(9), 646-656. https://doi.org/10.1080/14992027.2018.1464216
22. Van der Wilt, G. J., & Oortwijn, W. (2022). Health technology assessment: A matter of facts and values. *International Journal of Technology Assessment in Health Care*, *38*(1), e53. https://doi.org/10.1017/s0266462322000101
23. WHO. (2023). *Deafness and hearing loss*. World Health Organization. Retrieved 26 mei 2015 from http://www.who.int/mediacentre/factsheets/fs300/en/



2

STRATEGIES FOR RESEARCHING PROGRAMS' IMPACT ON CAPABILITY: A SCOPING REVIEW

Rijke, W. J., Meerman, J., Bloemen, B., Venkatapuram, S., Van der Klink, J., & Van der Wilt, G. J. (2023). Strategies for Researching Programs' Impact on Capability: A Scoping Review. *Journal of Human Development and Capabilities 24*(3), 401–423. https://doi.org/10.1080/19452829.2023.2209027

Abstract

Researchers seeking to assess the impact of a program on the capability of its target audience face numerous methodological challenges. The purpose of our review was to see to what extent such challenges are recognized and what choices researchers made in order to address them, and why. We identified 3354 studies by searching five databases in addition to cross-checking references from selected studies. A total of 71 studies met our pre-defined selection criteria: empirical studies reporting data on how interventions impacted the beneficiaries' capability, providing sufficient detail on how impact was measured, in English language. Four independent raters assessed those studies on four domains: descriptive information, consideration of causal attribution, operationalization of capability, and interpretation of findings. Challenges related to capability impact assessment were not widely explicitly acknowledged, and available measures to address these challenges were not being used routinely. Major weaknesses included little attention to causal attribution, infrequent justification of the specific content of capability, and failure to research the constitutive elements of capability and their interactions. Research into a program's impact on the capability of its recipients is challenging for several reasons, but options are available to further improve the quality of this type of research.

Introduction

The capability approach (CA) is a normative-empirical framework which asserts that human well-being should be primarily assessed from *capabilities*, or the real freedoms people have to be and do things they have reason to value (Sen, 1992, 1999). The approach has been developed as an alternative to the limitations of measures such as utility, commodities holdings, or liberties, among others that serve as a proxy of well-being (Van Staveren, 2008; Venkatapuram, 2011). Problems associated with these measures include the phenomenon of adaptive preferences (or response shift) (Elster, 1982; Festinger, 1957; Sen, 1987; Teschl & Comim, 2005), while others disregard the questions of whether and how individuals can transform those possessions to create something that is of value to them, or ignore the contextual conditions that produce inequalities in well-being (so-called conversion factors; Sen, 1992). In contrast, the CA recognizes and integrates the process of personal and social construction of capabilities, as well as identifies the importance of an objective perspective in assessing deprivations to counter subjective reporting biases (Alkire, 2002).

Taken together, these critiques and positive arguments from the CA suggest that the impact of programs and interventions that aim to increase well-being are also best assessed from their impact on the target audience's individual or collective capabilities (Ibrahim, 2006; Keeley et al., 2015; Lorgelly et al., 2015; Mitchell et al., 2016; Nussbaum, 2011; Simon et al., 2013). Thus, the pressing question is how best to do that. The objective of this paper was to identify to what extent researchers evaluating the impact of programs or interventions on capability recognize the accompanied challenges, how they address these challenges, and how they support their interpretations. We followed the framework by Arksey and O'Malley (2005) for scoping reviews to identify, select and review relevant studies. The key findings are that although there are promising studies that report on their findings of capability impact assessment, there are still many challenges in conducting and reporting clearly on the impact of programs on recipients' capability.

Challenges associated with assessing the impact of interventions on recipients' capability

Clearly, (monitoring and) assessing the impact of a program or intervention on the capability of its target audience requires some form of operationalization of the capability concept. Some of the difficulties that are associated with this task have been previously recognized

(Robeyns, 2003, 2005). Here, we will focus on four such operational challenges associated with assessing impact of interventions or programs on recipients' capability. These include:

- Identification of the content of capability, relevant to the particular context - what is it that people should be able to be or do?
- Establishing whether people are able to do or be something when, in fact, they are not being or doing such things. In other words, how can one plausibly establish whether people have (or don't have) 'real freedoms'?
- Causal attribution: if there are indications that a target audience's capability has expanded after an intervention, can this be confidently ascribed to the program or intervention under study?
- Determining an appropriate time frame for such studies: how much time would it realistically take for a target audience's capability to expand in a meaningful way, taking into account relevant contextual characteristics? In the following discussion, we will briefly expand on each of these challenges.

Deciding on capability's relevant content

Assessment of an intervention's impact on the capability of its intended beneficiaries requires that the capability content is specified. For example, for a community level intervention, what beings and doings are considered valuable that they should, to a sufficient degree, be accessible or realizable for all members of the community? Broadly speaking, two different answers have been given as to how such content may be established (Claassen, 2011). Sen (1992) holds that a public deliberative process is needed to achieve this end. In contrast, others (most notably Nussbaum, 2000) have argued that core capabilities may be identified that are foundational or of generic relevance and validity to all human beings. Combinations of these two approaches have also been suggested (e.g., Burchardt & Vizard, 2011). Without taking sides in this debate, the important point here is that researchers of a program's impact on a capability/ies should specify its content and indicate how it was established.

Assessing people's freedom

A second challenge associated with capability impact assessment is that capability refers to the real *opportunities* that people have to realize valuable doings and beings. In this sense, capability is a measure of freedom or real possibilities, not mere achievements. Measuring opportunities is difficult. Furthermore, there is the issue of whether the things that people end up doing and being in their lives can be considered to be a result of their own choosing, or whether they are largely outcomes from structures and constraints imposed upon them.

Hence, establishing whether more people display valued modes of doing and being (or display the modes to a greater degree than before), difficult as it may be, is not an adequate indicator of capability expansion in the sense valued by the CA. The CA distinguishes between capabilities on the one hand and displayed modes of being on the other. Therefore, non-achievement of certain modes of being may be a result of a person's own choosing and not from actual constraints in his or her capabilities. There are several options for capability impact researchers to address the challenge of assessing this freedom space.

Firstly, they may rely on self-reports from research subjects. Using questionnaires or interviews, subjects are asked to report whether, in what way and to what extent, their real opportunities for realizing specific valued doings and beings have increased since the onset of the intervention of interest. A possible drawback of such an approach is that people may either over- or underestimate their own capability. Strictly speaking, this approach is more likely to capture people's views on their (changes in) self-efficacy (Bandura, 1978), rather than their capability.

A second approach would be to query subjects about their actual functionings, or to observe their behavior in their daily settings. The reasoning is that functioning, when present, implies pre-existing capability. A drawback associated with this approach is, similar to above, that non-achievement need not imply absence of capability, but the choice not to do so. This would raise further questions regarding what factors impacted such choices, and if those choices were truly free choices.

A third approach that capability impact researchers can take is to identify and explore the possibility conditions for specific capabilities in a particular context (Robeyns, 2005). When, for instance, cycling has been identified as a specific type of doing that people ought to be capable of, possibility conditions would include the presence of certain motor and sensory capacities on the part of an individual, having a bicycle at one's disposal, the presence of safe cycle paths, etc. To assess the impact of a program on a target audience's capability, researchers would not so much rely on subjects' reports, nor on some sort of participant observation, but on establishing to what extent such possibility conditions are met to a greater extent as compared to prior the program's rollout. A drawback of such an approach would be that it heavily relies on presumed relations between theoretical possibility conditions and capability which, in reality, may not hold.

These three approaches for assessing people's real freedoms need not, of course, exclude each other. Indeed, combining two or all three approaches may work to achieve triangulation (Wolff & De-Shalit, 2007).

Causal attribution

Even when there are indications that the unfolding program or intervention is associated with the strengthening of recipients' capability of the sort that was hoped for, it may be uncertain whether the changes were directly or wholly caused by the intervention. This is not specific to the assessment of capability, of course. Alternative explanations could include for instance maturation (or, more generally, changes that would have occurred, independently of the intervention), confounding, bias, or natural variation (Marsden & Torgerson, 2012). Several solutions exist to rule out such alternative explanations for observed changes, either in the initial design of the study or the analysis of the data (e.g., Rogers, 2014). These include, but are not confined to, comparative research and random assignment of research subjects to experimental or control conditions, blinding of one or more of the parties to the allocation, and statistical analysis of the findings. Such designs or data production may not, however, always be feasible, or appropriate, in the context of assessing interventions aiming for capability expansion (e.g., Black, 1996). In such instances, researchers can adopt various other strategies to strengthen claims of causality (Maxwell, 2004).

Time horizon

Finally, capability expansion may take some time to materialize and, conversely, changes in capability, when achieved, may not always be sustained or robust over time. Although this may not be unique to capability, it is an extremely relevant challenge with capability interventions due to the special character of capabilities. Therefore, the timing of the assessment of capability impact post the unfolding of the intervention can be critical, and it may be necessary to conduct assessments at multiple moments over time (Mayne, 2008).

To put this review in context, we wish to highlight two recent publications that provide excellent reviews of a number of capability measurement instruments (i.e., ICECAP, ASCOT, OCAP, OxCap, and ACQ-CMH) and their use in the context of economic evaluation (Helter et al., 2019; Proud et al., 2019). While these reviews consider health related capability measurement instruments and their ability to capture the outcomes of value, our present review should be considered complementary to this health economic evaluation focused work. The present review is interested in all approaches to measure capability impacts, in all different domains of well-being.

Methods

We used the framework of Arksey and O'Malley (2005) for conducting scoping reviews. This framework prescribes identifying the research question of the scoping review, identifying relevant studies, selecting relevant studies, charting the data, and reporting results. Each of the steps is discussed below.

Identifying the research question

Researchers who seek to assess the impact of a program or intervention on the capability of its target audience are faced with a number of specific methodological challenges. The purpose of our review is to see to what extent such challenges are recognized by researchers and, if so, what choices researchers made in order to address them, and how these choices were justified.

Identifying relevant studies

Developing a search strategy for identifying relevant studies was challenging for the following reasons: firstly, the term 'capability' has a general meaning, not necessarily referring to Sen's concept; secondly, capability is a generic concept of well-being, used in a wide range of domains, including health care, education, housing policy, employment, and development aid; thirdly, reports of capability impact studies can be found in a wide range of bibliographic databases, and in the form of journal papers, book chapters, books and reports.

Because of these reasons, a search strategy to identify potentially relevant studies was developed inductively. We started by identifying ten relevant and diverse studies through manual searching. The characteristics of these studies are presented in Appendix A. Possibilities for relevant search terms and databases to be included were derived from this seeding set. In turn, the search strategy to be developed had to yield at least each of these manually identified 10 studies. The search strategy is available on request from the corresponding author. It included five databases (PubMed, SCOPUS, Sociological Abstracts, International Bibliography of the social sciences, and Econlit). Boolean operators (e.g., AND, OR, and NOT) were adapted as appropriate for each database. The search strategy as used in PubMed is presented in Box 1. The search was completed by cross-checking references from selected studies. We collected and managed the studies in reference management program EndNote version X9 in September 2020.

Box 1. The search strategy as used in PubMed.

((capability approach[tiab] OR capabilities approach[tiab] OR Amartya Sen[tiab])
AND
(evaluate [tiab] OR evaluates [tiab] OR evaluation[tiab] OR evaluating[tiab] OR evaluations[tiab] OR evaluated[tiab] OR programme[tiab] OR programmes[tiab] OR programs[tiab] OR project[tiab] OR projects[tiab] OR intervention[tiab] OR interventions[tiab] OR impacts[tiab] OR impact[tiab] OR impacted[tiab]))
OR (impact[ti]
AND capability[ti])

Selecting relevant studies

We included studies if they met the following inclusion criteria:

- an empirical study,
- reporting data on how specific interventions or programs had impacted on the capability (as "the real freedoms people have to be and do things they have reason to value") of the program's beneficiaries,
- providing sufficient detail on how impact of an intervention was measured (in the paper itself or in appropriately referenced papers),
- English language.

Although the interventions or programs in the included studies did not have to be specifically designed to impact capability or well-being, the authors did have to claim an impact on the recipients' capability in order to be included. We did not exclude studies based on year of publication.

Charting the data

Charting consisted of the extraction and summarizing of relevant characteristics and data from the individual studies, taking into account the four types of challenges that were identified to be associated with capability impact assessment. We developed a checklist (Appendix B) iteratively with feedback from all four reviewers of the initial identification of relevant studies (Details omitted for double-blind reviewing). For critical appraisal of causal attribution, criteria were adopted that are appropriate for quantitative (Shadish et al., 2002) or qualitative research (Giacomini & Cook, 2000). The checklist aimed to guide reviewers to provide answers to the following four domains:

- *Descriptive information*. This included questions on how the target population was disadvantaged and what the disadvantaged target group should be able to do (the maintained norm), according to the authors.

- *Consideration of causal attribution in research design:* questions derived from quantitative causal attribution theories on prospective or retrospective assessment, control group, randomization, and blinding.
- *The operationalization of capability.* Here, reviewers could describe the design (time horizon, quantitative, qualitative, or mixed methods) and the capability approach elements (resources, conversion factors, and functionings) included.
- *Discussion of the interpretation of findings.* This part involved a critical review of the reported hypotheses, outcomes, and conclusions.

For every included study, two reviewers independently filled out the questionnaire. In the cases of inconsistencies, reviewers discussed in order to achieve consensus. Although each of the reviewers is familiar with the capability approach, their backgrounds differ, with a focus on capability in relation to health and healthcare (JM), research methodology (BB), impact assessment (GJvdW), and capability in relation to disability (WR), respectively.

Results

In- & exclusion of literature

We summarized findings in tables and graphs; a complete synthesis (based on achieved consensus between reviewers) of all items per individual study is presented in Appendix C. The literature search produced 3354 references, see Figure 1.

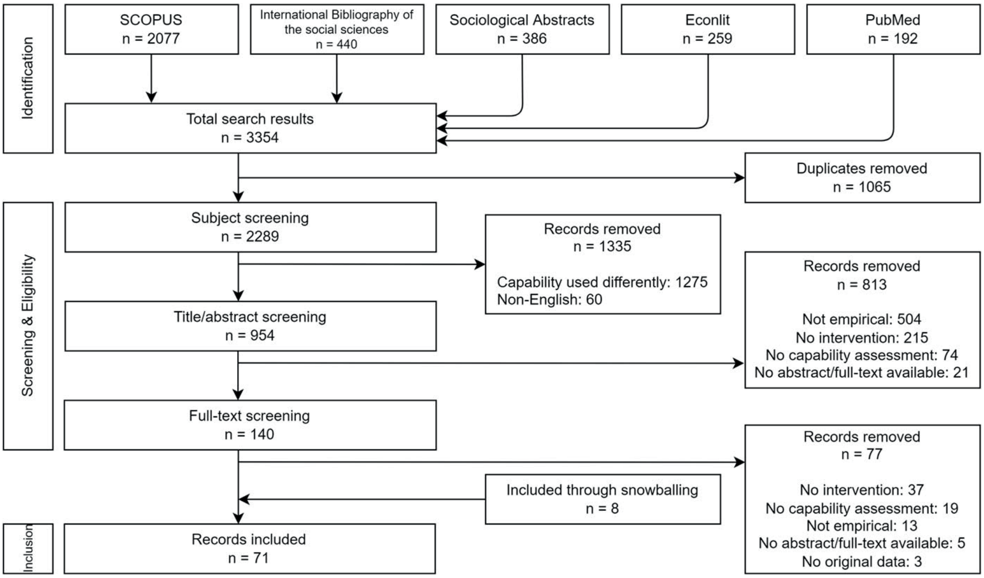


Figure 1. Flow diagram of inclusion process.

After removing duplicates, we screened 2289 unique studies for English language and use of the term 'capability' in terms of the capability approach. Titles and abstracts of the remaining 954 studies were screened for empirical study and study objective (assessment of impact of a specific program or intervention on a target audience's capability). After full-text screening of the remaining 140 studies, we assessed 71 studies using the checklist that we developed for the review (Appendix B). For 20 studies (28%) further discussion by reviewers was needed before full consensus on the abstract could be reached.

Descriptive information

As the checklist consisted of both open (e.g., "What is the target population?") and closed questions (e.g., a multiple-choice question asking, "Which capability elements were assessed?"), we listed the summary of answers to multiple choice questions in Table 1 and presented more elaborate details on the answers to open questions verbatim.

Table 1. Summary of study characteristics (n = 71, unless stated otherwise) (full synthesis in Appendix C)

Questionnaire topics	Findings (n of inclusions)
Descriptive information	
Format of the report	Journal article (67), thesis (2), book (2)
Sample size (number of individuals on whom data are being reported); (n = 66), not reported/unclear in 5 studies	Minimum: 3 1st quartile: 20.5 Median: 37.5 3rd quartile: 81.5 Maximum: 2540
Was there evidence presented suggesting unduly deprived capability among the target population prior to the intervention?	Yes (63), maybe (6), no (2)
Country	India (8), South Africa (7), Nigeria (4), United Kingdom (4), Mexico (3), Scotland (3), Other (36)
Consideration of causal attribution in research design	
Pre-post assessment	No (66), yes (5)
Control group	No (58), yes (13)
Random assignment of subjects	No (70), cannot be judged properly (1)
Blinded	Not blinded (71)
The operationalization of capability	
Capability elements assessed:	Functionings (62), resources (52), conversion factors (52)

Table 1. *(Continued)*

Questionnaire topics	Findings (n of inclusions)
Assessment of interaction between capability elements	Yes (44), no (26), cannot be judged properly (1)
Type of study:	Qualitative (52), mixed methods (17), quantitative (2)
Source of information on capability impact	Subjects/self-reported (70), person(s) close to subjects (31), document analysis (15), statistics (8), researchers (7)
Retrospective vs prospective	Retrospective (66), prospective (5)
Discussion of the interpretation of findings	
Authors' conclusions regarding impact of the intervention on participants' capability:	Positive (37), mixed (30), negative (1), unclear (3)

The majority of the 71 studies had a qualitative component in its research design: 52 studies used exclusively qualitative methods, such as interviews, while 17 studies mixed qualitative and quantitative methods. Only 2 studies used a pure quantitative research design. In 25 of 71 studies (35%), the target population of the intervention consisted of children or adolescents; in 17 studies (24%), the target group consisted of women. Other prevalent characteristics of target populations were indications of poverty (15 studies) and disability (6 studies). The sample size varied from a minimum of 3 participants (a case study employing participant observation as research method) to a maximum of 2540 (survey), with a median of 37.5. In 63 of the studies (89%), the authors provided arguments and / or data to support the notion that at the start of the study, the capability of the target population was constrained.

Of the 71 studies, 24 reported on interventions related to development aid, 20 on education-related interventions, 11 on unemployment programs, and 9 on health-related interventions. The 7 other studies reported on interventions related to decision making, sports, sociability, or on multiple domains. Studies were conducted across the globe, with India (8) and South Africa (7) as most frequent sites. There were 30 countries that each yielded a single capability impact study.

Causal attribution of observed impact of intervention on capability

No studies blinded either respondents or researchers, or randomly assigned their subjects to their research group(s). Approximately one in five studies included a control group, while five of 71 studies adopted a before – after design. Over half of the studies (38) did not report clearly the time that passed since the start of intervention; in 12 studies, the assessment took place while the intervention was still ongoing. Of the remaining 21 studies, the shortest follow-up time was 1 month, the longest 18 years. Median follow-up time was two years.

The operationalization of capability

The studies varied considerably in terms of the content of capability (i.e., what is it that the target audience ought to be able to do or be?), as well as the way this focus was established. Broadly, studies could be categorized in three types. The first type are studies that used capability lists that have been published in the literature, including the ones developed by Nussbaum (2000), Ibrahim and Alkire (2007), Powell & McGrath (2014), and Gigler (2014). We identified eight studies using this approach. Secondly, 18 studies focused on specific doings or beings that were considered of value to the program's target audience and where relevant inequalities were presumed to exist. Examples include being able to hear, being able to be employed, being able to access electricity, and being able to have financial security. In general, no further justification was provided for the selection of those doings or beings as the basis for capability impact assessment (e.g., as an outcome of some deliberative process, as suggested by Sen, or on the basis of some list of capabilities that were considered applicable in the relevant context). The remaining 45 studies assessed an intervention and investigated changes in specific endpoints. When changes materialized, these were interpreted in terms of an expansion or tapering of capability.

The majority of the studies (n = 61) aimed to provide insight into changes over time (putatively caused by the intervention under study) in multiple components of capability, i.e., resources, conversion factors and functionings. Of the 71 studies, 44 reported on an interaction between those capability components. Such postulated interaction was, however, often derived from informal observations by respondents or the researchers themselves.

Researchers' interpretations of findings as evidence of impact on recipients' capability

Particularly in case of an abstract concept such as capability, researchers will have to find ways for demonstrating whether their findings can, in fact, be interpreted as evidence of changes (or lack thereof) in capability. When instruments such as ICE-CAP or OxCap are being used, this critically hinges on evidence of the validity of such instruments (Helter et al., 2019). In other cases -the subject of this review- researchers need to find other ways for supporting the credibility of their interpretation of research findings. Here, we will briefly summarize two strategies that were observed in multiple studies.

Triangulation

Particularly when certain design measures such as randomization or blinding are considered infeasible, inappropriate, or unethical, triangulation may offer researchers opportunities to more confidently causally ascribe observed outcomes to an intervention (Hammerton & Munafò, 2021). An example of such triangulation is the study by Alkire (2002). In this study, the seven basic goods as developed by John Finnis (1980) were used to further specify the capability concept. Interviews were held with beneficiaries of a development program, asking them to reflect on how, in retrospect, their lives had changed (if at all) since the start of the program. If certain basic goods did not appear in the interview, researchers asked questions to probe whether in these dimensions things had, in fact, not significantly changed.

Multiple researchers independently analyzed the records of these interviews to see whether self-reported changes could be related to any of the seven basic goods. Results were presented in tables, listing the basic goods and quotes from interviews that were interpreted by the researchers as evidence of changes in these basic goods. Through the quotes, the reader can develop a concrete picture of the changes that were experienced and reported by the interviewees as associated with the deployment of the program. The reader can also judge whether he accepts the interpretation of the reported changes as evidence of change in the concerning basic good. Apart from the use of extensive quotes from interviews, Alkire corroborated her findings by conducting participant observations and by collecting data on changes in resources and conversion factors, a strategy that may be denoted as strong triangulation (Wolff & De-Shalit, 2007).

Another example is the study by Lindeman (2014), who defined capability as “the integration of abilities, means and opportunities to reach desired well-being”. In her study she followed recipients of a low-cost housing project in Tanzania, collecting photos, notes, and memos. In addition, she conducted in-depth and shorter interviews.

Use of a specific framework or theory of change

A second strategy that we found in multiple studies is the use of a specific framework or theory of change to capture capability and how it came about. Biggeri and Ferrannini (2014) proposed the opportunity gap (O-gap) analysis, a framework that emphasized feedback loops between capability elements in time. Another framework by Mink, Van der Marel, Parmar, and Kandachar (2015) was meant for product design, called the Opportunity Detection Kit. They evaluated the impact of a cooking stove in rural South India. A third example is the choice framework, used by Kleine (2010). Kleine conducted a qualitative assessment of the impact of ICTs on disadvantaged micro-entrepreneurs in Chile. Her choice framework, based on the capability approach, considers structure, agency, degrees of empowerment and development outcomes. It provided comprehensive evidence for structural social barriers and personal factors that possibly limit and promote desired capabilities.

Discussion

The capability approach has attracted a vast amount of scholarly attention since the early 1980s, when it was first proposed. Many interventions and programs that are run to address disadvantages and well-being can be conceived as having as their ultimate goal helping people to develop or protect their capabilities. Hence, it stands to reason that researchers choose to evaluate such programs for the impact that they have on their target audience's capability. The challenges that are associated with such a task have been well recognized (Burchardt & Vizard, 2011; Chiappero-Martinetti & Roche, 2009; Hollywood et al., 2012; Leßmann, 2012; Mitchell et al., 2016). The results of this review indicate that these challenges are not widely explicitly acknowledged in the field of capability impact assessment, and that measures to address these challenges are not routinely used.

Our starting point was that researchers who wish to explore a program's impact on the capability of its target audience may be expected to pay attention to the following aspects:

- provide evidence or reasons why it is reasonable to assume that prior to the deployment of the program, the target audience's capability is unduly constrained in one way or another, resulting in some type of inequity.
- make explicit the standard by which this is the case: what is it that members of the target audience should be able to do or be, in what way and at what level (in other words: what is the content of capability that is deemed appropriate for the relevant context?).
- take measures that enhance the credibility of the causal attribution of the findings: if findings suggest that capability has changed, is it reasonable to assume that such change was, in fact, brought about by the program under study?
- justify the time frame of the study: given the nature of capability, emerging from the complex interactions between resources, conversion factors and functionings, its development may take considerable time. The question is, therefore, whether the researchers allowed for sufficient time for capability to develop.

In the following, we will discuss each of these aspects in more detail. We will close by discussing to what extent the findings of our review should prompt us to reconsider, at least partly, the criteria that we have used to appraise this specific body of literature.

Evidence of capability deprivation, the standard, and its justification

When the value of some program is inferred from its impact on capability, it is generally implied that prior to deployment of the program, the capability of its target audience is unduly compromised, in one way or another. The aim of the assessment is to see whether the program can at least to some extent remediate this. The question is, then: how do we know that the capability is compromised, what is the standard that is being employed here, and where does it come from? Each of these three questions merit discussion or clarification, so that those who learn about the results of a capability impact assessment can put them in perspective.

We found in our review that such questions are discussed only to a limited extent. Studies with proposed standards were limited (about one-third of the studies), and in general with little justification. Of these three questions, the issue of justification is perhaps the most challenging. As mentioned in the introduction, there seem to be two schools regarding the question how the content of capability (what is it, exactly, that people in a specific context ought to be able to do or be?) is to be established. On the one hand, lists have been drawn up, containing broad categories of doings and beings that are considered to be universally valid. On the other hand, Sen has always wanted to stay away from such, in his view probably overly prescriptive or overly specified lists. Instead, he preferred that some deliberative process is used in order to decide on the content of capability that is deemed appropriate for the participants' context. An example of this approach was the study by Biggeri and Ferrannini (2014) and their O-gap analysis. There, the content of capability was identified by the population of interest through participatory group interviews among people with disabilities and their caregivers. It may not, however, be necessary to choose between these two strategies. The reason for this is that the categories of doings and beings included in the various lists may be defined at a very general level. In such case, it is not possible to decide what would follow from a commitment to these broad categories in concrete situations right away. For this, these broad categories need to be specified (Richardson, 1990, 2018). Hence, the subject of a deliberation would be how these broad categories would best be specified, rather than defining those broad categories themselves. The use of lists, then, can be combined with organizing a deliberative process, provided that the presumed valued modes of doing and being are phrased in a sufficiently general way.

Capturing capability change

Capability may be conceived as a measure of freedom: the real opportunities people have to be and do things they have reason to value. Raising the question whether there is evidence that people's capability was expanded is tantamount to raising the question whether their freedom was enlarged. When there are indications that people have gained a clearer understanding of what constitute doings and beings that represent value to them, and that they have gradually expanded activities in such domains, this may be taken to suggest that their freedom has, indeed, increased. Exploring concomitant changes in resources and conversion factors can, then, shed light on how such change was brought about. What is being assumed, here, is that capability expansion is expressed in observable changes in people's doings and beings and associated possibility conditions (resources and conversion factors). The task of the researcher is to make sure that such changes, if present, have been accurately established, and that they can be plausibly ascribed to the program that was deployed (for the latter, see below). It would suggest that the researcher is not, or not solely, dependent on perceptions and reports by members of the target audience about changes in capability.

However, such conditions may not always hold. Programs may have resulted in removing obstacles for capability, without this being translated in altered behavior of the target audience. In such cases, researchers may need to rely on respondents' judgments or experiences, as reported in interviews or surveys. In order to enhance the reporting of these procedures, we urge researchers to provide an account of the population's capability disadvantage, the norm applied to this population and its determination, and the approach to determining capability change. Practical suggestions as to how this may be achieved are presented in Appendix D.

Causal attribution

As a specific type of intervention research, capability impact assessment cannot avoid the making of causal claims. Two types of such claims may be distinguished: causal attribution of observed changes, differences, or trends in capability to the program under study, and claims regarding changes in resources, conversion factors, functionings and their mutual interactions acting as constraints on or affordances for capability development. In quantitative intervention studies, randomization, blinding, (placebo) control and statistical analysis are the chief means of rendering confounding, bias and chance less likely explanations of observed changes or differences. Our review showed that such measures are rarely, if at all, used (in fact, of the 71 studies, 7% included a prospective design, 18% used a control group, and no studies used random assignment of subjects or blinding). Researchers might rebut that such measures are largely inappropriate in this particular field of research, or simply unfeasible. That might, indeed, be the case, seeing that no studies in our review blinded or randomized their designs. However, we would then expect other types of measures that would support causal interpretation of the findings, and these, we found, are sparse as well. For example, there were only two studies that included both a prospective design and a control group (Mariscal Avilés et al., 2016; Mauro et al., 2015), and the latter was one of two quantitative designs.

It needs to be acknowledged, however, that the use of qualitative research in establishing causal relations is equivocal (Maxwell, 2004). In quantitative research, the focus is on discovering patterns in data (regularities and irregularities), allegedly produced by a causal mechanism that itself is not directly observable. Causal attribution is considered to be more likely if competing explanations (confounding, bias, chance) can be ruled out by using the sort of measures mentioned above. More often than not, researchers remain agnostic regarding the exact nature of the causal mechanism itself (black box evaluation, see, for instance, Ramaswamy et al., 2018). A different notion of causality, seen more often in qualitative research, holds that at least certain aspects of causal mechanisms can be empirically observed. It holds that these empirically observable elements are not merely traces of some causal mechanism that is or has been at work, but that these constitute elements of the causal mechanism itself (Maxwell, 2004). The focus, here, is not merely on establishing patterns in the (qualitative) data, but also to make inferences about the likely nature of the underlying causal mechanism through abductive reasoning (Aliseda, 2009).

Clearly, when adopting this strategy, researchers can be led astray in two different ways. Firstly, by erroneously making claims about patterns in the observed data, and, secondly, by drawing wrong conclusions about the nature of the alleged causal mechanism. Strategies that have been suggested (e.g., by Maxwell, 2004) to protect researchers from making such errors include:

- long-term and deep involvement of researchers in the practice that is being studied,
- the production of rich data, revealing various aspects of the objects or processes being studied.
- development of an account that puts a wide range of findings in a coherent framework.
- making observations on phenomena in a number of different ways, e.g., through participatory observation, interviewing, surveys, and document analysis (triangulation).
- searching for discrepant evidence, that is, findings that seem to challenge either the alleged pattern in the data or the proposed explanation, and
- member checking.

Jointly, these recommendations may be considered a strong plea for so-called theory-driven evaluation (Chen, 2012). We have incorporated these recommendations in a brief guidance to capability impact assessment (Appendix D).

Reflection on the evaluative framework that we employed

The framework that we used in order to appraise capability impact studies corresponds with criteria for validity assessment that have been suggested in the literature, even though the phrasing used may differ. As such, we think the framework is a reasonable starting point, with one important exception. We held that, generally speaking, prospective research would be preferable to retrospective research. The obvious reason for this was that prospective research is not afflicted with the complications that are posed by recall bias. However, this may not be entirely true in the case of capability impact assessment. If, as discussed above, researchers need to some extent to rely on respondents' reports of capability change, a prospective approach may be quite problematic. It would require that respondents are asked to reflect, prospectively, on what would constitute, for them, valuable doings and beings, and how that compares to their current situation. When conducted retrospectively, respondents can be asked to indicate how their daily life has changed in relation to the roll-out of the program. This may be an easier task, and, therefore, constitute a more valid approach. Having collected such information, it is up to the researchers to relate reported changes to broader categories of valued modes of doing and being. This approach was taken by, for instance, Alkire (2002), Cabraal (2010), and Powel (2012).

Limitations

A key limitation of our study is that we do not know whether we have missed important capability impact studies and, if so, how that would have affected our conclusions. Indeed, there may be studies that we were unable to retrieve with our search strategy, and that are more consistent with the criteria that we proposed. If that were the case, it would be, in a way, good news, and the situation would be less dispiriting than our review suggests. Our conclusion would, however, still be that there is a sizeable number of studies in this area that do not explicitly address the various common and unique challenges associated with capability impact assessment. Having said that, we do wish to point out that the diversity among the studies that we did find was substantial and included studies that can serve as inspiring example for future studies.

There are three further limitations that we wish to acknowledge. Firstly, we did not differentiate between individual and collective capabilities (Ibrahim, 2006). The focus in the studies that were included in this review seems to have been on individual capabilities, but this may at least be partly due to not making the distinction in our search of the literature.

Secondly, our focus has been on capability (how well people's lives are going), and not on agency (who or what controls them) (Crocker & Robeyns, 2009). As such, this review is necessarily silent on whether, and if so how, researchers have also addressed the issue of agency in the context of capability impact assessment.

Thirdly and finally, it is important to note that the goal of our study was to see whether researchers acknowledge the varied and considerable challenges associated with capability impact assessment and, if so, how they try to meet these challenges. This practice-based focus incurs a limitation, of course, in the sense that methods that could be quite useful in this respect but that have not yet been used in reports of capability impact assessment failed to appear in our search. Among these are, for example, are Krishnakumar's work on structural equation modeling, Andreassen and Tommaso's work on random utility models and Bayesian stochastic frontier models (Andreassen & Tommaso, 2018; Henderson, 2022; Krishnakumar & Wendelspiess Chávez Juárez, 2014).

Strengths

This article addressed a pertinent issue of evaluating the impact of programs on capabilities. In recent times, impact evaluation has become a common practice for programs aimed at enhancing people's well-being. The development of sound practices for evaluating programs' impact on capabilities is crucial in advancing knowledge in the subject. Our study endeavored to determine the extent to which researchers evaluating the impact on capabilities recognize specific challenges, how they address them, and the rationale behind their decisions. The findings revealed that there is still much to learn and comprehend regarding impact evaluation concerning capabilities. We used these findings in order to formulate specific recommendations that researchers may want to contemplate when designing and reporting capability impact assessments (Appendix D).

Conclusion: capability, justice, responsibility

This paper set out to see to what extent authors recognize and address the methodological challenges that accompany capability impact assessment. Using the framework of Arksey and O'Malley (2005) for scoping reviews, we found 71 empirical studies that reported methodology and data on how interventions impacted the beneficiaries' capability. In these studies, there was generally much to be desired in areas of causal attribution, clear reporting on justification on capability content, and including the constitutive elements of capability.

Writing on the responsibilities that are associated with effective power, Sen observes that

> *'if someone has the power to make a difference that he or she can see will reduce injustice in the world, then there is a strong and reasoned argument for doing just that…Freedom in general and agency freedom in particular are parts of an effective power that a person has, and it would be a mistake to see capability, linked with these ideas of freedom, only as a notion of human advantage: it is also a central concern in understanding our obligations. This consideration yields a major contrast between happiness and capability as basic informational ingredients in a theory of justice, since happiness does not generate obligations in the way that capability inescapably must do, if the argument on the responsibility of effective power is recognized.' (Sen, 2009, p. 270 – 271)*

Although Sen seems to have individual citizens in mind here, the reasoning could also be applied to governments that, one might assume, have 'the power to make a difference' in the sense described above. Evaluating programs for their potential to strengthen the capability of their target audience can be conceived as a means to help governments 'see' where and how they can make a difference. It also draws its findings into the realm of justice: if a program can be demonstrated to help groups whose capability is compromised to overcome constraints and expand their capability, this is not merely a nice thing to do, but a moral obligation. We have seen that conducting such studies well is a huge challenge.

Given the complexities involved, programs that are enacted in order to expand the capability of its target audience are likely to be effective in only some of the members, in some respect, some of the time. Perhaps the key object of capability impact studies would be to better understand this heterogeneity, enabling to help people develop their capability more effectively in the future. Articulating program theory, making the content of capability explicit, providing justification for the proposed specification of capability, and paying more closely attention to causality issues are, in our view, promising ways of achieving this end.

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References

1. Aliseda, A. (2009). Abductive Reasoning: Challenges Ahead. Theoria : An International Journal for Theory, History and Fundations of Science, 22(3).
2. Alkire, S. (2002). Valuing freedoms: Sen's capability approach and poverty reduction. Oxford University Press. Table of contents only http://www.loc.gov/catdir/enhancements/fy0611/2001055463-t.html
3. Publisher description http://www.loc.gov/catdir/enhancements/fy0611/2001055463-d.html
4. Contributor biographical information http://www.loc.gov/catdir/enhancements/fy0723/2001055463-b.html
5. Andreassen, L., & Tommaso, M. L. (2018). Estimating capabilities with random scale models: women's freedom of movement. Social Choice and Welfare, 50(4), 625-661. https://doi.org/10.1007/s00355-017-1099-8
6. Arksey, H., & O'Malley, L. (2005). Scoping studies: towards a methodological framework. International Journal of Social Research Methodology, 8(1), 19-32. https://doi.org/10.1080/1364557032000119616
7. Bandura, A. (1978). Reflections on self-efficacy. Advances in Behaviour Research and Therapy, 1(4), 237-269. https://doi.org/https://doi.org/10.1016/0146-6402(78)90012-7
8. Biggeri, M., & Ferrannini, A. (2014). Opportunity Gap Analysis: Procedures and Methods for Applying the Capability Approach in Development Initiatives [Article]. Journal of Human Development and Capabilities, 15(1), 60-78. https://doi.org/10.1080/19452829.2013.837036
9. Black, N. (1996). Why we need observational studies to evaluate the effectiveness of health care. BMJ (Clinical Research Ed.), 312(7040), 1215-1218. https://doi.org/10.1136/bmj.312.7040.1215
10. Burchardt, T., & Vizard, P. (2011). 'Operationalizing' the Capability Approach as a Basis for Equality and Human Rights Monitoring in Twenty-first-century Britain. Journal of Human Development and Capabilities, 12(1), 91-119. https://doi.org/10.1080/19452829.2011.541790
11. Cabraal, A. (2010). The Impact of Microfinance on the Capabilities of Participants RMIT University]. Melbourne.
12. Chen, H. T. (2012). Theory-driven evaluation: Conceptual framework, application and advancement. In R. Strobl, O. Lobermeier, & W. Heitmeyer (Eds.), Evaluation von Programmen und Projekten für eine demokratische Kultur (pp. 17-40). Springer Fachmedien Wiesbaden. https://doi.org/10.1007/978-3-531-19009-9_2
13. Chiappero-Martinetti, E., & Roche, J. M. (2009). Operationalization of the Capability Approach, from Theory to Practice: A Review of Techniques and Empirical Applications. In Debating Global Society. Reach and Limits of the Capability Approach. Grafica Sipiel.
14. Claassen, R. (2011). Making Capability Lists: Philosophy versus Democracy. Political Studies, 59(3), 491-508. https://doi.org/https://doi.org/10.1111/j.1467-9248.2010.00862.x
15. Crocker, D., & Robeyns, I. (2009). Capability and agency. In C. W. Morris (Ed.), Amartya Sen. Cambridge University Press.
16. Elster, J. (1982). Utilitarianism and the genesis of wants. In A. Sen & B. Williams (Eds.), Utilitarianism and Beyond (pp. 219 - 238). Cambridge University Press.
17. Fernández-Baldor, Á., Boni, A., Lillo, P., & Hueso, A. (2013). Are technological projects reducing social inequalities and improving people's well-being? A capability approach analysis of renewable energy-based electrification projects in Cajamarca, Peru. Journal of Human Development and Capabilities, 15(1), 13-27. https://doi.org/10.1080/19452829.2013.837035
18. Festinger, L. (1957). A theory of cognitive dissonance. Row, Peterson.
19. Finnis, J. (1980). Natural Law and Natural Rights (Vol. 31). Oxford University Press UK.
20. Giacomini, M. K., & Cook, D. J. (2000). Users' Guides to the Medical Literature: XXIII. Qualitative Research in Health Care A. Are the results of the study valid? JAMA, 284(3), 357-362. https://doi.org/10.1001/jama.284.3.357

21. Gigler, B.-S. (2014). Informational Capabilities: The Missing Link for Understanding the Impact of ICT on Development. In Closing the Feedback Loop: Can Technology Bridge the Accountability Gap? (pp. 17-42). The World Bank. https://doi.org/doi:10.1596/978-1-4648-0191-4_ch2
22. 10.1596/978-1-4648-0191-4_ch2
23. Hammerton, G., & Munafò, M. R. (2021). Causal inference with observational data: the need for triangulation of evidence. Psychological Medicine, 51(4), 563-578. https://doi.org/10.1017/s0033291720005127
24. Helter, T. M., Coast, J., Laszewska, A., Stamm, T., & Simon, J. (2019). Capability instruments in economic evaluations of health-related interventions: a comparative review of the literature. Quality of Life Research https://doi.org/10.1007/s11136-019-02393-5
25. Henderson, H. (2022). The Moral Foundations of Impact Evaluation. Journal of Human Development and Capabilities, 23(3), 425-454. https://doi.org/10.1080/19452829.2021.2014424
26. Hollywood, E., Egdell, V., McQuaid, R., & Michel-Schertges, D. (2012). Methodological Issues in Operationalising the Capability Approach in Empirical Research: an Example of Cross-Country Research on Youth Unemployment in the EU. Social Work & Society, 10(1).
27. Ibrahim, S., & Alkire, S. (2007). Agency and Empowerment: A Proposal for Internationally Comparable Indicators. Oxford Development Studies, 35(4), 379-403. https://doi.org/10.1080/13600810701701897
28. Ibrahim, S. S. (2006). From Individual to Collective Capabilities: The Capability Approach as a Conceptual Framework for Self-help [Article]. Journal of Human Development, 7(3), 397-416. https://doi.org/10.1080/14649880600815982
29. Keeley, T., Al-Janabi, H., Nicholls, E., Foster, N. E., Jowett, S., & Coast, J. (2015). A longitudinal assessment of the responsiveness of the ICECAP-A in a randomised controlled trial of a knee pain intervention. Quality of Life Research 24(10), 2319-2331. https://doi.org/10.1007/s11136-015-0980-0
30. Kleine, D. (2010). Technologies of choice? : ICTs, development, and the capabilities approach. MIT Press.
31. Krishnakumar, J., & Wendelspiess Chávez Juárez, F. (2014). Estimating Capabilities with Strucutral Equation Models: How Well are We Doing in a 'Real' World? Social Science Research Network. https://doi.org/10.2139/ssrn.2448115
32. Leßmann, O. (2012). Applying the Capability Approach Empirically: An Overview with Special Attention to Labor. Management Revue, 23(2), 98-118. http://www.jstor.org/stable/41783711
33. Lindeman, S. (2014). "Until We Live Like They Live in Europe": A Multilevel Framework for Community Empowerment in Subsistence Markets [Article]. Journal of Macromarketing, 34(2), 171-185. https://doi.org/10.1177/0276146713514753
34. Lorgelly, P. K., Lorimer, K., Fenwick, E. A., Briggs, A. H., & Anand, P. (2015). Operationalising the capability approach as an outcome measure in public health: The development of the OCAP-18. Soc Sci Med, 142, 68-81. https://doi.org/10.1016/j.socscimed.2015.08.002
35. Mariscal Avilés, J., Benítez Larghi, S., & Martínez Aguayo, M. A. (2016). The informational life of the poor: A study of digital access in three Mexican towns [Article]. Telecommunications Policy, 40(7), 661-672. https://doi.org/10.1016/j.telpol.2015.11.001
36. Marsden, E., & Torgerson, C. J. (2012). Single group, pre- and post-test research designs: Some methodological concerns. Oxford Review of Education, 38(5), 583-616. https://doi.org/10.1080/03054985.2012.731208
37. Mauro, V., Biggeri, M., & Grilli, L. (2015). Does Community-Based Rehabilitation Enhance the Multidimensional Well-Being of Deprived Persons With Disabilities? A Multilevel Impact Evaluation. World Development, 76, 190-202. https://doi.org/https://doi.org/10.1016/j.worlddev.2015.07.004
38. Maxwell, J. A. (2004). Using Qualitative Methods for Causal Explanation. Field Methods, 16(3), 243-264. https://doi.org/10.1177/1525822X04266831

39. Mayne, J. (2008). Contribution analysis: An approach to exploring cause and effect. https://hdl.handle.net/10568/70124

40. Michel, S., & Randriamanampisoa, H. (2017). The capability approach as a framework for assessing the role of microcredit in resource conversion: the case of rural households in the Madagascar highlands. Oxford Development Studies, 46(2), 215-235. https://doi.org/10.1080/13600818.2017.1368471

41. Mink, A., Van der Marel, F., Parmar, V., & Kandachar, P. (2015). Approaching design for development from a capability perspective [Article]. Current Science, 109(9), 1639-1650. https://doi.org/10.18520/v109/i9/1639-1650

42. Mitchell, P. M., Roberts, T. E., Barton, P. M., & Coast, J. (2016). Applications of the Capability Approach in the Health Field: A Literature Review. Social indicators Research, 133(1), 345-371. https://doi.org/10.1007/s11205-016-1356-8

43. Nussbaum, M. C. (2000). Women and human development : the capabilities approach. Cambridge University Press. Book review (Education Review) http://edrev.asu.edu/reviews/rev105.htm

44. Publisher description http://www.loc.gov/catdir/description/cam029/99015850.html

45. Table of contents http://www.loc.gov/catdir/toc/cam025/99015850.html

46. Nussbaum, M. C. (2011). Creating Capabilities. Harvard University Press. http://www.jstor.org/stable/j.ctt2jbt31

47. Powell, L. (2012). Reimagining the purpose of VET - Expanding the capability to aspire in South African Further Education and Training students [Article]. International Journal of Educational Development, 32(5), 643-653. https://doi.org/10.1016/j.ijedudev.2012.01.008

48. Powell, L., & McGrath, S. (2014). Exploring the value of the capability approach for vocational education and training evaluation: Reflections from South Africa. In Education, Learning, Training: Critical Issues for Development (pp. 126-148). https://doi.org/10.1163/9789004281158_008

49. Proud, L., McLoughlin, C., & Kinghorn, P. (2019). ICECAP-O, the current state of play: a systematic review of studies reporting the psychometric properties and use of the instrument over the decade since its publication. Quality of Life Research 28(6), 1429-1439. https://doi.org/10.1007/s11136-019-02114-y

50. Ramaswamy, R., Reed, J., Livesley, N., Boguslavsky, V., Garcia-Elorrio, E., Sax, S., Houleymata, D., Kimble, L., & Parry, G. (2018). Unpacking the black box of improvement. International Journal for Quality in Health Care 30(suppl_1), 15-19. https://doi.org/10.1093/intqhc/mzy009

51. Richardson, H. S. (1990). Specifying Norms as a Way to Resolve Concrete Ethical Problems. Philosophy & Public Affairs, 19(4), 279-310. http://www.jstor.org/stable/2265316

52. Richardson, H. S. (2018). Articulating the Moral Community: Toward a Constructive Ethical Pragmatism. Oup Usa.

53. Robeyns, I. (2003). The Capability Approach: An Interdisciplinary Introduction. International Conference on the Capability Approach, Pavia, Italy.

54. Robeyns, I. (2005). The Capability Approach: a theoretical survey. Journal of Human Development, 6(1), 93-117. https://doi.org/10.1080/146498805200034266

55. Rogers, P. (2014). Overview: Strategies for Causal Attribution: Methodological Briefs - Impact Evaluation No. 6. https://ideas.repec.org/p/ucf/metbri/innpub751.html

56. Sen, A. (1987). Commodities and capabilities. Oxford University Press.

57. Sen, A. (1992). Inequality reexamined. Harvard University Press.

58. Sen, A. (1999). Economics and health. Lancet, 354, 20-20. <Go to ISI>://WOS:000084342100021

59. Shadish, W. R., Cook, T. D., & Campbell, D. T. (2002). Experimental and Quasi-Experimental Designs for Generalized Causal Inference. Unknown Publisher.

60. Simon, J., Anand, P., Gray, A., Rugkasa, J., Yeeles, K., & Burns, T. (2013). Operationalising the capability approach for outcome measurement in mental health research. Social Science & Medicine, 98, 187-196. https://doi.org/10.1016/j.socscimed.2013.09.019

61. Teschl, M., & Comim, F. (2005). Adaptive Preferences and Capabilities: Some Preliminary Conceptual Explorations. Review of Social Economy, 63(2), 229-247. https://doi.org/10.1080/00346760500130374

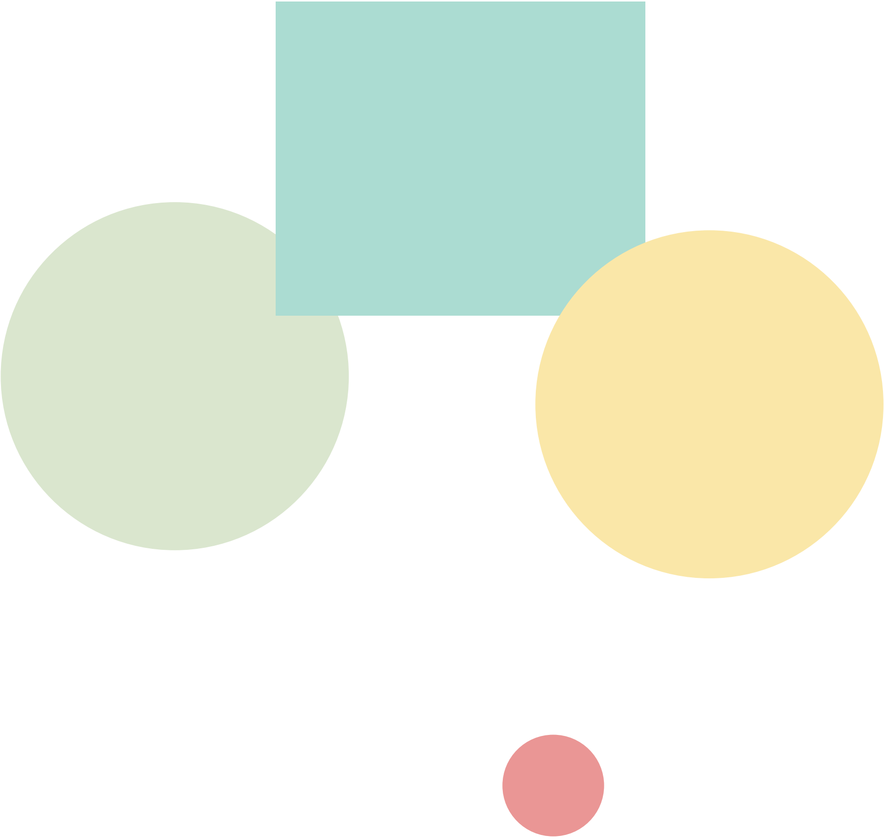
62. Van Staveren, I. (2008). Capabilities and Well-being. In. http://hdl.handle.net/1765/32799

63. Venkatapuram, S. (2011). Health Justice: An Argument from the Capabilities Approach. Polity Press.

64. Wolff, J., & De-Shalit, A. (2007). Disadvantage. Oxford University Press.

Appendices for Chapter 2

The Appendices for Chapter 2 can be found online: https://www.tandfonline.com/doi/suppl/10.1080/19452829.2023.2209027



3

CAPABILITY OF DEAF CHILDREN WITH A COCHLEAR IMPLANT

Rijke, W. J., Vermeulen, A. M., Wendrich, K., Mylanus, E., Langereis, M. C., & Van der Wilt, G. J. (2021). Capability of deaf children with a cochlear implant.
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https://doi.org/10.1080/09638288.2019.1689580

Abstract

*Introduction***.** The main idea underlying this paper is that impairments such as deafness are particularly relevant to the extent that they lead to deprivation of *capability*. Likewise, the impact of healthcare services such as cochlear implants and subsequent rehabilitation can best be inferred from the extent that they protect or restore capability of those affected.

*Methods***.** To explore children's post-implant capabilities, we tested two newly developed digital, adaptive child self-report and parent-report questionnaires in 19 deaf children (aged 8-12 years) and their parents during rehabilitation, as well as in 23 age peers with normal hearing.

*Results***.** Despite the impressive speech-language results that were recorded with cochlear implants, the post-implant capabilities of the deaf children we evaluated differed from those of their hearing peers, with the cochlear implant group appearing particularly disadvantaged in areas such as accessing information, communication, social participation, and participation in school.

*Conclusion***.** Deaf children with cochlear implants who are performing well on linguistic and auditory tests can still experience serious limitations in desired functioning. Our findings suggest that a capability approach may reveal aspects of what is being achieved through rehabilitation that might otherwise remain unnoticed, and that could help to further improve the well-being of our patients.

Introduction

Rehabilitation is about helping (former) patients to find or regain a mode and level of functioning that enables them to lead a gratifying and satisfying life. This normative concept implies that the patient’s aspirations are defined, taking into account his or her personal context, potential, motivation, and interests. A host of instruments, questionnaires, and scales have been developed to assess functioning and changes therein during rehabilitation. [1] In the study presented here, we will be exploring *capability* as a potentially useful concept to assist caregivers and deaf children in defining individual goals and in determining the associated achievements after cochlear implantation.

The concept of capability was developed by Nobel Prize laureate Amartya Sen as an alternative to utility for the measurement of human well-being. [2-4] According to Sen, an individual’s well-being should be primarily gleaned from the real opportunities an individual has for being and doing the things he has reason to value. [5, 6] Hence, capability extends beyond an individual’s actual functioning by asking what range of valued activities and modes of being are available to him. The idea of capability then differs from other available models and instruments in the sense that it aims to establish the degree of freedom a patient enjoys or lacks in choosing his or her own way of life. In other words, to what extent does a patient’s life reflect own choices and to what extent is it determined by factors inherent to the individual patient and his/her social and physical environment? Accordingly, capability is conceived as a function of the resources that are available to an individual and his or her ability to convert those resources into something that represents value to him. Among such conversion factors are an individual’s social and physical conditions, as well as his own physical, mental, and social competencies. [7]

Although the concept has attracted extensive interest from a wide range of disciplines globally, its operationalisation is still considered a challenge. [7, 8] Key issues here include 1) the delineation of what constitute, in a particular context, valuable activities and modes of being, 2) the lack of methods to establish whether someone might be capable of being or doing something, especially if that person has, for one reason or another, refrained from entering in certain activities or modes of being so far, and 3): the identification of the resources and conversion factors that are critical to the enactment of such activities or attainment of the desired mode of being.

In this paper, we will present the first results obtained with a child- and parent-report questionnaire that was specifically developed to explore the capability of deaf children wearing a cochlear implant. In the Western world, the majority of the prelingually deaf children (i.e. those with an onset of deafness before the age of 4) receive such an implant.

[9] In terms of their post-implant performance on hearing and speech tests, these children can generally achieve levels that are close to those of their normal-hearing peers.[10-15] Also in terms of self-reported quality of life, their scores tend not to differ from those obtained in their peers.[16-19] However, performance scores on standardised hearing and speech tests may merely predict poor performance in day-to-day conditions (e.g. at school, in public spaces, at home), while self-reported quality of life measures may be confounded by the response shift phenomenon, i.e. the respondents' adaptation to their (new) living conditions.[2, 3, 20] The assessment of capability could then reveal whether, in spite of the cochlear implant and subsequent rehabilitation, children still experience constraints in pursuing their aspirations in terms of achievements and modes of being. If this proves to be the case, possible underlying causes can be explored, differentiating between the lack of requisite resources and factors impeding their conversion, potentially offering ways to remediate the situation.

After detailing our study populations, we will briefly describe the development of our post-implantation capability questionnaires, after which we will compare their outcomes to the performance results obtained with standardised hearing and speech tests.

Materials and methods

Participants

We invited 19 deaf children with cochlear implants (consecutive sampling) in the ages between 8 and 12 years attending grades 3-6 of a local mainstream primary school or a regional primary school for the deaf) and their parent(s) / caregiver(s) to participate in the study during their annual follow-up at the out-patient clinic of our academic hospital. We recruited 23 age-matched normal-hearing children from local mainstream primary schools. Table 1 lists the demographic and clinical characteristics for the two study groups.

Table 1. Demographic characteristics of the children with cochlear implants and the age-matched normal-hearing controls.

Characteristic	Children with CI	Normal-hearing children
n	19	23
Age$_{years}$, M (SD)	10.3 (1.3)	10.5 (1.1)
Age of Implantation$_{years}$, M (SD)	3.3 (2.2)	NA
Gender, m/f	5/14	11/12
Unilateral/bilateral cochlear implantation	6/13	NA

Table 1. *(Continued)*

Characteristic		Children with CI	Normal-hearing children
Education, mainstream/special		11/8	23/0
Aetiology	Pneumococcal meningitis	1	NA
	Auditory neuropathy spectrum disorder	1	NA
	Hereditary deafness	1	NA
	Usher syndrome I	1	NA
	Pendred syndrome	1	NA
	DFNB1, DFNB3, DFNB8	3	NA
	Unknown	11	NA

Assessments

Capability

For our study we developed two digital, adaptive child and parent self-report questionnaires. “Types of doings and beings”, or functionings, that children in our particular age group living in developed countries might value were derived from the relevant literature [15, 21-24], from conversations with parents of children with cochlear implants conducted at our clinic, and input from members of the cochlear implant team of our hospital. This resulted in nine domains: School participation, Information access, Relationship with parents, Social participation, Social skills, Communication, Assertiveness, Independence, and Psychological well-being. We initially formulated 40 items asking about functionings within each domain; this list was reduced to 22 by combining overlapping concepts. All 22 items are scored on a 3-point Likert scale, ranging from positive to negative. For each domain, the questionnaire starts by inquiring about the perceived state of affairs through a statement (e.g. “I participate in sports activities”). Depending on the answer, different questions are presented: in case of “true,” a question appears asking about any difficulties relating to performances with the topic. To distinguish between non-performance due to inability or different interests, the respondent is asked why performance is not possible, or why it is difficult. The parents independently complete the same questionnaire, giving their estimation of their child’s capability, where the phrasing of items is adapted to match the parental perspective. Note that it was only the parents of the children with a cochlear implant that completed this questionnaire since we were primarily interested to learn whether the ratings of the children with impaired hearing differed from their parents’ ratings. Concordance in the responses of the parent-child pairs was calculated using Cohen’s Kappa coefficients.

The children with cochlear implants and their parents completed the questionnaire separately during their annual appointment at the outpatient clinic or at home, while the normal-hearing children did so at school.

Depending on the responses, three capability levels were distinguished for each of the 22 domains: optimal capability (level A) in case of performance with little or no difficulty, moderate capability (level B) in case of difficulties in performing, to minimal/absent capability (level C) in case of non-performance and perceived inability to perform. Table 2 shows the breakdown of the capability levels.

Table 2. Capability levels as defined based on response combinations

Capability level	Response combination
A (Optimal)	1.1 statement about functioning very true, easily performed OR
	2.1 statement about functioning a bit true, easily performed
B (Moderate)	1.2, 1.3 statement about functioning very true, but performance a bit or very difficult, OR
	2.2, 2.3 statement about functioning a bit true, performance a bit or very difficult, OR
	3.1, 3.2 statement about functioning not true, but can be performed
C (None)	3.3 statement about functioning not true, performance not possible

Speech perception in noise

Speech-perception abilities in noise were assessed with the Bosman Dutch open-set identification test, containing consonant – vowel – consonant words (Bosman & Smoorenburg, 1995). Stimuli were presented via loudspeakers to prevent lip-reading in a sound-treated booth at a presentation intensity of 65 dB SPL with a 65 dB SPL noise level, resulting in a 0db speech/noise ratio. Response consisted of the oral repetition of the presented word. Speech perception was quantified as the percentage of phonemes that was correctly repeated. The clinical norm score of 59% was used as the cut-off point [25].

Word comprehension

Word comprehension was assessed with the Peabody Picture Vocabulary Test-III-NL (PPVT) [26]. Stimuli consisted of words presented live by the experimenter with lip-reading being possible. The children were asked to identify the stimulus word from four pictures presented to them. Outcomes were expressed as correct words identified, where a minimum quotient score of 85 (one SD below average) was used as the cut-off threshold [26].

Analyses

The capability levels (A – C) were determined per domain for each child. The differences in domain scores between the cochlear implant and the control group were tested for statistical significance using non-parametric Mann-Whitney U tests. We used chi-square tests to differentiate between the two conditions in terms of optimal (A) capability items. Correlations between capability levels and speech and hearing performance outcomes were assessed using non-parametric Spearman correlation tests. Internal consistency analysis was applied to test the coherence of the nine domains using SPSS, version 22. A p-level of 0.05 (two-sided) was considered statistically significant.

Ethical considerations

The Radboud University Medical Centre's Committee on Research Involving Human Subjects (CMO) approved the study protocol (reference 2016-2845). Written informed consent was obtained from the children's parents. The children were allowed to withdraw from the study at any point without them or their parents having to provide reasons for ending their participation.

Results

The distribution of the capability levels across the various domains for our two study groups is shown in Figure 1.

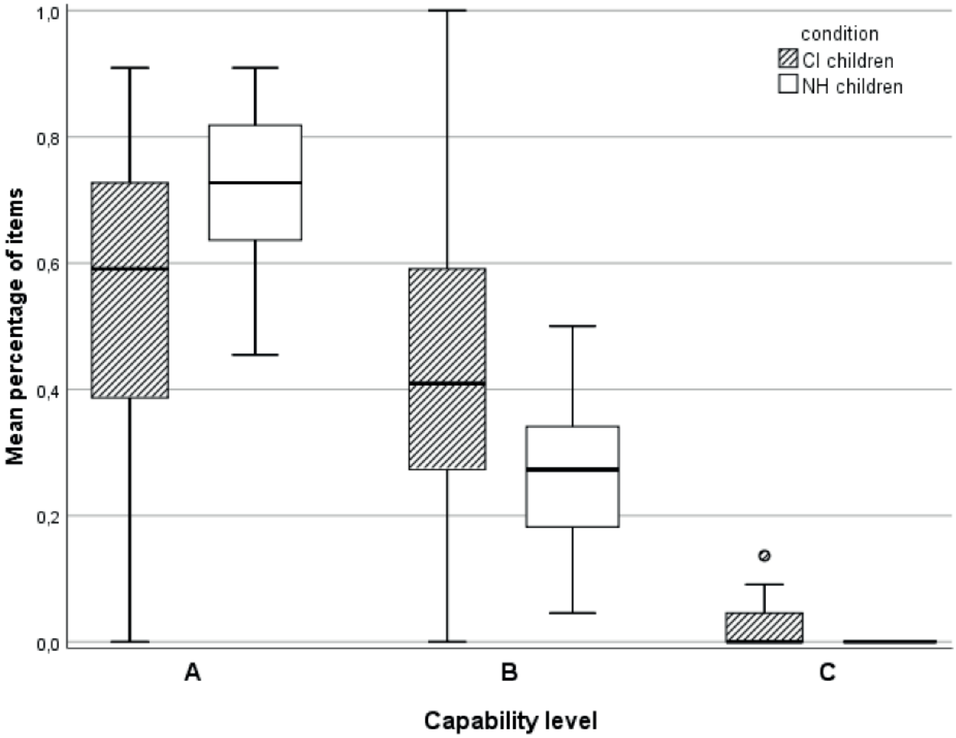

Figure 1. Box plots of the percentage of items per capability level for the children with cochlear implants (CI) and the normal-hearing children (NH).

The cochlear implant group scored significantly less often within the optimal capability range (level A) than the control group (54%, SD = 25%, versus 72%, SD = 12%, U = 121.5, p = .014), while the normal-hearing children were significantly less often categorised at level B (moderate capability) (27%, SD = 12%, versus 44%, SD = 25%, U = 122.5, p = .015). No significant differences were observed between the ratings of the children with cochlear implants and their parents.

Of the 19 children with cochlear implants six were classified at capability level C for at least one item (vs. 3 of the 23 normal-hearing children). The internal consistency analysis revealed that the 22 items could be considered independent (Cronbach's α < .5).

Table 3. Results of chi-square tests and descriptive statistics for Capability Level per study group

Item	Capability level	Child-normal hearing	Child-cochlear implant	χ^2	df	p
Understanding the teacher	Optimal (A)	18 (78%)	7 (37%)	7.466	2	.024
	Sub-optimal (B or C)	5 (22%)	12 (63%)			
Searching for information on the internet	Optimal (A)	19 (83%)	9 (47%)	8.972	3	.03
	Sub-optimal (B or C)	4 (17%)	10 (53%)			
Meeting with friends	Optimal (A)	22 (96%)	9 (47%)	13.190	4	.01
	Sub-optimal (B or C)	1 (4%)	10 (53%)			
Tell someone when s(he) doesn't understand	Optimal (A)	19 (83%)	6 (32%)	14.655	3	.002
	Sub-optimal (B or C)	4 (17%)	13 (68%)			
Getting freedom from parents	Optimal (A)	22 (96%)	12 (63%)	7.966	3	.047
	Sub-optimal (B or C)	1 (4%)	7 (37%)			

The mean percentage of phonemes the children with cochlear implants correctly repeated (speech perception in noise test) is 69% (SD = 15%). Figure 2 shows the relationships between these scores and the children's optimal (level A) capabilities. The horizontal reference line divides the data into two equal parts, separating the children with less than half of their answers leading to optimal capabilities from those with more than half, where the vertical reference line separates the adequate from the poor performers based on the 59% cut-off threshold (clinical norm score). [25]

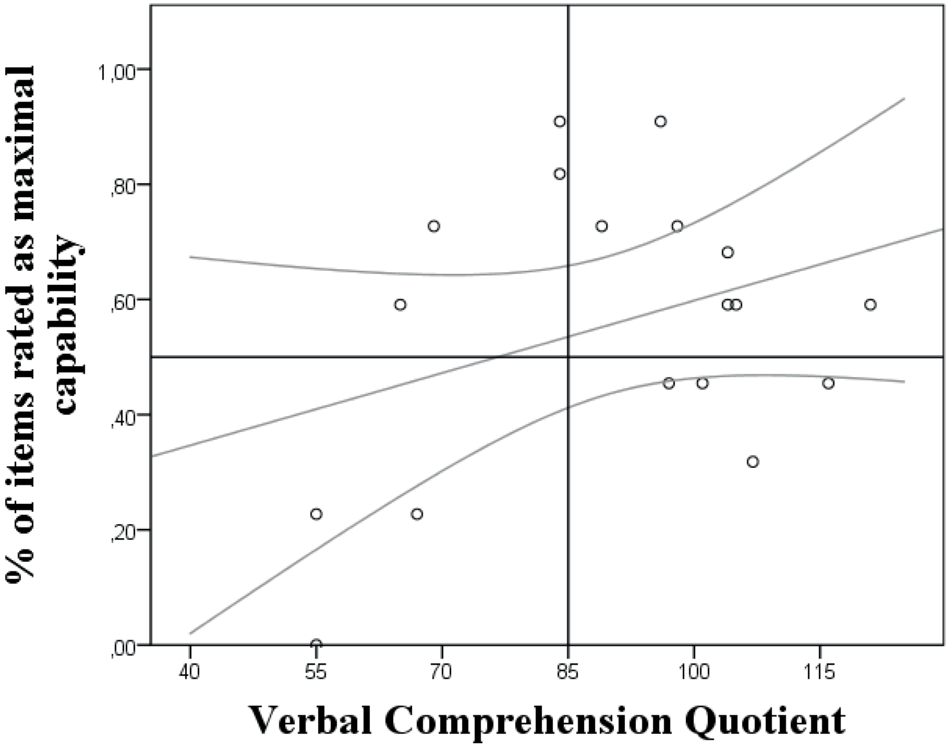

Figure 2. Phoneme scores for the speech perception in noise test and the capabilities for the children with cochlear implants. The grey lines are regression lines and 95% confidence intervals; the vertical and horizontal reference lines indicate cut-off points for the two outcomes.

Figure 3 shows the associations between the capabilities and word comprehension results of the cochlear implant group, expressed as verbal comprehension quotients (M = 90, SD = 20). Deviating more than one standard deviation (15) from the test's norm (100) is considered poor performance and indicated by the vertical reference line.

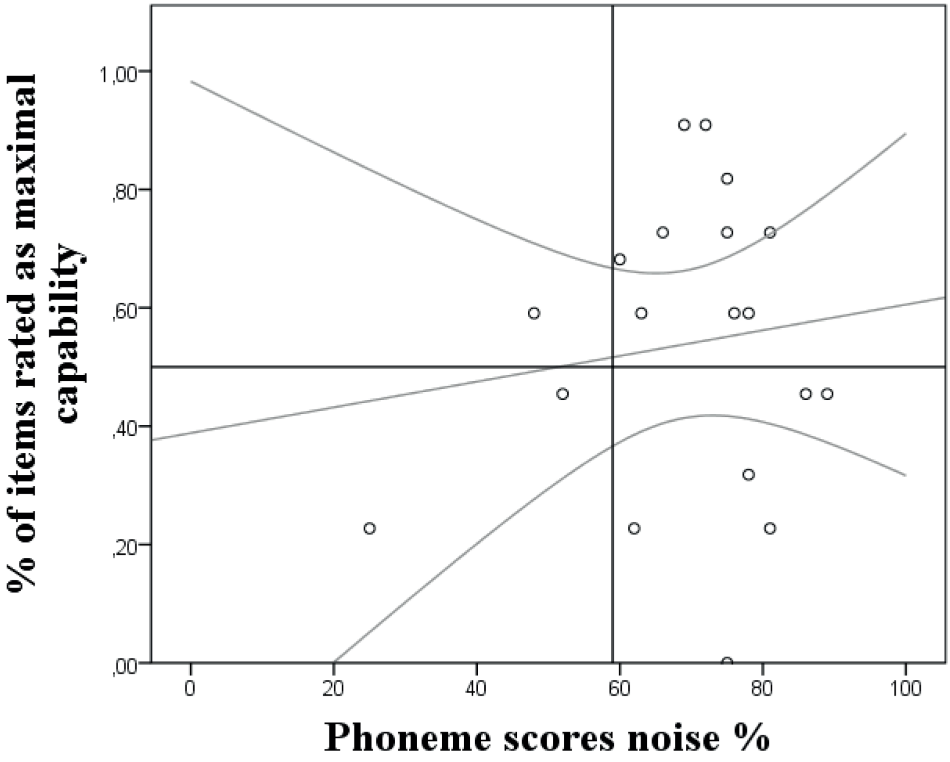

Figure 3. Word comprehension as expressed in the verbal comprehension quotient and the capabilities for the children with cochlear implants. The grey lines are regression lines and 95% confidence intervals; the vertical and horizontal reference lines indicate cut-off points for the two outcomes.

The children with good and sufficient verbal comprehension and phoneme performance (depicted in the two quadrants to the right-hand side of the vertical line) still differed widely in terms of capabilities, having the most problems with going out on their own, solving their own problems, and understanding the feelings of other children. More than half of the ratings of the four children depicted in the upper-left quadrant were classified as capability level A, specifically high degree of freedom from parents, having fun, and good relationship with their parents, while their performance on the clinical measures was insufficient.

Child-parent correlations

The overall agreement on child- and parent-reported capabilities (cochlear implant group only) was relatively low, with only seven of the 19 child-parent dyads showing significant agreement on all 22 items, with Cohen's Kappa coefficients ranging from poor ($\kappa = .16$, $p = .04$) to fair agreement ($\kappa = .63$, $p < .001$).

Open questions

The children with cochlear implants reported significantly lower capability levels on five of the 22 items than their normal-hearing peers. Table 4 presents a summary of their answers on the open questions (e.g. "Why is it difficult for you to achieve …") of these five items. No significant differences were found on the remaining 17 items.

Mention is made of difficulties hearing teachers or keeping up with the signs when sign language is used, with other factors including lack of vocabulary, difficulties speaking clearly and typing on a keyboard. Also, some environmental issues are mentioned, such as noise in the classroom and living far away from school and friends. Social problems that are reported include feeling ashamed when they need to ask for help, being bullied, or being nervous of other people's reactions.

Table 4. Examples of capability constraints reported by children with cochlear implants

Item	Answer
Understanding the teacher	"The teacher signs too fast and she sometimes uses difficult signs or words." – Girl (11)
	"Sometimes I do not hear it." – Girl (10)
Information on the internet	"I don't know what words to use [in my search terms]." – Boy (9)
	"I find it hard to type." – Girl (9)
Meeting with friends	"My friends live very far away, so I would be home too late." – Girl (8)
	"I find it difficult when friends want something different from what I want." – Boy (9)
Tell someone when s(he) doesn't understand	"I cannot talk clearly" – Girl (11)
	"If I don't know someone, I don't know how they are going to react." – Girl (10)
Freedom from parents	"Those are my parents' rules." – Girl (9)
	"I'm not allowed to ride my bike when it's getting dark." – Girl (10)

Discussion

A key question, in any rehabilitation context, is in what way and to what extent illnesses (acute or chronic) interfere with the daily lives of those directly affected, and how rehabilitation succeeds in remediating this. There are various approaches to assess disease-related impact and changes following interventions and rehabilitation, each with their own strengths and weaknesses. In the case of deaf children who have received a cochlear implant, speech perception (in noise) and verbal word comprehension are considered important parameters. However, using a child and parent version of an adaptive self-report questionnaire we explored the effects of cochlear implants on a wider range of capabilities of these children and our findings provide preliminary evidence that mentioned hearing-related measures are relatively poor proxies of the true impact of cochlear implants. Although we by no means wish to suggest that these conventional tests are not useful to monitor hearing-related changes, we do suggest that exploring other post-implant capabilities may provide valuable insights into the wider effects of the treatment and rehabilitation given that, even with significantly improved speech-language functions, we found the post-implant capabilities of the deaf children we assessed to still differ from those of their normal-hearing peers, with the cochlear implant group particularly lagging behind in domains such as accessing information, communication, social and in-school participation.

This is in contrast with results from studies on self-reported quality of life, suggesting that deaf children with cochlear implants are usually on a par with their normal hearing peers. [16-19, 27] The difference might be explained by a differential impact of response shift, the general phenomenon of adjustments of humans to adverse conditions (including chronic illness or disability) over time. [28] We would hypothesize that this phenomenon is manifest in particular when questionnaires are being used that query respondents about their experienced quality of life, such as the KIDSCREEN, KINDL and CHIP-CE. [29-31] In contrast, in the present study, the questionnaire queries respondents about their assessment of their capability to perform valued tasks. We intend to explore this issue further, using methods that have been described in the literature for assessing response shift such as card sorting, the then-test, or idiographic assessment of personal goals. [32]

Our capability questionnaire helps members of the cochlear implant team and the children and their parents to identify problem areas that may still exist in spite of the child's adequate performance on conventional measures, where the additional outcomes may prompt them to find causes and solutions for the child's constrained capabilities. Conversely, it may be highly informative to explore the mechanisms underlying apparently adequate capabilities in spite of relatively poor hearing-related performance. Of course, the causes and remedy of (certain) discrepancies in assessment outcomes may be beyond the realm of clinical or ambulatory care, but in the interest of the child and the need to optimise care services, it seems sensible to include other than clinical factors that also warrant attention, even if this involves referrals to other remedial or (health)care services. The questionnaire that we have presented in this paper could support cochlear implant teams in their evaluations and shared decisions.

Clearly, the nature of the capability concept requires a different approach from cochlear implant team members as well as an instrument with relevant, explicitly phrased and adaptive questions. Firstly, agreement should be sought among cochlear implant team members, the children, their parents, and other stakeholders regarding the nature of the "doings and beings" that may be considered of value in age categories and individual contexts. Secondly, the focus should then be on whether the child would be able to achieve these given its personal circumstances. We opted to first inquire about the actual, self-perceived state of affairs and whether the child or parent saw any problems in the area at hand. Our reasoning, here, was that in case of engagement or experiences, capability is implied. In case no involvement or achievement was reported, we sought to determine whether this was due to the child having different interests or whether the child did take an interest but considered him/herself incapable of achieving the activity or state, which, evidently, would reflect a different type of constrained capability. In the former case, where the child shows little interest in an activity or state that is *generally* considered of value, the lack of capability will be of little significance to the child, while in the latter case, where it did aspire to the activity or state but reported failure to achieve it, remedial intervention may be considered.

At the group level, the deficits in capability involved the domains of accessing information, participating socially, and feeling independent as described by the children reporting non-participation/no experience in the topic that they did aspire to, while foreseeing difficulties should they try and engage in it. This information can help identify the daily-life problems after cochlear implantation and rehabilitation and inspire changes in the latter process. At the patient level, the proposed capability approach could help to explore opportunities to further a child's capabilities in problem areas.

Limitations and future directions

Our findings are a first step towards the development of a child- and parent-report instrument that can help cochlear implant teams monitor how the capabilities of post-implant children develop during their rehabilitation. The differences in capability between the children with cochlear implants and normal-hearing peers it revealed, appear to support its discriminant validity as one could expect these groups to differ on these themes. Application of the questionnaire in a larger sample of cochlear implant patients is needed to test other hypotheses and uncover potential adaptations before we can confirm the scale's reliability and (external) validity. [33]

Our inter-respondent reliability analysis showed poor agreement in the child and parental judgments, but this was to be expected since parents and children are known to vary in their perceptions of the quality of life of children learning to live with cochlear implants.[18, 19, 27] Taking validity as a test of hypotheses [33], we should base the premises on how we expect deaf children with cochlear implantss or any post-treatment patient from different socioecological backgrounds to score on such a capability instrument on the relevant literature and new empirical findings. We feel that the described approach as such is applicable in other rehabilitation contexts, where our questionnaire can help the various stakeholders to reflect on the types of capabilities ("doings and beings") that could be relevant to assess in their specific settings. Additional data might also be derived from participatory observations, for instance, and from empirically surveying prerequisites for capability.

Conclusion

Capability testing provides a different lens through which to look at patients after they have received a health intervention and to gauge the benefits and problems they experience during their rehabilitation process. Basically, it allows us to see whether and how they succeed in finding new degrees of freedom to shape a life of their own choosing. This requires that we, beyond conventional clinical indices, also explicitly consider the kind of activities and states that they aspire to and reflect on whether and how these can become attainable for any specific group or individual patient to further improve their well-being.

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Conflict of Interest Statement

The authors declare that there is no conflict of interest.

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References

1. Karimi M, Brazier J, Basarir H. The Capability Approach: A Critical Review of Its Application in Health Economics. Value Health. 2016 Sep - Oct;19(6):795-799. doi: 10.1016/j.jval.2016.05.006. PubMed PMID: 27712707.
2. Bellanca N, Biggeri M, Marchetta F. An extension of the capability approach: Towards a theory of dis-capability. ALTER - European Journal of Disability Research / Revue Européenne de Recherche sur le Handicap. 2011;5(3):158-176. doi: 10.1016/j.alter.2011.05.001.
3. Morris C. Measuring participation in childhood disability: how does the capability approach improve our understanding? Dev Med Child Neurol. 2009 Feb;51(2):92-94. doi: 10.1111/j.1469-8749.2008.03248.x. PubMed PMID: WOS:000262510000005; English.
4. Trani JF, Browne J, Kett M, et al. Access to health care, reproductive health and disability: a large scale survey in Sierra Leone. Soc Sci Med. 2011 Nov;73(10):1477-89. doi: 10.1016/j.socscimed.2011.08.040. PubMed PMID: 22014873.
5. Sen A. Equality of What? Cambridge: Cambridge University Press; 1980.
6. Sen A. Economics and health. Lancet. 1999 Dec;354:20-20. PubMed PMID: WOS:000084342100021; English.
7. Robeyns I. Sen's Capability Approach and Gender Inequality: Selecting Relevant Capabilities. Fem Econ. 2003;9(2-3):61-92. doi: 10.1080/1354570022000078024.
8. Robeyns I. The Capability Approach: a theoretical survey. Journal of Human Development. 2005 2005/03/01;6(1):93-117. doi: 10.1080/146498805200034266.
9. Petersen NK, Jorgensen AW, Ovesen T. Prevalence of various etiologies of hearing loss among cochlear implant recipients: Systematic review and meta-analysis. Int J Audiol. 2015;54(12):924-32. doi: 10.3109/14992027.2015.1091094. PubMed PMID: 26642892; PubMed Central PMCID: PMCPMC4732452.
10. Niparko JK, Tobey EA, Thal DJ, et al. Spoken language development in children following cochlear implantation. JAMA. 2010 Apr 21;303(15):1498-506. doi: 10.1001/jama.2010.451. PubMed PMID: 20407059; PubMed Central PMCID: PMCPMC3073449.
11. Boons T, De Raeve L, Langereis M, et al. Expressive vocabulary, morphology, syntax and narrative skills in profoundly deaf children after early cochlear implantation. Res Dev Disabil. 2013 Jun;34(6):2008-22. doi: 10.1016/j.ridd.2013.03.003. PubMed PMID: 23584181.
12. Boons T, De Raeve L, Langereis M, et al. Narrative spoken language skills in severely hearing impaired school-aged children with cochlear implants. Res Dev Disabil. 2013 Nov;34(11):3833-46. doi: 10.1016/j.ridd.2013.07.033. PubMed PMID: 24029803.
13. De Raeve L. A longitudinal study on auditory perception and speech intelligibility in deaf children implanted younger than 18 months in comparison to those implanted at later ages. Otol Neurotol. 2010 Oct;31(8):1261-7. doi: 10.1097/MAO.0b013e3181f1cde3. PubMed PMID: 20802371.
14. Peterson NR, Pisoni DB, Miyamoto RT. Cochlear implants and spoken language processing abilities: review and assessment of the literature. Restor Neurol Neurosci. 2010;28(2):237-50. doi: 10.3233/RNN-2010-0535. PubMed PMID: 20404411; PubMed Central PMCID: PMCPMC2947146.
15. Vermeulen AM, van Bon W, Schreuder R, et al. Reading comprehension of deaf children with cochlear implants. J Deaf Stud Deaf Educ. 2007 Summer;12(3):283-302. doi: 10.1093/deafed/enm017. PubMed PMID: 17537924.
16. Loy B, Warner-Czyz AD, Tong L, et al. The children speak: an examination of the quality of life of pediatric cochlear implant users. Otolaryngol Head Neck Surg. 2010 Feb;142(2):247-53. doi: 10.1016/j.otohns.2009.10.045. PubMed PMID: 20115983; PubMed Central PMCID: PMCPMC2852181.

17. Meserole RL, Carson CM, Riley AW, et al. Assessment of health-related quality of life 6 years after childhood cochlear implantation. Qual Life Res. 2014 Mar;23(2):719-31. doi: 10.1007/s11136-013-0509-3. PubMed PMID: 23975382; PubMed Central PMCID: PMCPMC3948324.

18. Razafimahefa-Raoelina T, Farinetti A, Nicollas R, et al. Self- and parental assessment of quality of life in child cochlear implant bearers. Eur Ann Otorhinolaryngol Head Neck Dis. 2016 Feb;133(1):31-5. doi: 10.1016/j.anorl.2015.10.002. PubMed PMID: 26520481.

19. Warner-Czyz AD, Loy B, Roland PS, et al. Parent versus child assessment of quality of life in children using cochlear implants. Int J Pediatr Otorhinolaryngol. 2009 Oct;73(10):1423-9. doi: 10.1016/j.ijporl.2009.07.009. PubMed PMID: 19674798; PubMed Central PMCID: PMCPMC2891383.

20. Hart CS. How Do Aspirations Matter? Journal of Human Development and Capabilities. 2016;17(3):324-341. doi: 10.1080/19452829.2016.1199540.

21. Kouwenberg M, Rieffe C, Theunissen SC, et al. Peer victimization experienced by children and adolescents who are deaf or hard of hearing. PLoS One. 2012;7(12):e52174. doi: 10.1371/journal.pone.0052174. PubMed PMID: 23284923; PubMed Central PMCID: PMCPMC3526587.

22. Schorr EA, Roth FP, Fox NA. Quality of life for children with cochlear implants: perceived benefits and problems and the perception of single words and emotional sounds. J Speech Lang Hear Res. 2009 Feb;52(1):141-52. doi: 10.1044/1092-4388(2008/07-0213). PubMed PMID: 18664684.

23. De Raeve L, Vermeulen A, Snik A. Verbal Cognition in Deaf Children Using Cochlear Implants: Effect of Unilateral and Bilateral Stimulation. Audiol Neuro-Otol. 2015;20(4):261-266. doi: 10.1159/000381003. PubMed PMID: WOS:000357596100007; English.

24. Bat-Chava Y, Martin D, Kosciw JG. Longitudinal improvements in communication and socialization of deaf children with cochlear implants and hearing aids: evidence from parental reports. J Child Psychol Psychiatry. 2005 Dec;46(12):1287-96. doi: 10.1111/j.1469-7610.2005.01426.x. PubMed PMID: 16313429.

25. Sparreboom M, Langereis MC, Snik AF, et al. Long-term outcomes on spatial hearing, speech recognition and receptive vocabulary after sequential bilateral cochlear implantation in children. Res Dev Disabil. 2014 Nov 5;36C:328-337. doi: 10.1016/j.ridd.2014.10.030. PubMed PMID: 25462493.

26. Dunn LMD, Leota M. Peabody Picture Vocabulary Test-III-NL, Nederlandse versie door Liesbeth Schlichting. Amsterdam: Harcourt Assessment B.V.; 2005.

27. Huber M. Health-related quality of life of Austrian children and adolescents with cochlear implants. Int J Pediatr Otorhinolaryngol. 2005 Aug;69(8):1089-101. doi: 10.1016/j.ijporl.2005.02.018. PubMed PMID: 15946746.

28. Albrecht GL, Devlieger PJ. The disability paradox: high quality of life against all odds. Soc Sci Med. 1999;48(8):977-988. doi: 10.1016/S0277-9536(98)00411-0.

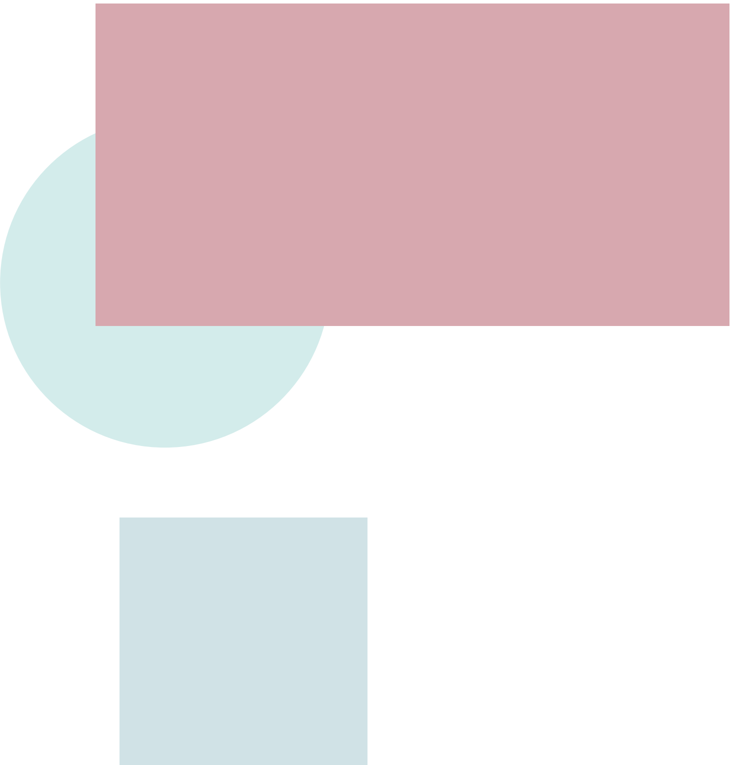
29. Riley AW, Forrest CB, Rebok GW, et al. The Child Report Form of the CHIP-Child Edition. Med Care. 2004;42(3):221-231. doi: 10.1097/01.mlr.0000114910.46921.73.

30. Ravens-Sieberer U, Gosch A, Rajmil L, et al. KIDSCREEN-52 quality-of-life measure for children and adolescents. Expert Rev Pharmacoecon Outcomes Res. 2005 Jun;5(3):353-64. doi: 10.1586/14737167.5.3.353. PubMed PMID: 19807604; eng.

31. Bullinger M, Brütt AL, Erhart M, et al. Psychometric properties of the KINDL-R questionnaire: results of the BELLA study. Eur Child Adolesc Psychiatry. 2009;17(S1):125-132. doi: 10.1007/s00787-008-1014-z.

32. Schwartz CE, Sprangers MAG. Methodological approaches for assessing response shift in longitudinal health-related quality-of-life research. Soc Sci Med. 1999;48:1531-1548.

33. Streiner DL, Norman GR. Health measurement scales : a practical guide to their development and use. 2nd ed. Oxford ; New York: Oxford University Press; 1995. (Oxford medical publications).



4

CAPABILITY OF CHILDREN WITH HEARING DEVICES: A MIXED METHODS STUDY

Rijke, W. J., Vermeulen, A. M., Willeboer, C., Knoors, H. E. T., Langereis, M. C., & Van der Wilt, G. J. (2023). Capability of Children with Hearing Devices: A Mixed Methods Study. *Journal of deaf studies and deaf education*, *28*(4), 363–372.
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Abstract

We investigated 34 deaf and hard-of-hearing children with hearing devices aged 8 to 12 years and 30 typical hearing peers. We used the Capability Approach to assess well-being in both groups through interviews. Capability is ‘the real freedom people have to do and to be what they have reason to value’. Speech perception, phonology, and receptive vocabulary data of the deaf and hard-of-hearing children, that were used retrospectively, showed a large variability. The analysis of the relation between clinical quantitative outcome measures and qualitative Capability interview outcomes suggests that at this age, differences in clinical performance do not appear to translate into considerable differences in Capability. Including Capability did offer insight in the factors that appeared to ensure this equivalence of Capability. We argue that Capability outcomes should be used to determine the focus of (auditory) rehabilitation and support, in line with the United Nations Convention on the Rights of the Child.

Introduction

Optimization of patients' functioning and enabling their participation in valued activities are core elements of rehabilitation. In fact, it is a nation's responsibility that persons with disabilities can exercise their right to make decisions for their lives and be active members of society (*Convention on the Rights of Persons with Disabilities*, 2006). To evaluate efforts that aim to contribute to this goal, there should be an account of freedom to make decisions, in addition to insights in what activities are considered valuable to individuals and the society they are part of. Societies are groups of people who live together in specific ways. Not living together is hardly an option for human beings, but how they live together is subject to a considerable degree of variation. Living together confers benefits to individual members, but some seem to succeed in gaining more benefit out of it than others. A continual question for societies is how such relative advantages and disadvantages should be assessed and what, if anything, should be done to mitigate them (Wolff & De-Shalit, 2007). There is no undisputed answer to this long-standing question. According to some, the increase in the aggregate surplus of pleasure over pain is the single appropriate yardstick (Lazari-Radek & Singer, 2014). However, such utilitarian views have been fiercely criticized (e.g., Rawls, 1999). Building on the work by Rawls, Nobel laureate Amartya Sen has suggested that relevant differences in advantages and disadvantages among people can best be captured in terms of their capability (Sen, 2009). In the capability approach, individual advantage or disadvantage is judged by a person's capability to do things he or she has reason to value; the focus is on the freedom that a person actually has to do this or be that (Sen, 2009, p. 231). The capability approach offers a specific informational focus in judging and comparing overall individual advantages (Sen, 2009, p. 232). As such, it proposes a specific way of answering questions like: are, in a specific society or community, individuals with a particular disability disadvantaged as compared to their non-such-disabled peers? Specifically, it invites us to address such question by probing into the freedom that such persons have to do or be things they have reason to value.

The Capability Approach is not a measure of self-reported (health-related) quality of life. The quality of life of DHH children and TH children is often found to be similar ((Loy et al., 2010; Meserole et al., 2014; Razafimahefa-Raoelina et al., 2016; Warner-Czyz et al., 2009), while it would be unlikely to assume they are similar in their advantages and disadvantages. Sen developed the capability concept explicitly as a metric for expressing the relative advantages and disadvantages that people have. He held that in this respect, the real opportunities that people have to do and be things they have reason to value is more relevant than subjective wellbeing or possession of primary goods (Sen, 2009). He also emphasized that capability is the outcome of the interplay between resources, conversion factors, and functionings ('doings and beings'), visualized in figure 1.

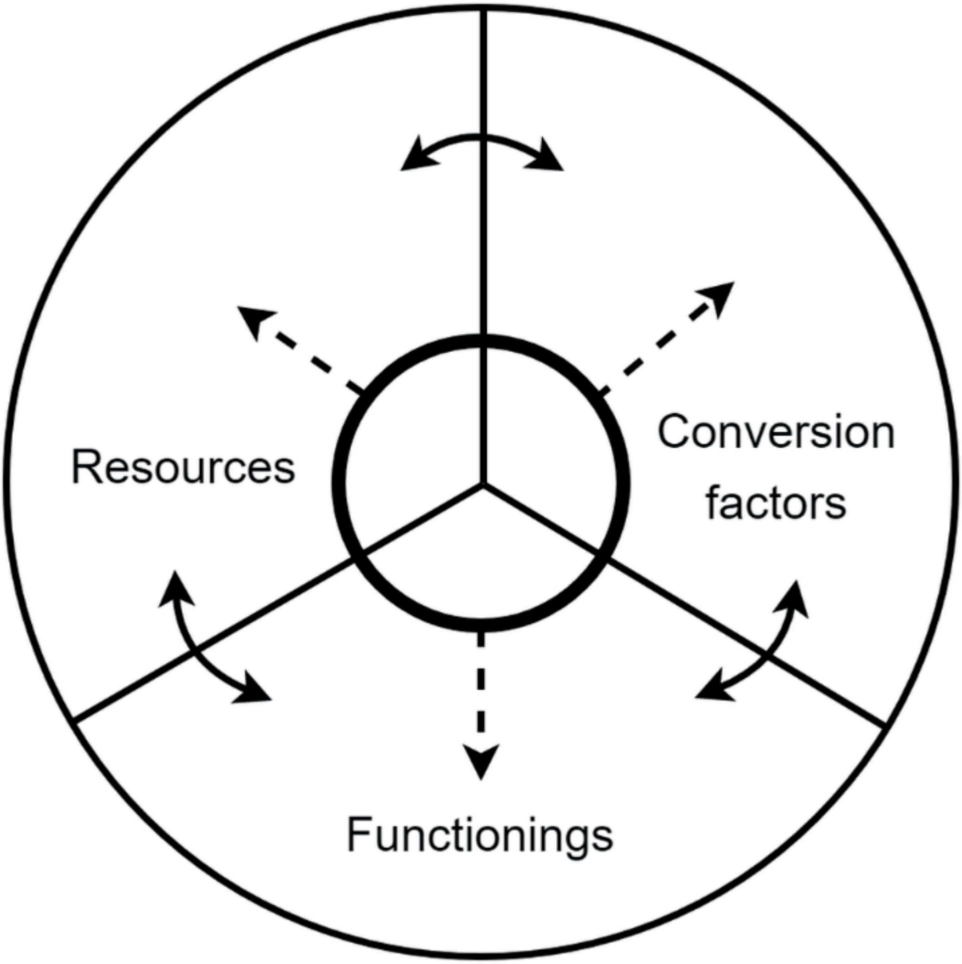


Figure 1. The concept of capability. Capability is the set of real opportunities that people have to be and to what they have reason to value. Capability is an interplay of realised opportunities (called functionings), the necessary resources and personal, social, and environmental factors (called conversion factors).

Resources can be conceived as production factors, such as hearing devices, Hearing Assistive Technologies, or even money. Conversion factors are all personal, social, and environmental factors that determine whether people can actually deploy those resources in such a way as to achieve something of value. For example, a personal conversion factor that determines the value of a hearing device is the experienced gain/benefit of it. Social conversion factors can be acceptance and understanding from others, while environmental conversion factors might be related to acoustics. Functionings are the things that people then actually do and are, such as hearing another person, speaking, reading, or socializing.

It could be argued that rehabilitation should result in strengthening recipients' Capability. The question is, however, what counts as evidence of enhanced Capability, and how such evidence can best be obtained. Capability enables people to freely choose to do (e.g., to meet with friends) and be (e.g., healthy, independent) anything they have reason to value. Hence, adopting the Capability Approach in (auditory) rehabilitation and support would require two things:

- a reflection on the nature of the valued modes of doing and being in a particular context: what may be considered of such general value that it should, at least to some extent, be attainable for all members of that community?
- an analysis of the conditions of opportunity (resources, conversion factors and functionings, and their interplay).

Although the capability concept appears quite congenial to the theory and practice of rehabilitation, its application to the field is still in its infancy. In the recent years, there have been some excellent reviews of several capability measurement instruments (Proud et al., 2019; Ubels et al., 2022) and their use in economic evaluations (Helter et al., 2019). These reviews show how capability can capture the outcomes of value in health and economic evaluations. However, they also conclude that these instruments fail to reflect the burdens people experience to achieve capability, while also unable to include the participants' contexts. We noticed the same limitations in a previous study, measuring capability in deaf children with cochlear implants through a questionnaire (Rijke et al., 2019).

The objective of the current study was to observe and study deaf and hard-of-hearing (DHH) children through a capability lens. Especially for (auditory) rehabilitation purposes, it would be relevant to know how the capability approach can be of added value.

Materials and methods

Participants

During the inclusion period of the study (12 months), we included 64 children between the age of 8 and 12 years old that attended primary education: 34 DHH children and 30 TH children. DHH children all used unilateral or bilateral hearing devices: 23 had cochlear implants, and 11 had hearing aids. The hearing aid children had hearing losses starting at 25 dB (average thresholds at 1, 2, and 4 kHz). DHH children were approached to enroll in the study before their annual fitting of their hearing device and follow up evaluation of their development in their out-patient clinic. We excluded non-Dutch speaking children or children with additional severe complex needs, who were not able to express themselves in an interview setting. We did not preselect for other factors. We included TH children to explore what interests, functionings, resources, and conversion factors are distinct for DHH children, and what rehabilitation should provide for them in order to maximize their Capability in a society focused primarily on typical hearing people. Mainstream primary schools were approached for the inclusion of TH children, who were interviewed in groups of five. It was not practical nor ethically warranted to invite TH children to the hospital to ensure the same interviewing context as DHH children.

Assessments

In order to determine capability, information on interests, resources, conversion factors, and functionings was collected both qualitatively and quantitatively in DHH children. We included standard auditory and psycholinguistic assessments: speech perception, receptive spoken language vocabulary, verbal working memory, and phonological processing. These assessments were included to explore how potential differences in the qualitative outcomes could be explained by poor or high scores on speech and auditory tests. The clinical measures concern the mechanisms of construction, maintenance and processing, and the retrieval of meaning of phonological memory traces that are involved in communication in spoken language (Nittrouer et al., 2013; Pisoni et al., 2011). Verbal working memory and phonological processing are a prerequisite for language development. Both TH children and DHH children were interviewed; the clinical indicators were only assessed in the latter.

Capability interview

All participating children and their parents were informed that the overall goal of the interview was to learn more about how they are doing, what is important in their daily lives, and what factors are helping or hindering them in doing or being what they think is valuable. The interviews with the DHH children were carried out after the regular check-up of their hearing devices, to ascertain optimal speech perception during the interview. Children could choose whether a parent was present during the interview. No interviews were interrupted, aside from one interview with TH children; this was shortly halted due to outside construction noises. Interviews were fully audio recorded, and intelligent (non-verbatim) transcripts were subsequently created. The children had not met the interviewer (the first author) previously. The interviewer (male, late-twenties, typical hearing) had a background in psychology and was trained in qualitative research. The interviews were in spoken Dutch. Prior to the interviews, the child's need for a sign language interpreter was inquired with the parents but was waived for all children. One child attended a school where sign supported speech was used. He said that unless there was loud music, he could hear and understand the interviewer.

The main questions in the interview were centered to daily activities: *"Would you tell me something about a typical day, and a typical week? What do you do, where do you go, and what do you need to do those things?"* These questions were used to stimulate the child to formulate as much as possible without priming from the interviewer. When describing a typical week, themes like school, leisure activities, sports, social events, and family time came up. To ensure we systematically captured as broad a range of themes as possible, we framed the interview with the seven basic goods proposed by John Finnis (1980): life, knowledge, play, sociability, practical reasonableness, aesthetic experience, and transcendence. The interviewer ensured these were addressed in the interviews. Answers were typically met with questions to elaborate (i.e., *"How?", "Why?", "Can you tell me more about that?"*) and questions about the child's choices, reasoning, resources, support, and obstacles, such as *"Are there things that you would like to do or be, that you are not capable of right now?"* and "*What do you use most to achieve that?*".

Speech perception

Speech perception abilities were assessed with the NVA Dutch open set identification test, containing meaningful consonant – vowel – consonant words (Bosman & Smoorenburg, 1995). Stimuli were presented in a sound-treated booth at a presentation level of 65 dB SPL and 45 dB SPL in quiet, and subsequently at 65 dB SPL with a 65 dB SPL noise level, resulting in a 0 dB speech/noise ratio. Words and noise originated in the same loudspeaker, with continuous noise with spectral speech characteristics. Stimuli were presented via loudspeakers, where no speech reading was possible. Response was given by repetitions of the perceived item. Speech perception was quantified as the percentage phonemes correctly repeated. This resulted in three scores: speech perception at 65 dB, 45 dB, and 65 dB in noise.

Receptive spoken language vocabulary

Receptive spoken language vocabulary was assessed with the Dutch version of the Peabody Picture Vocabulary Test-III-NL (PPVT) (Dunn, 2005). The PPVT can be assessed in people aged 2 through 90. Stimuli consisted of words that were presented live, speechreading was possible. The task consisted of identifying the stimulus-word out of four pictures. Spoken language vocabulary was expressed in one score, the word quotient, which is calculated based on age norms. The average quotient is 100 with an average standard deviation of 15.

Verbal working memory

Verbal working memory was assessed with two subtests of the Clinical Evaluation of Language Fundamentals (CELF) 4: digit span forward and digit span backwards. In these tasks, spoken digit strings of increasing lengths must be repeated forward or backwards (Semel et al., 2003). Forward repetition reflects the ability to store information in the phonological loop of the verbal working memory. Backwards repetition appeals on the slightly different ability to process information in verbal working memory. Verbal working memory is therefore expressed in two scores, where the average norm score is 10 with a standard deviation of 3.

Phonological processing

A non-word repetition task was used to assess phonological processing. With no speech reading possible, 16 Dutch non-words had to be repeated, for example /ji'nus/. This task focusses on measuring the encoding skills and phonological storage. The words consist of two to five syllables. Phonological processing was expressed in a single score, the correct percentage of repeated phonemes. On average, school-going children with TH score 92.4% with a standard deviation of 2.9% (Bree et al., 2007).

Analyses

Qualitative data were analyzed using a deductive (or directed) qualitative content analysis (Mayring, 2000). This type of content analysis has the researcher starting with predetermined codes from an existing theory, which in this case is the capability approach. Excerpts were coded as either interest, resource, conversion factor, or functioning, following the central elements in the capability approach. In the coding process, interests are what a child identifies as important, fun, or desirable. Resources are the materials and means that children depend on to realize their interests. Conversion factors are the personal, environmental, and social factors that influence how resources lead to capability. Functionings are activities and states children are and do. These are often dependent of resources and conversion factors. Codes could overlap, as an excerpt could contain information on more than one code (e.g., a cochlear implant can be both a resource as a conversion factor, depending on the interest). The coding process was computer assisted, using ATLAS.ti version 8 for Windows. Every answer was selected and coded to fit the closest description of an interest, resources, conversion factor, or functioning. The interrater reliability analysis, represented by Kappa, was performed in six interviews with another PhD-student to determine consistency among raters (Giacomini & Cook, 2000; MacPhail et al., 2016). After coding, documents were generated by ATLAS.ti with codes per group. For example, a document could hold all resources (code) for TH children (group). These were then listed in tables that are discussed in the Results section.

The following quantitative clinical indicators were used to support our qualitative analysis: Speech perception in quiet at 65 and 45 dB, in noise at 65 dB SPL SN=0, receptive vocabulary, digit span forward and backward, and phonological processing. To explore how results from clinical indicators relate to interview outcomes, we selected children who performed either poorly (in the lowest quartile) or highly (in the highest quartile) on three or more of the seven clinical indicators and explored their interview outcomes. Potential differences in clinical indicators between children with hearing aids or cochlear implants are beyond the scope of this paper and will therefore not be reported.

Results

The following results describe differences between DHH children and TH children. The interrater reliability was .84, which is considered high. Table 1 lists the demographic characteristics.

Table 1. Demographic characteristics of the children with cochlear implants, hearing aids and typical hearing children.

Characteristic		Children with cochlear implant(s)	Children with hearing aid(s)	Typical hearing children
n		23	11	30
Age in years	M (SD)*	10.1 (1.2)	9.2 (0.6)	11.1 (1.0)
	Range	7.8-12.0	8.3-10.4	9.0-12.0
Age of first aid in years	M (SD)	3.4 (2.3)	3.7 (2.4)	Not applicable
	Range	1.1-8.1	0.1-6.4	Not applicable
Gender	m	16	5	12
	f	7	6	18
Aids*	unilateral	7	0	Not applicable
	bilateral	16	11	
Education*	Mainstream	13	11	30
	special	10	0	0

*Significant difference between groups

Groups were statistically different in age (H (2) = 11.188, p = .004), unilateral or bilateral fitting (X^2 (1) = 4.213, p = .04), and mainstream or special education (X^2 (2) = 21.127, p < .001).

Clinical indicators

The majority of the participated DHH children perform adequate on the clinical indicators. Five children scored in the lowest quartile of at least three of the seven clinical indicators. To explore the interviews supported by the clinical indicators, we calculated the percentile of every clinical indicator for every DHH child. We displayed these percentiles in Figure 2, where every vertical line is a DHH child, in order of poor performance to high performance.

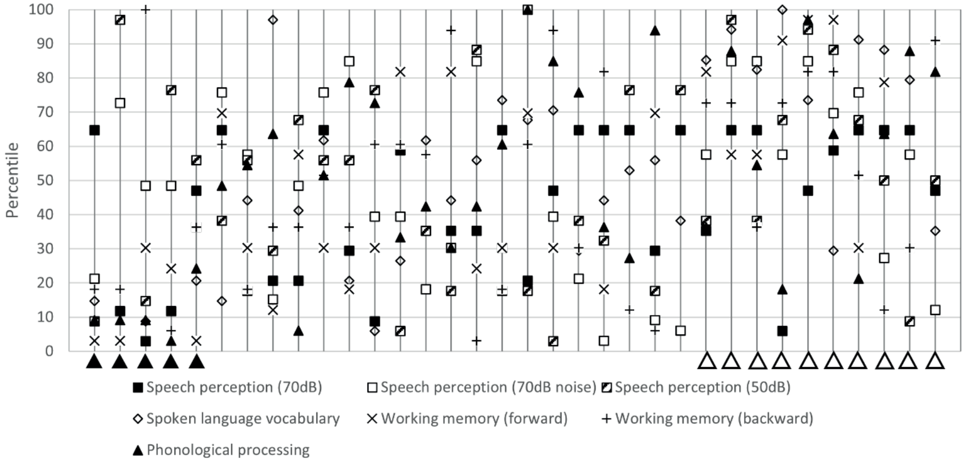


Figure 2. Performance of 34 deaf and hard-of-hearing children on clinical indicators in percentiles. Every vertical line is a DHH respondent. Poor and high performers are marked with solid and transparent triangles, respectively.

The outcomes of the five children who performed poorly on the clinical indicators are interesting for further investigation. What are their characteristics and what do they say in the interviews on their capability? All five scored in the lowest quartile of spoken language vocabulary and phonological processing. They were all boys with a cochlear implant in special education. In contrast, ten of 34 DHH children scored in the highest quartile of at least three of the seven clinical indicators. They were six girls, four boys, all attending mainstream education. Seven of the ten had cochlear implants. Their interview outcomes are discussed further in the Results section, under *Interview outcomes from children with poor or high performance on clinical indicators*.

Functionings, resources, and conversion factors

When talking about their daily lives, DHH children mentioned similar 'doings and beings' as TH children. Children of both groups went to school, with some children with cochlear implants being enrolled in special education. Both DHH and TH children cycled to go to school, sports, or other activities. However, children attending special education did rely on their parents to give them a ride to school and to other activities. All children participated in Physical Education in school, liked to play outside, and most children were a member of a sports club. However, while DHH children tended to engage in similar daily activities (functionings) as their hearing peers did, they were dependent on supporting resources and conversion factors to be able to do so. These functionings, resources, and conversion factors are listed in Table 2. When these supporting resources and conversion factors were absent, they acted as barriers for Capability.

Table 2. Functionings of typical hearing children compared to functionings of deaf and hard-of-hearing children, and related resources and conversion factors.

Typical hearing	Deaf and hard-of-hearing		
Functionings	Functionings	Resources	Conversion factors
General, i.e., not related to specific functionings	=	Cochlear implant or hearing aid	Full batteries, big earpieces
		Hearing Assistive Technologies	Correct use by wearer, acceptance of peers, feel different
		Flashing light doorbell Vibrating alarm clock	Uncomfortable sounds
			Dependence on lip reading
			Feel dependence on hearing device
			More assertiveness is needed to get others to help
			Parents are afraid hearing device could get lost, broken
			Loud noises lead to high beeps
School	=	Hearing Assistive Technologies	Acoustics, direction of sound, echo in Physical Education class, acceptance and understanding from peers, teachers
		Peripatetic teaching	
		Special Education (smaller classrooms, adapted acoustics, teachers capable of sign language)	Taxi, additional support
Sports	=	Accessories for hearing device and Hearing Assistive Technologies: (swimming) caps, cords, headbands, (water) cases, clips, cables.	Parents: play a role in choosing sport or safety measures.
Tennis, gymnastics, ballet, hockey, competitive swimming, korfball, soccer	= Ice skating, volleyball, horseback riding, kickboxing		Vulnerability of hearing devices: could fall off, is not waterproof, could take a hit. Swimming interpreter.
	No sailing		Hearing device could get lost

Table 2. *(Continued)*

Typical hearing	Deaf and hard-of-hearing		
Functionings	Functionings	Resources	Conversion factors
Riding the bike, both alone, together, talking	=		Help from others in traffic, some have trouble identifying direction of sound, hearing cars.
Swimming	Not hearing others while swimming	Water case	Lip reading, supporting signs, sign language, having to dry ears and hair before being able to put on hearing device
Play outside	=		Sweater with cap to protect cochlear implants
Spend time with friends	=		Late home from school (when attending special education)
Holiday	=		Not being able to fly due to cabin pressure
Trampoline	=		Headpiece falls of when jumping
Watching tv / Netflix / YouTube		Hearing Assistive Technologies	Subtitles, direct audio streaming
Music listening, making	=	Hearing Assistive Technologies	Direct audio streaming
Sleepovers	=	Charger	

Note. An equal sign (=) depicts similar functionings compared to typical hearing children

Other functionings that were mentioned by both TH children and DHH children were spending time with family, playing games, playing on the playground, drawing and crafting, reading, playing with LEGO sets, and singing along with music. In conversations with DHH children, parental involvement was a frequent topic compared to TH children. Parental engagement was mentioned as companionship or support and guidance when deciding what extracurricular activities are appropriate.

> *"My best friend is… that big guy there! [points to father]. In school I have friends, but not best friends." – boy, 8, cochlear implants, mainstream education*

> *"I always wear my hearing aids. Except with sleeping, showering, and swimming. And sailing because my parents were nervous about that. Because I could lose one." – boy, 9, hearing aids, mainstream education*

During analysis, it stood out that while there was little difference in the number of children that engaged in activities related to music (17 of 30 TH children compared to 17 of 34 DHH children), there was a difference in the kind of activities. In TH children who engaged in music related activities, 11 of 17 children played an instrument, compared to 7 of 17 DHH children, where the majority preferred to sing and dance. Two TH children mentioned that they participated in a musical or theater production.

Interests

Interests represent what children identified as important, fun, or desirable. Table 3 compares interests of TH children and DHH children.

Table 3. Interests of typical hearing children compared to deaf and hard-of-hearing children

Typical hearing	Deaf and hard-of-hearing children
Physical Education, love hate relationship with school, sports	=
Listening to music	=
Singing	=
Dancing	=
Playing an instrument	=
Musical	
Theatre (acting)	
	Be able to hear people or media
	Be able to be normal
	Others not to notice their deafness
	Others to be aware of what it’s like to have hearing loss
	Feel like not being able to become a teacher, because of her hearing loss
	Be able to hear traffic, direction, and chat while cycling
	Be able to shower with sounds
	Be able to use sign language when hearing is not possible
	Be able to turn off their hearing devices to have silence, when sleeping or fighting
	Be able to play sports without restrictions of their hearing loss, use of their hearing devices, assistive equipment, or protective gear for their device. Be able to hear whistles of referees.
	Be able to swim and still hear, without the need for waterproof housings.

Note. An equal sign (=) depicts similar functionings compared to typical hearing children

DHH children frequently mentioned situations in which they would like to be able to hear people or media (videos and music). Children reported that they would like to be 'normal' (boy, 9, cochlear implants, mainstream education), other people to not notice their deafness (boy, 9, hearing aids, mainstream education), and they would like other people to be aware of what it is like to have a hearing loss (girl, 8, hearing aids, mainstream education). One girl felt like she would not be able to become a teacher, because of her hearing loss:

> *"I like a lot of professions for later, but I can't decide yet. And some are off for me, because I can't do it with hearing aids, like a teacher or something like that." – girl, 9, hearing aids, mainstream education*

Most children liked sports. DHH children did mention challenges during sports that TH children did not. They would have liked to play sports without the restrictions that come along with their hearing loss or the use of their hearing devices or assistive equipment. Their comments included they would like to be able to detect the sound of whistles of referees and they do not like wearing protective gear for the device. These children never brought up quitting their sport despite these restrictions, however.

> *"I'm not allowed to only wear just a cap [when ice-skating], because my mother's afraid the cochlear implant will break if I fall. So, I must wear a helmet. […] it's a shame, because I'm now in the competition team, and it's about hundredths and thousands and that helmet…" – Girl, 11, cochlear implants, mainstream education*

> *"On sailing camp, I didn't wear my hearing aids because my mother said I could lose one." – Boy,9, hearing aids, mainstream education*

Interview outcomes from children with poor or high performance on clinical indicators

The interview responses from DHH children who performed poorly on clinical indicators showed that they did not have many friends and preferred to engage in activities alone. Children who scored in the lowest quartile in only two of the seven indicators did not express statements such as engaging in activities alone or not having many friends. One boy mentioned in the interview that he sometimes has trouble distinguishing voices amongst people. He used Hearing Assistive Technologies in school only. He also played sports, liked gaming, and playing with LEGO sets. Another boy mentioned having a very close relationship with his father, saying he is his best friend. He played tennis and liked to play volleyball. His biggest issue with his cochlear implants was that he cannot use them while swimming.

Relatively high performing children did not report experiencing major problems in their daily lives, and their daily use of hearing aids or cochlear implants ranged from wearing it only to school to wearing it all day, every day, and using Hearing Assistive Technologies and waterproof cases. Although major problems in functioning are averted, these ten children did include the girl who can't reach top speeds in ice-skating due to the helmet she wears for her cochlear implants and a girl that was not allowed to wear her cochlear implant when sailing with friends, as she could lose it. In addition, these ten collectively report difficulties in busy classrooms, hearing direction in traffic, and batteries being empty in inconvenient moments.

Discussion

An encouraging key finding of our study was that DHH children barely differed from TH children in terms of self-reported functionings (what they do/are). However, depending on performance on clinical indicators, they appeared to be dependent on specific conversion factors. These included Hearing Assistive Technologies, the management and coping with environmental noise, and the technical features of the devices, such as connectivity with other devices and volume control. For many children, assistive devices are a way of controlling input from their surroundings. How the devices function as conversion factor seems to determine the degree of freedom DHH children experience. Another conversion factor is parental involvement, both for support and for advice when deciding how to use cochlear implants or hearing aids during extracurricular activities. Although the dependency of children on their parents for converting capability into functionings is not surprising (Ballet et al., 2011; Biggeri et al., 2006), it is notable how their parents were mentioned frequently in interviews with DHH children as compared to TH children. This is especially noteworthy as no question in the interviews specifically addressed parental involvement. DHH children described this involvement as both supportive (e.g., an 8-year-old's father being described as his best friend) and obstructive (e.g., not being allowed to sail). Multiple recent studies made observations that identified parents' involvement in DHH children as multifaceted (Erbasi et al., 2018), higher among mothers than fathers (Brand et al., 2018), and resulting in parental stress (Zaidman-Zait et al., 2015). Previous studies reported that teachers had considerably lower expectations of DHH children which resulted in permitting them to take less responsibility (Meinzen-Derr et al., 2018; Reed et al., 2008; Smith, 2008). This is problematic, as it could lead to a state of learned helplessness and a higher dependency on others, such as their parents or teachers (Mathews, 2015; Wolters et al., 2012).

Being different

Another notable finding is that both children with hearing aids and cochlear implants express interests not heard in TH children. They report the desire to not differ from their TH peers, to be 'normal' and that others do not notice their deafness. Moreover, they want to be accepted and understood by their peers. At the same time, they want their special needs to be acknowledged. They wish others to understand that communicating in a busy classroom is challenging and tiring, and that they need sign language when spoken language does not suffice, and that they need to ask others to reiterate something they said. While sign language is often a second language for children with hearing aids and cochlear implants, the wish to be able to communicate at all times should be recognized. The interplay between wanting to be normal but still wanting to be acknowledged is worth noting, as problems may arise when deafness is not fully accepted or coped with at a later age (Castellanos et al., 2018; Wolters, 2013). Also, children that receive additional support, such as special education, attend school further away from home and cycle less, which might have repercussions for social relationships in their neighborhood (Dirks & Knoors, 2019).

Remarkably, whilst it being their most important resource, many of the DHH children noted that the best feature of their hearing device is that it could be turned off. Hearing through a hearing device is known to be effortful and fatiguing, as sounds and speech discrimination can be extremely limited in noisy environments, making fluent communication challenging (Hicks & Tharpe, 2002; Lewis et al., 2016; Ohlenforst et al., 2017). Frequent and prolonged daily use is encouraged, however, as it is correlated with higher speech perception scores (Easwar et al., 2018; Guerzoni & Cuda, 2017).

Comparing clinical indicators and interview outcomes

Relatively poor performance on one or two clinical indicators (such as speech perception and phonological processing) did not appear problematic based on interview outcomes. Children tended to compensate on different areas, leading to fewer problems in pursuing valuable activities. When children performed poorly on three or more indicators, compensating seemed more difficult. These five children, all attending special education, talked about situations with less social interactions, and more involvement from their parents. These findings require more in-depth research as to why compensating might be difficult. Explanations could be related to problems in managing social contacts (Antia et al., 2012), less developed language skills (Hall et al., 2019), or perhaps suboptimal development of executive functions (Boerrigter, 2021).

Limitations and implications

A limitation of this study is the potential bias in responses from children. Interviews with TH children took place in their own school, compared to the out-patient clinic for DHH children. TH children all attended the same school, potentially a bias for the choice of activities available in that area. In addition, although group conversations stimulated input, it could have had an impact on openness and honesty. Also, the participating children varied in age and education (as the demographics indicated), but also social contexts and personal histories (as the interviews illustrated). Some studies suggest that potential social challenges develop not at primary school age, but later, during adolescence (Brice & Strauss, 2016; Wolters et al., 2012; Zaidman-Zait & Most, 2020). Impact on capability in different age groups would therefore also be an important follow-up evaluation.

It is important to note that in qualitative research, there is not only the potential bias in responses from children. The personality, background, and perspective of the interviewer might distort responses and follow-up questions. In this case, the interviewer was typical hearing. Although the interview methodology was grounded in theory, it would be interesting for future research to compare interview responses with an interviewer from the Deaf community. Additionally, interviews with TH children and DHH children who are classmates could provide insights in the effects of different school environments.

Finally, although Finnis' basic goods provided a useful framework for the capability interview, it has limitations in its use in children. The seven dimensions (life, knowledge, play, sociability, practical reasonableness, aesthetic experience, and transcendence), relate strongly to adults, which possibly explains why certain subjects (e.g., transcendence) were mentioned only infrequently. These findings therefore cannot be extrapolated to all DHH children, nor were they intended to. Nevertheless, these findings may help us in two specific ways.

First, the added value of measuring capability becomes apparent. The capability approach immediately and logically directs attention to questioning the content of capability: what is it that these children in this context should be able to do. And when constraints for capability appear, the capability model with resources, conversion factors, and functionings leads to identifying action points to rectify these constraints.

Second, the outcomes of the interviews, combined with clinical indicators, underscore particular areas that auditory rehabilitation professionals need to address in order to enhance the capabilities of DHH children. Auditory rehabilitation is aimed at achieving several objectives, as outlined by the American Speech-Language-Hearing Association (2018), including (a) enhancing the listening pathway through training, (b) facilitating the use of listening technology, (c) fostering language development, (d) compensating for auditory dysfunction through visual access, and (e) providing personalized counseling to individuals and their families. Sen's Capability framework aligns with this in terms of resources (b), functioning (a,c,d), and conversion (d,e). Our study identified crucially important themes that may be considered obstacles to achieving capability including (1) difficulty accessing communication, (2) frustration at the limits of devices, (3) overbearing and dictating parents, (4) lack of peer relationships, (5) correlation to auditory skills/visual access, (6) negative self-perception. All of these obstacles should be addressed in auditory rehabilitation.

Combining speech perception and personalized interviews has high potential to become the preferred approach in the rehabilitation of DHH children, suggests Van der Straaten (2022). Children who have relatively high scores on clinical indicators, generally have good abilities to accomplish their daily activities. Still, they can experience limitations in doing what is valuable to them. Contrarily, children with relatively low clinical scores seem to require help in achieving valuable states. They do not, however, necessarily feel limited to lead valuable lives.

Conclusion

DHH children who participated in this study often led lives where they, in terms of capability, could do and be things that they have reason to value, not too different form their TH peers. They had friends, played sports, had hobbies, and enjoyed time with family. Considering these children were part of the same society, it is not surprising they strived for similar functionings, a similar norm. In striving to equality in the capability of DHH children and TH children there are two options: To use the normative level of TH children and identify necessary resources, conversion factors, and functionings, and provide and secure these for DHH children. This option to establish capability seems only reachable for children who obtain adequate clinical indicators. Another option is to strive for equal capabilities compared to those of DHH persons in Deaf Communities. This is to call into question how certain societal norms are defined (Sparrow, 2005). For example, to achieve adequate communication, spoken language might not be the only mode, when sign language is available and culturally accepted. For children with relatively poor clinical indicators, this second option might be preferable. From a capability perspective, speaking and hearing are very valuable functionings leading to many freedoms, but they are a means to an end, which is communication. Sign language, in this example, can be an important valuable functioning, provided that necessary resources and conversion factors are maintained.

We would like to point out that these options for DHH children are described from the perspective of these children themselves. As discussed in the introduction, however, there is the society’s responsibility to make sure that persons with disabilities can exercise their right to make decisions for their lives and be active members of society. The (change of) behavior towards children with disabilities of *typical hearing* children and adults should therefore also be considered when we aim to improve and protect the capability of DHH children. Typical hearing children and adults should be invited to increase their social interactions with DHH children, which is particularly challenging for DHH children who perform poorly on clinical indicators.

DHH children in this study were more vulnerable than TH children. While comparable to TH children in functionings, DHH children rely on a range of conversion factors to make sure their hearing tools become enforcers of capability in all aspects of daily life. Their hearing aids or cochlear implants are important resources for all of them: it makes it easier to do or to be things they have reason to value. Other prerequisite, supportive, factors include transportation to their school, Hearing Assistive Technologies to improve adverse listening conditions, and the need for empathy, inclusion, and participation. Furthermore, clinical indicators provide valuable information on auditory gain for speech perception of hearing devices. Additionally, collecting information on capability could be a beneficial approach in rehabilitation to improve involvement of the child, by discussing together with parents, and health and education professionals, what they strive for, even if that is outside our direct sphere of influence.

Declaration of Interest Statement

The authors declare that there is no conflict of interest.

References

1. American Speech-Language-Hearing Association. (2018). *Scope of Practice in Audiology*. www.asha.org/policy/
2. Antia, S., Kreimeyer, K., Metz, K., & Spolsky, S. C. (2012). Peer Interactions of Deaf and Hard-of-Hearing Children. *The Oxford Handbook of Deaf Studies, Language, and Education: Second Edition*, *1*. https://doi.org/10.1093/oxfordhb/9780199750986.013.0013
3. Ballet, J., Biggeri, M., & Comim, F. (2011). Children's Agency and the Capability Approach: A Conceptual Framework. In M. Biggeri, J. Ballet, & F. Comim (Eds.), *Children and the Capability Approach* (pp. 22-45). Palgrave Macmillan.
4. Biggeri, M., Libanora, R., Mariani, S., & Menchini, L. (2006). Children Conceptualizing their Capabilities: Results of a Survey Conducted during the First Children's World Congress on Child Labour*. *Journal of Human Development*, *7*(1), 59-83. https://doi.org/10.1080/14649880500501179
5. Boerrigter, M. (2021). *Long-term psychosocial and executive function outcomes in children and adolescents with cochlear implants* Radboud University]. Nijmegen.
6. Bosman, A. J., & Smoorenburg, G. F. (1995). Intelligibility of Dutch CVC syllables and sentences for listeners with normal hearing and with three types of hearing impairment. *Audiology 34*(5), 260-284.
7. Brand, D., Zaidman-Zait, A., & Most, T. (2018). Parent Couples' Coping Resources and Involvement in their Children's Intervention Program. *The Journal of Deaf Studies and Deaf Education*, *23*(3), 189-199. https://doi.org/10.1093/deafed/eny011
8. Bree, E. d., Rispens, J., & Gerrits, E. (2007). Non-word repetition in Dutch children with (a risk of) dyslexia and SLI. *Clinical Linguistics & Phonetics*, *21*(11-12), 935-944. https://doi.org/10.1080/02699200701576892
9. Brice, P. J., & Strauss, G. (2016). Deaf adolescents in a hearing world: a review of factors affecting psychosocial adaptation. *Adolesc Health Med Ther*, *7*, 67-76. https://doi.org/10.2147/ahmt.S60261
10. Castellanos, I., Kronenberger, W. G., & Pisoni, D. B. (2018). Psychosocial Outcomes in Long-Term Cochlear Implant Users. *Ear and Hearing*, *39*(3), 527-539. https://doi.org/10.1097/aud.0000000000000504
11. *Convention on the Rights of Persons with Disabilities*. (2006). UN General Assembly
12. Dirks, E., & Knoors, H. (2019). Fiets je mee? Fietservaring en fietsbeleving van dove en slechthorende kinderen. *VHZ-online*. https://vhz-online.nl/fiets-je-mee-fietservaring-en-fietsbeleving-van-dove-en-slechthorende-kinderen
13. Dunn, L. M. D., Leota M. (2005). *Peabody Picture Vocabulary Test-III-NL, Nederlandse versie door Liesbeth Schlichting*. Harcourt Assessment B.V.
14. Easwar, V., Sanfilippo, J., Papsin, B., & Gordon, K. (2018). Impact of Consistency in Daily Device Use on Speech Perception Abilities in Children with Cochlear Implants: Datalogging Evidence. *Journal of the American Academy of Audiology*, *29*(9), 835-846. https://doi.org/10.3766/jaaa.17051
15. Erbasi, E., Scarinci, N., Hickson, L., & Ching, T. Y. C. (2018). Parental involvement in the care and intervention of children with hearing loss. *International Journal of Audiology*, *57*(sup2), S15-s26. https://doi.org/10.1080/14992027.2016.1220679
16. Finnis, J. (1980). *Natural Law and Natural Rights* (Vol. 31). Oxford University Press UK.
17. Giacomini, M. K., & Cook, D. J. (2000). Users' Guides to the Medical Literature: XXIII. Qualitative Research in Health Care A. Are the results of the study valid? *JAMA*, *284*(3), 357-362. https://doi.org/10.1001/jama.284.3.357
18. Guerzoni, L., & Cuda, D. (2017). Speech processor data logging helps in predicting early linguistic outcomes in implanted children. *International Journal of Pediatric Otorhinolaryngology*, *101*, 81-86. https://doi.org/10.1016/j.ijporl.2017.07.026

19. Hall, M. L., Hall, W. C., & Caselli, N. K. (2019). Deaf children need language, not (just) speech. *First Language*, *39*(4), 367-395. https://doi.org/10.1177/0142723719834102

20. Helter, T. M., Coast, J., Laszewska, A., Stamm, T., & Simon, J. (2019). Capability instruments in economic evaluations of health-related interventions: a comparative review of the literature. *Quality of Life Research* https://doi.org/10.1007/s11136-019-02393-5

21. Hicks, C. B., & Tharpe, A. M. (2002). Listening Effort and Fatigue in School-Age Children With and Without Hearing Loss. *Journal of Speech, Language, and Hearing Research*, *45*(3), 573-584. https://doi.org/doi:10.1044/1092-4388(2002/046)

22. Lazari-Radek, K. d., & Singer, P. (2014). *The Point of View of the Universe: Sidgwick and Contemporary Ethics*. Oxford University Press. https://doi.org/10.1093/acprof:oso/9780199603695.001.0001

23. Lewis, D., Schmid, K., O'Leary, S., Spalding, J., Heinrichs-Graham, E., & High, R. (2016). Effects of Noise on Speech Recognition and Listening Effort in Children With Normal Hearing and Children With Mild Bilateral or Unilateral Hearing Loss. *Journal of Speech, Language, and Hearing Research*, *59*(5), 1218-1232. https://doi.org/doi:10.1044/2016_JSLHR-H-15-0207

24. Loy, B., Warner-Czyz, A. D., Tong, L., Tobey, E. A., & Roland, P. S. (2010). The children speak: an examination of the quality of life of pediatric cochlear implant users. *Otolaryngol Head Neck Surg*, *142*(2), 247-253. https://doi.org/10.1016/j.otohns.2009.10.045

25. MacPhail, C., Khoza, N., Abler, L., & Ranganathan, M. (2016). Process guidelines for establishing Intercoder Reliability in qualitative studies. *Qualitative Research*, *16*(2), 198-212. https://doi.org/10.1177/1468794115577012

26. Mathews, E. S. (2015). Towards an Independent Future: Life Skills Training and Vulnerable Deaf Adults. *Irish Journal of Applied Social Studies*, *15*(1). https://doi.org/10.21427/D7442K

27. Mayring, P. (2000). Qualitative Content Analysis. *Qualitative Social Research*, *1*(2). http://nbn-resolving.de/urn:nbn:de:0114-fqs0002204

28. Meinzen-Derr, J., Sheldon, R., Grether, S., Altaye, M., Smith, L., Choo, D. I., & Wiley, S. (2018). Language Underperformance in Young Children Who Are Deaf or Hard-of-Hearing: Are the Expectations Too Low? *Journal of Developmental and Behavioral Pediatrics 39*(2), 116-125. https://doi.org/10.1097/dbp.0000000000000509

29. Meserole, R. L., Carson, C. M., Riley, A. W., Wang, N. Y., Quittner, A. L., Eisenberg, L. S., Tobey, E. A., Francis, H. W., & Niparko, J. K. (2014). Assessment of health-related quality of life 6 years after childhood cochlear implantation. *Quality of Life Research 23*(2), 719-731. https://doi.org/10.1007/s11136-013-0509-3

30. Nittrouer, S., Caldwell-Tarr, A., & Lowenstein, J. H. (2013). Working memory in children with cochlear implants: Problems are in storage, not processing. *International Journal of Pediatric Otorhinolaryngology*, *77*(11), 1886-1898. https://doi.org/https://doi.org/10.1016/j.ijporl.2013.09.001

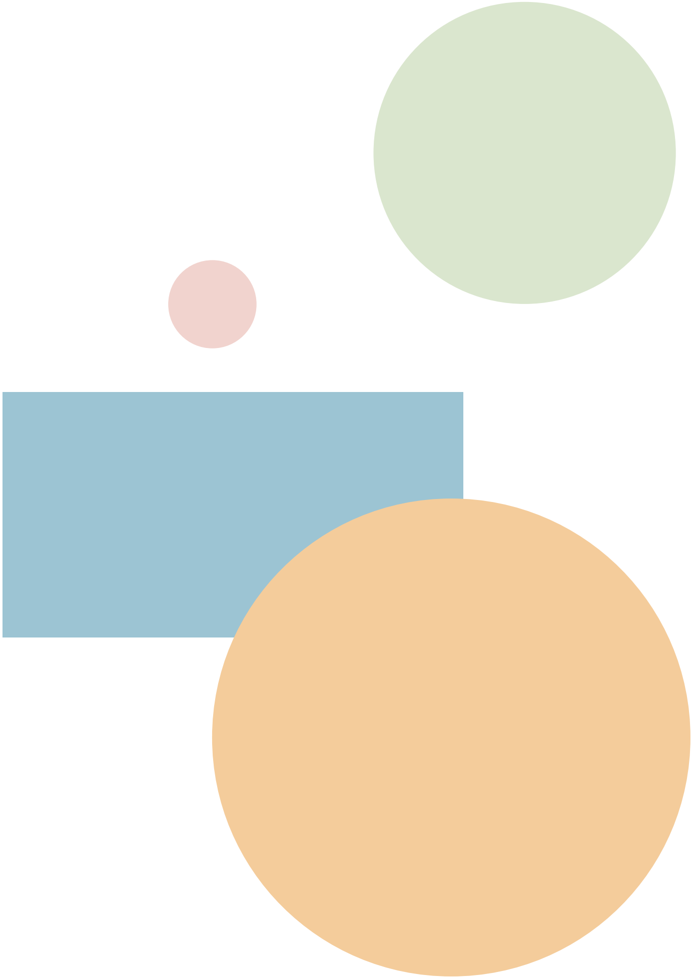
31. Ohlenforst, B., Zekveld, A. A., Jansma, E. P., Wang, Y., Naylor, G., Lorens, A., Lunner, T., & Kramer, S. E. (2017). Effects of Hearing Impairment and Hearing Aid Amplification on Listening Effort: A Systematic Review. *Ear and Hearing*, *38*(3), 267-281. https://doi.org/10.1097/AUD.0000000000000396

32. Pisoni, D. B., Kronenberger, W. G., Roman, A. S., & Geers, A. E. (2011). Measures of digit span and verbal rehearsal speed in deaf children after more than 10 years of cochlear implantation. *Ear and Hearing*, *32*(1 Suppl), 60s-74s. https://doi.org/10.1097/AUD.0b013e3181ffd58e

33. Proud, L., McLoughlin, C., & Kinghorn, P. (2019). ICECAP-O, the current state of play: a systematic review of studies reporting the psychometric properties and use of the instrument over the decade since its publication. *Quality of Life Research 28*(6), 1429-1439. https://doi.org/10.1007/s11136-019-02114-y

34. Rawls, J. (1999). *A Theory of Justice: Revised Edition*. Harvard University Press.

35. Razafimahefa-Raoelina, T., Farinetti, A., Nicollas, R., Triglia, J. M., Roman, S., & Anderson, L. (2016). Self- and parental assessment of quality of life in child cochlear implant bearers. *European Annals of Otorhinolaryngology, Head and Neck Diseases*, *133*(1), 31-35. https://doi.org/10.1016/j.anorl.2015.10.002
36. Reed, S., Antia, S. D., & Kreimeyer, K. H. (2008). Academic status of deaf and hard-of-hearing students in public schools: student, home, and service facilitators and detractors. *Journal of Deaf Studies and Deaf Education*, *13*(4), 485-502. https://doi.org/10.1093/deafed/enn006
37. Rijke, W. J., Vermeulen, A. M., Wendrich, K., Mylanus, E., Langereis, M. C., & Van der Wilt, G. J. (2019). Capability of deaf children with a cochlear implant. *Disability and Rehabilitation*, 1-6. https://doi.org/10.1080/09638288.2019.1689580
38. Semel, E., Wiig, E., & Secord, W. (2003). *Clinical evaluation of language fundamentals - 4th edition*. The Psychological Corporation.
39. Sen, A. (2009). *The idea of justice*. Allen Lane.
40. Smith, D. H. (2008). Giving the Spoon Back: Higher Teacher Expectations of Achievement for Students Who Are Deaf. *The Qualitative Report*, *13*(4), 657-694. https://doi.org/10.46743/2160-3715/2008.1578
41. Sparrow, R. (2005). Defending deaf culture: The case of cochlear implants. *The Journal of Political Philosophy*, *13*(2), 135-152.
42. Ubels, J., Hernandez-Villafuerte, K., & Schlander, M. (2022). The Value of Freedom: A Review of the Current Developments and Conceptual Issues in the Measurement of Capability. *Journal of Human Development and Capabilities*, *23*(3), 327-353. https://doi.org/10.1080/19452829.2022.2053506
43. Van der Straaten, T. F. K. (2022). *Opportunities within and after rehabilitation for patients with hearing loss* Leiden University]. Leiden.
44. Warner-Czyz, A. D., Loy, B., Roland, P. S., Tong, L., & Tobey, E. A. (2009). Parent versus child assessment of quality of life in children using cochlear implants. *International Journal of Pediatric Otorhinolaryngology*, *73*(10), 1423-1429. https://doi.org/10.1016/j.ijporl.2009.07.009
45. Wolff, J., & De-Shalit, A. (2007). *Disadvantage*. Oxford University Press.
46. Wolters, N. (2013). *Social participation of deaf youth in school: Predictors and consequences of acceptance and popularity of deaf early adolescents before and after a major school transition* [Dissertation, Radboud University]. Nijmegen.
47. Wolters, N., Knoors, H., Cillessen, A. H., & Verhoeven, L. (2012). Impact of peer and teacher relations on deaf early adolescents' well-being: comparisons before and after a major school transition. *Journal of Deaf Studies and Deaf Education*, *17*(4), 463-482. https://doi.org/10.1093/deafed/ens021
48. Zaidman-Zait, A., & Most, T. (2020). Pragmatics and Peer Relationships Among Deaf, Hard of Hearing, and Hearing Adolescents. *Pediatrics*, *146*(Suppl 3), S298-s303. https://doi.org/10.1542/peds.2020-0242J
49. Zaidman-Zait, A., Most, T., Tarrasch, R., Haddad-eid, E., & Brand, D. (2015). The Impact of Childhood Hearing Loss on the Family: Mothers’ and Fathers’ Stress and Coping Resources. *The Journal of Deaf Studies and Deaf Education*, *21*(1), 23-33. https://doi.org/10.1093/deafed/env038



5

WELL-BEING AS CAPABILITY: FINDINGS IN HEARING-IMPAIRED ADOLESCENTS AND YOUNG ADULTS WITH A HEARING AID OR COCHLEAR IMPLANT

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Abstract

In the Western world, for deaf and hard-of-hearing children, hearing aids or cochlear implants are available to provide access to sound, with the overall goal of increasing their well-being. If and how this goal is achieved becomes increasingly multifarious when these children reach adolescence and young adulthood, and start to participate in society in other ways. An approach to well-being that includes personal differences and the relative advantages and disadvantages that people have, is the capability approach, as developed by Nobel Prize laureate Amartya Sen. Capability is the set of real opportunities people have to do and be things they have reason to value. We interviewed 59 young people, aged 13 through 25, with cochlear implants (37) or hearing aids (22) to capture their capability. We found that their hearing devices enabled them to actively participate in a predominantly hearing society, with few differences between cochlear implant and hearing aid recipients. They did, however, report challenges associated with prejudices and expectations, and with feeling poorly understood, all of which appeared to impact their capability. Through the lens of capability, alleged differences between hearing aid and cochlear implant recipients began to fade. We discuss the implications for initiatives focused on the long term support young recipients of hearing devices to meet their specific requirements over time.

Introduction

Deaf and hard-of-hearing (DHH) children who participate in hearing societies, may experience significant challenges in social, emotional, and psychological areas (Antia et al., 2012; Kouwenberg et al., 2012; Wolters, 2013; Snoddon and Underwood, 2014). When these children enter puberty and adolescence, they start arranging their lives more to their own choosing, are able to reflect on choices, and participate independently in society, such as sports, jobs, school, and hobbies. These developmental tasks entail establishing self-governance and autonomy though peer group interactions. Hearing devices such as cochlear implants and hearing aids aim to facilitate this for DHH children. These devices, however, impact more than communication and perception of sounds, especially during adolescence. Identity formation, relational and sexual development, and the transition from primary to secondary education are some characteristics of this phase of life and are at risk for DHH young people when communication is hindered (Klimstra et al., 2010; Tolman and McClelland, 2011). Despite substantial auditory gain from hearing devices, enabling speech perception that facilitates spoken language acquisition and academic skills, DHH adolescents and young adults still appear disadvantaged in psychosocial areas compared to typical hearing peers, such as self-perceived social acceptance, physical appearance, and self-worth (Marschark et al., 2007; van Gent, 2012; Wolters, 2013). Evaluation of hearing devices is currently mainly concerned with the functionality of the hearing devices, since its conditional for any further effects. Corresponding measures such as speech perception and indicators for academic skills (such as vocabulary and working memory), are therefore an essential first step in evaluating hearing devices. But to further evaluate the impact of hearing loss and the value and limitations of hearing devices, we believe there should be an assessment of how hearing devices contribute to a person's ability to lead a life of their own choosing, and what they require to achieve it.

To meet the developmental tasks in a hearing society these young people with hearing impairments experience specific challenges due to the impairment and technical limitations of the devices. Although speech perception in case of moderate hearing impairment with the use of hearing aids has been found comparable to that of profoundly hearing-impaired adolescents and young adults who use cochlear implants, the impact of these devices is distinct. For young people with cochlear implants, the auditory gain of the device is significantly larger, which might increase device dependency. This might effect this ability to lead a life of their own choosing and their requirements.

The capability approach, developed by Nobel prize laureate Amartya Sen, is an approach to capture well-being (Sen, 1979). Capability is defined as the set of real freedoms people have to do and be what they have reason to value. A capability set emerges from the interaction between available resources, conversion factors, and achieved capabilities, called functionings (Robeyns, 2003). For example, a certain activity that might be of interest to a young adult with hearing aids is to meet with friends. By assessing capability, we would gather information about necessary resources, such as hearing aids, transport, and money. In addition to resources, he or she might need acceptance of friends, living in close proximity, permission from parents, and self-esteem. These personal, social, and environmental factors together are the conversion factors. Functionings are observable activities and states of being, such as playing a game, laughing, and communicating. Information on all these elements would reflect the young adult's real freedom (i.e., capability) to meet with friends. An assessment of capability in DHH young people has an important role in identifying key factors in support for achieving their personal goals in societal participation to improve the impact of health care. This would require both an account of what these particular young people have reason to value (their interests on an individual level), and an analysis of their activities (functionings) and conditions (resources and conversion factors). We aimed to learn about the capability of young people who use cochlear implants or hearing aids by asking about their daily lives, what they strive for, and what they need to accomplish this.

Methods

Participants

We included 59 young people who received hearing aids (22) or cochlear implants (37). We selected participants when they had a minimal age of 12 years old and a maximum age of 25 years old. The characteristics of the participants are listed in Table 1, including available information on hearing loss and speech perception abilities. We only selected hearing aid users with at least 35 dB hearing loss at the better ear (pure-tone average of 1, 2 and 4 kHz). Hearing aid users received audiological care in a regional audiological centre and resided in both urban and rural areas and attended mainstream or special educational settings. Cochlear implant users received audiological care in a cochlear implant centre with a national function, also including residents from urban and rural areas that attended mainstream or special educational settings. We did not preselect for education level, gender, or other demographic characteristics. We excluded participants who could not be understood by the interviewer, for example non-Dutch speaking participants and those with additional (cognitive) severe complex needs.

Table 1. Demographic characteristics of the respondents, distinguishing recipients of hearing aids and cochlear implants

Characteristic			Recipients of cochlear implant(s)	Recipients of hearing aid(s)
n			37	22
Age in years	M (SD)		17.3 (3.7)	17.3 (3.6)
	Range		12.6-25.0	12.8-24.1
Age of first aid in years, M (SD)			4.0 (3.6)	4.8 (2.8)
Gender	male		17	15
	female		20	7
Education (in dutch)	secondary special education (vso)		3	2
	secondary education (vo)		21	11
	secondary vocational education		9	6
	(mbo)		4	1
	higher education (hbo)		0	2
	university education (wo)			
Hearing device	unilateral		13	0
	bilateral		21	22
	bimodal		3	
Hearing loss in dB (pure-tone average at 1, 2 and 4 kHz)	M (SD)		> 85*	56.1 (12.8)
	Range			37-77
	Missing			4
Speech perception (% correctly repeated phonemes)	65 dB in quiet	M (SD)	93.6 (6.8)	94.5 (9.9)
	45 dB in quiet	Range	67-100	60-100
		Missing	0	3
		M (SD)	87.1 (10.3)	73.8 (22.2)
		Range	45-100	24-100
		Missing	4	3
Speech supported by sign language	Yes		6	1
	No		31	21
Interview setting	Online		13	5
	Face-to-face		24	17

**Note.* Audiological inclusion criteria for cochlear implantation is > 85 dB hearing loss

Data collection

We used a qualitative design (i.e., interviews) to capture capability. During a period of two years (2019 and 2020), patients were invited via mail to participate prior to their annual fitting of their hearing device and follow up evaluation of their development in their out-patient clinic. The interviews were conducted in a consulting room in the out-patient clinic. Due to covid-19 restrictions, 18 interviews were conducted digitally with a videoconference app (Whereby). One participant used a sign language interpreter, while three participants were accompanied by their parents. The interviewer (WR, male, late-twenties, typical hearing) had a background in psychology, was trained and experienced in qualitative research, and had not met participants earlier. Participants were informed before participating, and the goal of the research was reiterated prior to the interview. Interviews lasted between 30 and 50 minutes.

To understand the nature and development of capability in DHH young people who use cochlear implants and/or hearing aids, we used a deductive qualitative approach. Through one-on-one interviews we aimed to collect information on participants' resources, conversion factors, functionings, and interests. We framed the interviews based on the methodology used by Alkire (2002). We started by asking participants to tell about their daily lives, and asked them to elaborate on interests, conditions, and activities. We used mainly open questions to encourage input from participants, while using seven topics as a framework of conversation. These topics were based on Finnis' basic goods: knowledge, life, play, aesthetic experience, sociability, practical reasonableness, and transcendence (Finnis, 1980). The interview protocol can be found in Appendix A. Interviews were fully audio recorded and converted to intelligent (non-verbatim) transcripts.

Analysis

We deducted elements from the capability approach using directive content analysis, a methodological orientation using an existing theory (Mayring, 2000). Resources were coded as the materials and means necessary to achieve valuable functionings. The environmental, personal, and social factors that influence resources and functionings were coded as conversion factors. Functionings are what people do and are. When participants told us what they found important or interesting it was coded as 'interest'. Codes could overlap, for instance when subjects talked about playing a sport they liked (both functioning and interest). To determine the interrater reliability, a random set of eight interviews were coded by two independent raters; the first author and a PhD-student from another department (MacPhail et al., 2016). Coding and analysis were computer assisted, using ATLAS.ti version 8 for Windows. The determined interrater reliability between the two raters of the codes was .81, which means a high number of quotes were identically coded.

Ethical considerations

The research ethics committee of the Radboud University Nijmegen Medical Centre states that the abovementioned study (reference number of the study: 2017-3684) doesn't fall within the remit of the Medical Research Involving Human Subjects Act (WMO).

Findings

We structured the quotes of the respondents according to themes based on the impact of hearing loss and the value and limitations of hearing devices: what respondents articulated they gained in possibilities by device use, what wishes or preferences might have been adapted to cope, what preconceptions of others they experienced in societal situations, and what disadvantages they might have experienced. Gained possibilities relate to the increase in capability, while experienced disadvantages might indicate obstructions in resources or conversion factors. Their experienced preconceptions of others is a social conversion factor that is especially relevant during puberty and adolescence. Their adapted preferences could portray a certain degree of freedom, as some functionings might not have been available to them.

The following will describe the capability of the respondents in two ways. First, we will present interview outcomes framed by the four themes: gained possibilities, adapted preferences, preconceptions of others, and experienced disadvantages. Per theme, we will attempt to portray the general findings, supported by specific quotes from respondents.

Then we will present an overview of the functionings, resources, conversion factors, and interests of the respondents. On a group level, a cochlear implant or hearing aid was the most obvious distinguishing factor between participants, as depicted in Table 1. We will present outcomes from the interviews with available context, such as age, gender, and education.

Structured outcomes

Gained possibilities

According to respondents, cochlear implants and hearing aids provide not only the ability to hear more and better (24-year-old female, one cochlear implant since 9 years of age), but also opportunities they feel they would not have had without it, such as their job (23-year-old female, two cochlear implants, first since 9 years of age). They feel they can communicate, but also have silence to relax (19-year-old female, one cochlear implant since 20 months old, and 20-year-old male, two hearing aids, first since 6 years of age).

Interviewer: “What is the biggest advantage of having a cochlear implant?”

> *“Well, sometimes I forget I'm deaf. That's the greatest happiness I've had in my life. Some think you take away an identity, but for me it has given an identity. I couldn't have made it this far without it. I don't know what that would have been like, of course, but it's been so nice for me. I get fair chances. For example, if you apply for a job, the chances of getting hired are a lot less if you're deaf. So, I don't write it down either. And then I can show them during a job interview.”* **– 18-year-old male, wears one cochlear implant (since 12 months of age), student secondary vocational education.**

> *“I used to listen music only rarely. Five years ago, a new hearing aid. They threw in a ComPilot [wireless accessory]. When music was played, the correct tones were played. That has greatly increased my ability to listen to music. For example, I listened to a lot of Acda and the Munnik, very easy music to listen to for lyrics. And singing along. Because I didn't care much for melody and beats. So, I also really hated instrumental music, classical music. While now, I'll just listen to it all. I really listen to a lot of music now. Now I listen to everything together.”* **– 20-year-old male, wears two hearing aids (first since 6 years of age), student academic education.**

Adapted preferences

Respondents from all participating ages found ways to deal with previously difficult hearing-related situations. They adapted their desires, but also learned in which situations they could thrive. For example, cycling at the back of a group so that voices come toward them from the front, thus facilitating perception, or taking strategic positions in a room that enable speech reading. They also asked teammates or friends for assistance during sport activities. Furthermore, one of them switched from working in a noisy bakery to stocking shelves.

> *“Sometimes I feel like I really want to be hearing, but that feeling is going down more and more. Because in the past I was really like, ‘I would really like to be hearing’, but I didn't know my own culture and what benefits and disadvantages we have. And now I'm less like I want to be hearing, I'm glad I'm deaf. Really a lot of benefits. Perfect sleep, you don't want to know.”* **– 16-year-old female, wears one cochlear implant (since 20 months of age), attends mainstream high school.**

> *“I also find myself enjoying it more when we're playing a game, because I feel more involved than when we're having a conversation. Of course, I also like to have a conversation, but I find it more fun to play a game.”* **– 18-year-old male, wears one cochlear implant (since 5 years of age), attends mainstream high school.**

> *"At first, I sat at the front of the class, but I didn't like that. Now I sit at the back of the class, so that I can look into the class. Then I don't have to look around all the time to see where the sound is coming from. So, I have a little more of an overview of the class. Then I can pay more attention myself, because I don't have to look behind me."* **– 14-year-old female, wears two hearing aids (first since 6 years of age), attends mainstream high school.**

Preconceptions of others
Young DHH people shared experiences about living with cochlear implants and hearing aids, and the image and taboo hearing tools evoked. They said that everyone thinks in boxes, also in the deaf community; you're either with the deaf or the cochlear implants group.

> *"But I don't need to be put in a box. I am well aware that I am hearing impaired. One time, while going out, a hearing-impaired girl asked why I wasn't with hearing-impaired friends. Very weird. 'You pretend to be something you're not', she said. Almost aggressive. I think that's such a label. I don't need that."* **– 22-year-old male, wears two hearing aids (first since 4 years of age), student academic education.**

Also, people might overestimate or not understand what hearing tools can provide. While they lead to opportunities, there is still a lack of knowledge and awareness in society, participants said.

Interviewer: "How do you notice the prejudices?"

> *"The possibilities... With a cochlear implant you can certainly hear better. But that's the pitfall. With a cochlear implant you can't necessarily keep track of everything. It doesn't solve everything. My deaf community say that because of cochlear implants there are fewer deaf people. They think that with cochlear implants people know better because they can hear better, but they don't [know better]."* **– 24-year-old female, wears one cochlear implant (since 9 years of age), works as a nurse.**

Experienced disadvantages
There are certain disadvantages of living with hearing loss that came up more often than others. Hearing aids and cochlear implants are not waterproof, which can be problematic for sports (transpiration) or in the rain. Also, respondents said hearing through hearing technologies can be tiring, leading to headaches or losing concentration. In addition, hearing assistive technologies enable hearing in otherwise challenging, adverse listening situations, though they are not always experienced as such. Respondents mentioned the inconvenience

using these technologies in school, when they moved from one classroom to another with different teachers every hour. Others experienced technical malfunctioning or vulnerable parts breaking. For these respondents, the proper use of hearing assistive technologies was difficult to realize, and they were even considered a burden. One respondent said he believed he needed more motivation to achieve similar goals as typical-hearing people.

> *"But I have to persevere, because actually, as a hearing-impaired person, you simply need more motivation wanting to achieve the same as a good hearing person."* **– 21-year-old male, wears two hearing aids (first since 2 years of age), student secondary vocational education.**

> *"I really like listening to music. I also tried to make music myself, then with recorder lessons, but I just can't do that with my hearing. Singing seems like a lot of fun, but I can't do that either. And I'm not that much into painting or drawing."* **– 13-year-old female, wears two cochlear implants (first since 2 years of age), attends mainstream high school.**

Interviewer: "Did you use hearing assistive technologies in high school?"

> *"In the beginning, yes. But you notice that it was developed by hearing people. May sound weird. But hearing assistive equipment is very much... All you hear is the teacher. It's like the teacher is yelling in your ear. At least that's how I experience it. This is also the case with hearing aids, for example. When I am talking, it points at someone. That seems very useful, but in reality, it really is worthless. Because it doesn't do you any good."* **– 22-year-old male, wears two hearing aids (first since 5 years of age), student secondary vocational education.**

Interviewer: "What is the biggest disadvantage of having a cochlear implant?"

> *"Well, the hearing on batteries, I find that so annoying." – 19-year-old male, wears two cochlear implants (first since 26 months of age), works as an electrician.*

Capability

The input from the respondents led to an overview of functionings, resources, conversion factors, and interests that fits the participated DHH young people (see Table 2). For this is a qualitative approach, the focus was to identify which resources, conversion factors and functionings were essential for capability (we included all issues that were brought up).

Table 2. Participants' input in terms of capability elements. The table is organized in columns (vertical), not rows (horizontal). Elements between columns are therefore not linked.

In general			
Functionings	Resources	Conversion factors	Interests
Explain to others, but also not disclosing deafness	Cochlear implant**	Forgetting devices (personal factor that influences the use of the hearing device)	Not being different
Being laughed at	Hearing aid	Changing preferences, accepting deafness more	Not being overestimated in their ability to hear when aided
Last to laugh at jokes	Hearing assistive technologies	Positive attitude, more motivation than typical hearing peers	Not being ashamed for appearance cochlear implant**
Cycling at the back to increase sound perception*	Cords for sports	Maintenance, cleaning, vulnerability device and batteries	Being able to take phone calls in noise
Drive car		Prejudices, perceptions of others, taboo, people don't know how to communicate	Being able to lie on head with cochlear implant**
Sleep well		Appearance of cochlear implant**	Being able to turn off hearing device
			Not being labelled
			Consideration of others

Work and school			
Functionings	Resources	Conversion factors	Interests
Being (highly) educated, have job(s)	Resources associated with special education	Less energy	Being able to become anything when growing up**
No early shift after late shift at hospital**			
Sitting in front for lip reading**, sit in back for overview*			
Not meeting friends from school			

Leisure time			
Functionings	Resources	Conversion factors	Interests
Swimming together, swimming alone	Water case**	Not waterproof	Enjoying environmental sounds

Table 2. *(Continued)*

Leisure time		
Listening to music	Wireless connection with phone	Being able to play an instrument
Activities with organization for young deaf and hard-of-hearing people*	Rain makes hearing aids disfunction*	Playing games rather than conversations**
Go to the bar, go to festivals, cinema, parties	Music can be noise	Being able to participate in group conversations
Play sports (with and without hearing device)	Cochlear implant does not fit in horse cap**	
	Help from teammates	

*Exclusively mentioned by hearing aid users
**Exclusively mentioned by cochlear implant users

Despite differences in devices to remediate the effects of hearing loss (i.e., cochlear implants and hearing aids) the presented data tell a notably consistent story. With a few exceptions young people who experienced hearing loss and the subsequent treatment and guidance describe similar daily activities (functionings), requisite resources, personal, social, and environmental conversion factors, and interests. Interviewees shared details about their daily lives, both hearing-related and otherwise. In most aspects of their lives their hearing loss showed. They went to school or had jobs, but they needed additional resources, such as hearing-assistive-technologies. They met with friends, but not always with friends from school for participants attending special education, as they lived further away. They went to bars, festivals, parties, the cinema, but environmental noise complicated conversations. They played sports, but they relied on teammates for communication. They rode their bike, but rain or wind decreased sound perception. They expressed desires to being able to take phone calls in noise, which can be difficult. They enjoy time in silence (without their hearing devices) on one hand, but would like to be able to participate in group conversations more easily. They listened to music, but really enjoyed it with a direct input in their hearing device.

Discussion

Three insights emerged from our study, which we will consider before discussing limitations, implications, and the conclusion.

Firstly, through the lens of capability, alleged differences between hearing aid and cochlear implant recipients began to fade. Previous studies evaluating daily lives of hearing aid and cochlear implant users observed varied results on activities and quality of life. In Sweden, researchers found similar functioning in daily situations between young hearing aid and cochlear implant users (Anmyr et al., 2011), though they did find differences regarding neck and shoulder pain, usage of aids and hearing problems in certain activities. A multi-center study by Huber et al. (2015) showed that the mental health of young cochlear implant users without additional disabilities was comparable to typical-hearing peers, while Castellanos, Kronenberger and Pisoni (2018) stated that long-term cochlear implant users are at risk for difficulties in psychosocial adjustment, depending on delays and deficits in language and executive functioning.

Secondly, quotes that were obtained only from either young people with hearing aids or cochlear implants were sparse, although worth discussing briefly. One hearing aid user mentioned a strategy for receiving information. Instead of sitting up close to her teacher, one girl preferred the overview she had sitting in the back of class, seeing who talked. Unique to cochlear implant users was how they coped with the external parts of the device (i.e., a microphone, speech processor, external antenna and a magnet). They told how its appearance could result in shame or inconvenience, for example. One person strikingly illustrated how his sense of hearing depended on a device. “Hearing on batteries” was how he experienced dealing with it. Also, one cochlear implant user expressed her desire for more career opportunities. A past study did suggest that young cochlear implant users, although well integrated into the hearing world, had a significantly lower correspondence between career aspiration and actual occupation (Huber et al., 2008).

Thirdly, it seems that many challenges DHH young people encountered were not exclusively related to having difficulties hearing sounds, but rather to external perceptions and prejudices. They mentioned ‘not wanting to be different’, ‘not being labeled’, ‘being overestimated’, and ‘dealing with others’ perceptions’. And while hearing peers seemed to lack understanding, members of the Deaf community could be dismissive as well. These societal issues, related to acceptance and prejudices, are often raised by the Deaf community (Christiansen and Leigh, 2004). Ellington and Lim (2013) did report a lack of understanding by others that could lead to low self-esteem in DHH children. Respondents in the current study exclusively strived for the typical-hearing societal norm, living with the expectations and pressure. They expressed the feeling to need more motivation to get fair opportunities, as they were aware of the pitfall of listening with hearing devices; hearing more, but not everything. Providing and designing an inclusive society for people with disabilities is not a favor, but a duty established in the United Nations Convention on the rights of persons with disabilities (2006). In the Netherlands, much remains to be done in this area, especially for DHH young adults (Van Den Heuij et al., 2018).

Limitations and implications

We acknowledge the potential biases that accompany our study design. Our broad inclusion criteria resulted in a highly heterogeneous research sample with a broad variety of contexts and personal histories. Also, being interviewed through video from home (as 18 participants were) could have impacted communication, although it did not lead to substantive issues. The covid-19 regulations also prevented including a reference group of typical-hearing peers and complicated collecting information on clinical context (e.g., speech perception), which could have provided more insights on participants interview outcomes. We therefore cannot attribute causality to hearing aids or cochlear implants and capability, nor did we intend to. How DHH adolescents view themselves heavily depends on their context (such as ethnicity and culture), making studies with these target groups difficult to compare and extrapolate (Byatt et al., 2021). However, the present results are significant in at least two major respects.

First, the subject of evaluation of young people with cochlear implants and hearing aids is often focused on clinical outcomes (Sparreboom et al., 2014; Cushing and Papsin, 2015), (health-related) quality of life (Dixon et al., 2020), and school performance (Punch and Hyde, 2005; Sarant et al., 2015). This is, to our knowledge, the first assessment of capability in this research group, which led to insights on how young people with cochlear implants and hearing aids had remarkably similar capability outcomes. Their resources and conversion factors to lead valuable lives often coincided, as did their interests. Having the freedom to choose valuable functionings has been related to higher well-being in European citizens, while additionally reducing the importance of other factors such as health, friendship and financial security (Steckermeier, 2021).

Secondly, as capability might not differ significantly between users of cochlear implants and hearing aids, the efforts to strengthen their capability might be combined too. Respondents from both groups seemed to desire more awareness about living with hearing loss in their personal environment, in addition to a more informed public perception of hearing devices. The capability approach is, more than anything, a normative framework born from the realm of justice. Therefore, programs and interventions addressing these societal action points have a distinct moral value and should be supported as such.

Conclusion

Young DHH people who use either cochlear implants or hearing aids reported perceiving opportunities through the use of these hearing devices they would not have without them. Their hearing devices enabled them access to a predominately hearing society, in which they actively participated. Unfortunately, these young people explicitly express feelings of uncertainty and falling short when they compare themselves to typical hearing peers. When application of hearing devices aims to improve well-being and to prevent psychosocial problems, monitoring the development of a stable identity in DHH young people is essential. In their own perspective, these young people advocate more awareness of and insights in hearing loss in the broader society. An important practical issue are the weakness and limitations of the hardware. For initiatives focused on supporting DHH young people, these results are of considerable interest. In addition, manufacturers of hearing devices and hearing assistive technologies can benefit from feedback from these users too.

Traditional well-being evaluations of health interventions are often top-down, summative assessments aimed to facilitate cost-effectiveness or patient satisfaction. In our view, the current study shows how a formative focus on the development of well-being in terms of capability can lead to clues for personalized care, societal action points, and conversation topics for anyone involved with DDH young people. These subjects blur the line between care and policy, between responsibility and justice.

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Conflict of Interest Statement

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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References

1. Alkire, S. (2002). *Valuing freedoms: Sen's capability approach and poverty reduction.* Oxford ; New York: Oxford University Press.
2. Anmyr, L., Olsson, M., Larson, K., and Freijd, A. (2011). Children with hearing impairment – Living with cochlear implants or hearing aids. *International Journal of Pediatric Otorhinolaryngology* 75(6)**,** 844-849. doi: https://doi.org/10.1016/j.ijporl.2011.03.023.
3. Antia, S., Kreimeyer, K., Metz, K., and Spolsky, S.C. (2012). Peer Interactions of Deaf and Hard-of-Hearing Children. *The Oxford Handbook of Deaf Studies, Language, and Education: Second Edition* 1. doi: 10.1093/oxfordhb/9780199750986.013.0013.
4. Byatt, T.J., Duncan, J., Dally, K., and Beuzeville, L. (2021). Evolving Identities of Adolescents Who Are Deaf or Hard of Hearing: A Scoping Review. *Am Ann Deaf* 166(1)**,** 5-30. doi: 10.1353/aad.2021.0008.
5. Castellanos, I., Kronenberger, W.G., and Pisoni, D.B. (2018). Psychosocial Outcomes in Long-Term Cochlear Implant Users. *Ear Hear* 39(3)**,** 527-539. doi: 10.1097/aud.0000000000000504.
6. Christiansen, J.B., and Leigh, I.W. (2004). Children with cochlear implants: changing parent and deaf community perspectives. *Arch Otolaryngol Head Neck Surg* 130(5)**,** 673-677. doi: 10.1001/archotol.130.5.673.
7. Cushing, S.L., and Papsin, B.C. (2015). Taking the History and Performing the Physical Examination in a Child with Hearing Loss. *Otolaryngol Clin North Am* 48(6)**,** 903-912. doi: 10.1016/j.otc.2015.07.010.
8. Dixon, P.R., Feeny, D., Tomlinson, G., Cushing, S., Chen, J.M., and Krahn, M.D. (2020). Health-Related Quality of Life Changes Associated With Hearing Loss. *JAMA Otolaryngology–Head & Neck Surgery* 146(7)**,** 630-638. doi: 10.1001/jamaoto.2020.0674.
9. Ellington, T., and Lim, S. (2013). Adolescents' Aesthetic and Functional View of Hearing Aids or Cochlear Implants and Their Relationship to Self-Esteem Levels. *Fashion Practice* 5(1)**,** 59-80. doi: 10.2752/175693813X13559997788763.
10. Finnis, J. (1980). *Natural Law and Natural Rights.* Oxford University Press UK.
11. Huber, M., Burger, T., Illg, A., Kunze, S., Giourgas, A., Braun, L., et al. (2015). Mental health problems in adolescents with cochlear implants: peer problems persist after controlling for additional handicaps. *Frontiers in Psychology* 6(953). doi: 10.3389/fpsyg.2015.00953.
12. Huber, M., Wolfgang, H., and Klaus, A. (2008). Education and training of young people who grew up with cochlear implants. *International Journal of Pediatric Otorhinolaryngology* 72(9)**,** 1393-1403. doi: https://doi.org/10.1016/j.ijporl.2008.06.002.
13. Klimstra, T.A., Hale Iii, W.W., Raaijmakers, Q.A.W., Branje, S.J.T., and Meeus, W.H.J. (2010). Identity Formation in Adolescence: Change or Stability? *Journal of Youth and Adolescence* 39(2)**,** 150-162. doi: 10.1007/s10964-009-9401-4.
14. Kouwenberg, M., Rieffe, C., Theunissen, S.C., and de Rooij, M. (2012). Peer victimization experienced by children and adolescents who are deaf or hard of hearing. *PLoS One* 7(12)**,** e52174. doi: 10.1371/journal.pone.0052174.
15. MacPhail, C., Khoza, N., Abler, L., and Ranganathan, M. (2016). Process guidelines for establishing Intercoder Reliability in qualitative studies. *Qualitative Research* 16(2)**,** 198-212. doi: 10.1177/1468794115577012.
16. Marschark, M., Rhoten, C., and Fabich, M. (2007). Effects of Cochlear Implants on Children's Reading and Academic Achievement. *The Journal of Deaf Studies and Deaf Education* 12(3)**,** 269-282. doi: 10.1093/deafed/enm013.
17. Mayring, P. (2000). Qualitative Content Analysis. *Qualitative Social Research* 1(2).

18. Punch, R., and Hyde, M. (2005). The social participation and career decision-making of hard-of-hearing adolescents in regular classes. *Deafness & Education International* 7(3)**,** 122-138. doi: https://doi.org/10.1002/dei.1.

19. Robeyns, I. (2003). Sen's Capability Approach and Gender Inequality: Selecting Relevant Capabilities. *Feminist Economics* 9(2-3)**,** 61-92. doi: 10.1080/1354570022000078024.

20. Sarant, J.Z., Harris, D.C., and Bennet, L.A. (2015). Academic Outcomes for School-Aged Children With Severe-Profound Hearing Loss and Early Unilateral and Bilateral Cochlear Implants. *Journal of Speech, Language, and Hearing Research* 58(3)**,** 1017-1032. doi: doi:10.1044/2015_JSLHR-H-14-0075.

21. Sen, A. (1979). *Equality of What?* Cambridge: Cambridge University Press.

22. Snoddon, K., and Underwood, K. (2014). Toward a social relational model of Deaf childhood. *Disability & Society* 29(4)**,** 530-542. doi: 10.1080/09687599.2013.823081.

23. Sparreboom, M., Langereis, M.C., Snik, A.F., and Mylanus, E.A. (2014). Long-term outcomes on spatial hearing, speech recognition and receptive vocabulary after sequential bilateral cochlear implantation in children. *Res Dev Disabil* 36C**,** 328-337. doi: 10.1016/j.ridd.2014.10.030.

24. Steckermeier, L.C. (2021). The Value of Autonomy for the Good Life. An Empirical Investigation of Autonomy and Life Satisfaction in Europe. *Social Indicators Research* 154(2)**,** 693-723. doi: 10.1007/s11205-020-02565-8.

25. Tolman, D.L., and McClelland, S.I. (2011). Normative Sexuality Development in Adolescence: A Decade in Review, 2000–2009. *Journal of Research on Adolescence* 21(1)**,** 242-255. doi: https://doi.org/10.1111/j.1532-7795.2010.00726.x.

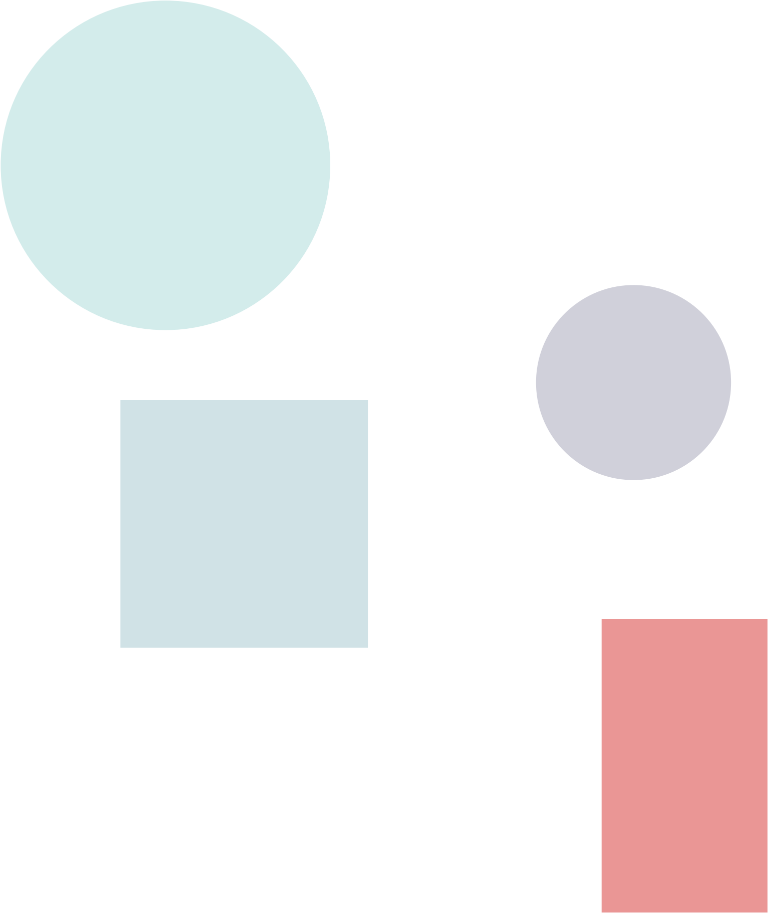
26. Van Den Heuij, K.M.L., Neijenhuis, K., and Coene, M. (2018). Acoustic environments that support equally accessible oral higher education as a human right. *International Journal of Speech-Language Pathology* 20(1)**,** 108-114. doi: 10.1080/17549507.2017.1413136.

27. van Gent, T. (2012). *Mental health problems in deaf and severely hard of hearing children and adolescents : findings on prevalence, pathogenesis and clinical complexities, and implications for prevention, diagnosis and intervention.* Doctorate, Leiden University.

28. Wolters, N. (2013). *Social participation of deaf youth in school: Predictors and consequences of acceptance and popularity of deaf early adolescents before and after a major school transition.* PhD Dissertation, Radboud University.

Appendix for Chapter 5

The Appendix for Chapter 5 can be found online: https://www.frontiersin.org/articles/10.3389/fpsyg.2022.895868/full#supplementary-material



6

HEALTH-RELATED QUALITY OF LIFE AND CAPABILITY WELL-BEING IN ADULTS WITH IMPAIRED HEARING.

A MIXED METHODS STUDY

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Abstract

Hearing impairment has a significant impact on individuals' lives, and various measures are available to mitigate the effects. Understanding how well these measures succeed is crucial, but a complex and challenging task. An important aspect is using appropriate measurement instruments. However, EuroQoL, a widely used health-related quality of life instrument in hearing impairment studies, has limited value. The capability approach to a person’s well-being is concerned with evaluating it in terms of his or her ability to achieve various valuable functionings (Sen, 1993). Therefore, instruments measuring capability, such as ICECAP-A, may be more beneficial. This study aimed to compare the outcomes of health-related quality of life measurements (EQ VAS and EQ-5D-5L) and capability measurements (ICECAP-A and semi-structured interviews) in three groups of adults with hearing impairment and a group of typical-hearing peers. The results suggests that, similar to EuroQoL, ICECAP-A may not capture relevant aspects of well-being in individuals with hearing impairment. We discuss the extent to which further adjustments of the measurement instruments can remediate the issue and to what extent these instruments may not capture the complex and fluctuating nature of human well-being.

Introduction

Health technologies can, and often do, bring about changes in their recipients' condition that extend well beyond the biomedical domain, permeating their general sense of well-being (e.g., Svenaeus, 2018). Not surprisingly, then, national Health Technology Agencies have incorporated additional criteria beyond clinical benefit (Angelis, Lange, & Kanavos, 2018). In their quest for standardization, some of these Agencies such as the National Institute for Health and Clinical Excellence (NICE) in England and Wales and the National Healthcare Institute in the Netherlands (ZIN) have stipulated that the EuroQoL-5D-5L (EQ-5D) be used to describe and value health-related quality of life. In patients with hearing impairments, however, the responsiveness and validity of the EQ-5D in measuring health-related quality of life were found to be relatively low (Summerfield & Barton, 2019; Yang, Longworth, & Brazier, 2013). Alongside other generic preference-based measures such as the Health Utility Index 3, this has prompted interest in novel approaches to the measurement of well-being, including the capability approach. Indeed, NICE and ZIN now actually recommend to include capability outcomes in the assessment of health interventions if non-health-related effects are anticipated to result from an intervention, too.

According to the capability approach, an individual's well-being should be primarily gleaned from the real opportunities an individual has for being and doing the things he has reason to value (Sen, 1979, 1999). Hence, capability extends beyond an individual's actual functioning by asking what range of valued activities and modes of being are available to him. The idea of capability then differs from other available models and instruments in the sense that it aims to establish the degree of freedom an individual enjoys or lacks in choosing his or her own way of life. In other words, to what extent does someone's life reflect own choices and to what extent is it determined by factors that are largely beyond his control? More specifically, capability is conceived as a function of the resources that are available to an individual and his or her ability to convert those resources into something that represents value to him. Among such conversion factors are an individual's social and physical conditions, as well as his own physical, mental, and social competencies (Robeyns, 2003).

Several instruments for measuring capability in the context of health have been developed (Till, Abu-Omar, Ferschl, Reimers, & Gelius, 2021). These endeavors have revealed that the description and valuation of individuals' capability face various challenges (Rijke et al., 2023). Firstly, it needs to be established which functionings actually matter in a specific context: what is it that individuals in a specific context should ideally be able to be or do, if they so wanted to? Secondly, it needs to be established to what extent such functioning are, in fact, achievable, or within reach of individuals: is it realistic to assume that they are, or would be, able to achieve those functionings? Thirdly, especially in the context of health-economic evaluation, some techniques may be needed in order to value specific capability sets. With respect to the first challenge, Sen (1999) has suggested that some deliberative process should be used to achieve local consensus on the functionings that really matter. Alternatively, lists of specific functionings have been developed that are considered to be of generic relevance (e.g., Nussbaum 2000). Regarding the second challenge, researchers can choose to rely on respondents' own assessment of their ability to realize specific functionings. Since people may sometimes over- or underestimate their abilities in this respect, researchers may choose to corroborate such findings, for instance by conducting additional inquiries into availability of resources and presence of relevant conversion factors. This approach was taken for instance by Alkire (2002). Regarding the third challenge, an as yet unresolved issue is how to take account of the fact that the realization of functionings entails trade-offs: the pursuit of a specific functioning may preclude the pursuit of another, and actual achievements are likely to reflect some type of individual preference (Karimi, Brazier, & Basarir, 2016).

The objective of the present study was to explore and compare, in individuals with impaired hearing, their self-reported health status as measured with the EQ-5D-5L, respondents' overall assessment of their health as measured with the EQ Visual Analogue Scale (VAS), and capability well-being as measured with the ICECAP-A and as inferred from semi-structured interviews. The study was conducted in four groups: individuals wearing a unilateral cochlear implant (CI), individuals who were referred for CI, but found ineligible, individuals who were found eligible for CI but who decided to refrain from the procedure, and non-hearing impaired peers who served as a reference group. The second and third group were included because, from a capability perspective, being hearing impaired and having decided not to proceed with the procedure may be quite different from being hearing impaired but found ineligible for the procedure.

We chose to use the ICECAP-A since it is one of the more widely used capability measurement instruments (Helter, Coast, Łaszewska, Stamm, & Simon, 2020). Semi-structured interviews were conducted to facilitate interpretation of the quantitative data. We hypothesized that the groups would not differ in self-reported health status (EQ-5D-5L) and overall assessment of their health (EQ VAS), but might differ in terms of their capability as assessed with the ICECAP-A and the semi-structured interviews.

Materials and methods

Participants

Research participants consisted of four groups. One group consisted of typically hearing individuals who were recruited through a commercial research agency and who served as reference group (group A). The other participants were selected from our own clinical records and consisted of patients who had been referred to our center because of severe or profound bi-lateral hearing loss within the previous 10 years. These formed three groups: patients who had been fitted with a uni-lateral CI (group B), patients who were considered ineligible for CI on the grounds of residual hearing (group C), and patients who were considered eligible, but who decided, for a variety of reasons, not to proceed with the procedure (group D). In accordance with national standards, eligibility for CI was based on a combination of factors, including level of hearing loss, the patient's motivation, and the integrity of the auditory system. Further inclusion criteria consisted of age (between 18 and 80 years), no severe co-morbidity, and sufficient command of Dutch language. Adults with a pre-lingual onset of deafness were excluded The inclusion period was between November 2020 and August 2021. Potential participants were approached and invited by their attending physician; if interested, they were asked to provide informed consent. We aimed to include 80 participants, 20 in each group. With this number, saturation is usually achieved in qualitative interviews (Hennink & Kaiser, 2022). For the quantitative data, these numbers allow for demonstrating statistical significance of relatively large differences only (Cohen's d = 0.8; beta = 0.2, alpha = 0.05, one-sided).

Assessments

Speech perception (3 assessments)

Speech perception abilities were assessed with the Bosman Dutch open set identification test, containing consonant – vowel – consonant words (Bosman & Smoorenburg, 1995). Participants were presented with stimuli in a sound-treated booth at three intensities: 65 dB SPL, 45 dB SPL, and 65 dB SPL with a 65 dB SPL noise level, resulting in a 0db speech/noise ratio. No lip-reading was possible, as stimuli were presented via loudspeakers. Participants were asked to repeat the perceived word, leading to a percentage of correctly repeated phonemes per intensity level. Speech perception was not assessed in the typical-hearing group (A).

Health-related quality of life (EQ-5D)

Health-related quality of life was assessed using the EuroQol 5D, Five-Level Version (EQ-5D-5L). Participants rate their health states on five domains: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Each dimension has five levels: no problems, slight problems, moderate problems, severe problems and extreme problems.

We used scoring values (tariff scores) for the Dutch population to convert participants' answers into a single utility score (Versteegh et al., 2016). In addition, participants were asked to rate their current health state on a visual analogue scale (EQ VAS) from 0 ('The worst health you can imagine') to 100 ('The best health you can imagine').

Well-being (ICECAP-A)

The ICEpop CAPability measure for Adults (ICECAP-A) is a capability-based measure for well-being, also used in health-economics. It asks respondents to rate, on a four-point scale, their ability to: feel settled and secure (stability), to have love, friendship and support (attachment), to be independent (autonomy), to achieve and progress (achievement), and to have enjoyment and pleasure (joy). These domains were identified on the basis of in-depth qualitative interviews with British citizens (Al-Janabi, Flynn, & Coast, 2012); weights for each of the four levels of all five domains were estimated using Best-Worst scaling techniques (Flynn et al., 2015). The Dutch version of the ICECAP-A was found to have adequate test-re-test reliability and construct validity (Rohrbach et al., 2022). The Dutch tariff (Rohrbach et al., 2021) was used to convert the answers to a single well-being score.

Capability interview

Capability interviews were conducted as follows. After brief introductions, the interviewer invited the research participant to walk him through a typical day during the week. The person being interviewed would then usually tell about his or her family situation (e.g., living alone, with partner, children, etc.) and about daily activities, e.g., preparing breakfast, making sure that the children go to school, going to work themselves, taking care of pets, going to visit someone for whom they act as caregiver, looking after the grandchildren, preparing a meal, do some shopping or housecleaning, taking time to read the papers, going out for a walk, doing volunteer work, etc etc. The interviewer would then ask for some more details, e.g. “Could you tell me a bit more about your work?” Usually, the person being interviewed would explain how long he or she has been doing this sort of work, whether it is satisfying, demanding, whether he or she gets along fine with colleagues, whether anything has changed, what they did before, how they got involved, etc. From this, it was usually a small step to ask to expand a little on their training and education, which, in turn, brought up memories of their youth: places where they had lived, where they went to school, parents, siblings, friends, etc. The next item that the reviewer would raise was leisure. This could involve sports (team or solitary), family, friends, (grand)children, pastime such as gardening or board games, hiking or cycling, alone or with partner or friends, travelling, watching movies, playing or listening to music, etc. Since this study was conducted at a time when COVID restrictions were in place, respondents would distinguish between what they would normally do, and what they were currently doing, or rather, not doing. Those with hearing impairment would also indicate the sort of activities they had have to give up because of progressive (or sudden) hearing loss. They would also indicate the sort of supportive technologies they were using, and how these enabled them to resume or continue carrying out particular activities. Those who were considered eligible for CI but who decided not to proceed with the procedure were asked to indicate the main reasons for their decision. As with respect to the issue of work, the researcher would ask the person who was being interviewed to elaborate on issues that were brought up, e.g., whether anything had changed, and if so, in relation to hearing or otherwise, whether things were easy or difficult, gave them pleasure, etc. Toward the end of the interview, which typically took about 30 minutes to conduct, the interviewer would ask a couple of specific questions: what really matters in the life of the person being interviewed, whether there are any things that the person would like to do or be, but unable to achieve, and whether he/she considered him/herself hearing, hearing impaired, or deaf. Also, the interviewer invited the person being interviewed to reflect on the main reasons why certain things were not or no longer possible for him or her to achieve.

In accordance with COVID-19-regulations, interviews were conducted behind a transparent screen. Also due to COVID-19-regulations, typical-hearing research participants completed questionnaires from home and were interviewed via a video-conferencing application.

Analyses

Quantitative measures

Potential differences in speech perception, EQ-5D-5L scores, EQ VAS scores, and ICECAP-A between groups were tested for statistical significance in SPSS, version 22, using ANOVA tests (parametric) and Brown-Forsythe tests (non-parametric). We corrected for multiple comparisons using Bonferroni (parametric) and Tamhane (non-parametric) corrections. Correlations between measures were tested using non-parametric Spearman's rho (ρ) tests. A p-level of .05 (two-sided) was considered statistically significant.

Interviews

All interviews were conducted by one of the co-authors (WR), who is not part of the clinical team involved in CI. Interviews were fully audio recorded, from which intelligent (i.e., non-verbatim) transcripts were created. The interviews were conducted in such a way as to ask respondents to tell us about their projects, the sort of activities that seemed to give shape to their lives to a greater or lesser extent. From this, we tried to identify underlying value commitment. For this purpose, we used the basic values as described by Finnis. These include life, knowledge, play, aesthetic experience, sociability (friendship), practical reasonableness, and religion.

Life, in the value framework of John Finnis, refers to the drive for self-preservation (Finnis, 2011, p. 86). It includes all activities that are directed toward the preservation or restoration of mental and physical health and the avoidance or relief of suffering, pain or malfunction. Its manifestations in daily life are numerous and diverse. Buckling up when driving a car, wearing a helmet when cycling, seeking professional medical care in case of bodily or mental complaints, complying with medical treatment and advice, taking exercise, and seeking a healthy diet can all be considered manifestations of a commitment to this basic good.

By *knowledge*, Finnis means the objective of an inquiry that is conducted out of curiosity. That is, an inquiry that is conducted for its own sake, driven by a desire to know, to find out the truth about something, simply out of an interest in or concern for truth and a desire to avoid ignorance or error as such.

Play refers to engaging in performances which have no point beyond the performance itself, enjoyed for their own sake. Its performance may be solitary or in groups, with an emphasis on intellectual effort or physical effort, strenuous or relaxed, highly structured or relatively informal, etc (Finnis, 2011, p. 87, p. 98).

Aesthetic experience refers to appreciating the beauty of something. Many things can be appreciated for their beauty, e.g., works of art (a painting, a sculpture, a piece of music, a theatrical performance), a landscape, a sunset, etc.

With respect to s*ociability (friendship)*, Finnis distinguishes a continuum, ranging from peace and harmony among persons to full friendships (Finnis, p. 88).

Each of the basic goods mentioned so far seem definitely worth seeking to realize. But each of them can be participated in an endless variety of ways and to highly different degrees of emphasis. Hence, Finnis writes, "our grasp of the basic values creates, not answers, the problem for intelligent decision" (Finnis, 2011, p. 100). Bringing one's intelligence, ingenuity, skills and craft to bear effectively on the problem of choosing one's actions and projects constitutes the basic value of *practical reasonableness* (ibid., p. 88 and pp 100 – 127).

Finally, having acknowledged the value of life itself, of practical reasonableness, aesthetic experience, play, knowledge, and friendship, a remaining question might still be: but what does it all mean? This question is covered by the basic good of *religion*. It refers to the desire, and ability, to think reasonably and –where possible- correctly about questions of the origins of cosmic order and of human freedom and reason, whatever the answer to those questions turns out to be, and even if the answers have to be agnostic or negative (Finnis, 2011, p.89). A commitment to this value can manifest itself in many ways, including the traditional and ritual ways of treating the bodies of dead members of a community, attending mass, taking (or giving) courses on spirituality, mysticism, Zen, etc, or reading (or writing) books on those subjects.

Parts of the interviews that we considered illustrative of one or more of these basic goods were translated into English and are being presented in this paper, alongside the basic goods that, in our view, were involved (see also Appendix 1). Hence, in terms of the capability model, we aimed to identify the functionings in which the people who participated in our study were engaged: the doing and beings they had reason to value, together with the purported underlying basic goods. We also asked whether they experienced any barriers in that respect, or whether things had changed in their lives, especially in relation to how their hearing impairment developed over time. We thus aimed to also collect information on the other two components of the capability framework: resources (e.g., hearing devices, cochlear implant, etc) and conversion factors (e.g., personal characteristics such as hearing acuity, social characteristics such as the adaptations that colleagues, family members, friends or neighbors were able and willing to make), and environmental factors.

Classifying research participants in terms of their capability

The final part of our analysis consisted of a classification of all interviewees in one of three capability classes: no or only minor capability constraints (class 1, or 'green'), very significant capability constraints (class 3, or 'red'), or moderate capability constraints (class 2, or ' orange'). Research participants were classified in group 1 if, overall, they seemed to be the ones who were in charge of major choices or decisions in life (e.g., education, work, type of leisure activities, etc). They were classified in group 3 when, on the contrary, it was external factors that seemed to mainly determine those choices and decisions. Research participants were classified in group 2 if there appeared to be reasonable balance between choices and decisions of their own making, and those that were primarily determined by external factors. This interpretive exercise was conducted by two of the co-authors (WR and GJvdW), independently of each other, and the extent of agreement between the two raters was determined by calculating the kappa coefficient (Cohen, 1960). Discrepancies in classification between the two raters were resolved by discussion. This part of the analysis resulted in a distribution of the research participants across the three capability classes, for each of the four groups.

Ethical considerations

Consent for conducting the study was obtained from the Ethical Review Board of Radboud University Medical Centre (reference number: 2019-5672).

Results

Participants

In total, 69 subjects participated in our study. For groups B, C, and D, 126 patients were invited to participate in our study. Of these, 49 were included (response rate 39%). One patient decided to withdraw consent for using the results of the interview.

There was a borderline statistically significant difference between groups in gender (Chi-square = 7, df = 1, n= 69, p = 0.07); in terms of age, the group of typical-hearing peers was younger than the group of CI recipients (Table 1).

Table 1. Descriptives of research sample and parametric test statistics for comparisons between groups.

		A Typical hearing adults		B Adults with CI		C Adults referred for CI, but ineligible		D Adults eligible for CI, but chose not to		Total		Test of Homogeneity of Variances	ANOVA (between groups)		Bonferroni	
												p	F	p	Groups	p
Gender	Male	10	(50%)	7	(35%)	4	(27%)	10	(71%)	31	(45%)					
	Female	10	(50%)	13	(65%)	11	(73%)	4	(29%)	38	(55%)					
Total		20	(100%)	20	(100%)	15	(100%)	14	(100%)	69	(100%)					
Age	M	49.9		57.6		63.5		53.2		55.9		.338	4.203	.009	A-B	.008
	SD	13.3		8.5		13.2		12.5		12.7						
Speech perception at 65 dB SPL	M	NA		79.8		72.0		48.0		68.3		.421	16.648	.000	B-C	.001
	SD	NA		12.7		19.6		16.3		20.7					C-D	.000
Speech perception at 45 dB SPL	M	NA		34.8		26.2		6.4		24.1		.413	10.894	.000	B-C	.012
	SD	NA		19.6		20.8		8.1		20.9					C-D	.000
Speech perception at 65 dB in noise SPL	M	NA		47.9		42.4		34.8		42.5		.589	2.432	.099	NA	NA
	SD	NA		17.1		16.3		17.8		17.6						

Note. NA = Not applicable

Furthermore, at a 65 dB SPL level, adults who were eligible for cochlear implantation but refrained (group D) had significantly lower speech perception scores than both cochlear implant users (group B) and hearing aid users ineligible for cochlear implants (group C). This was also the case for speech perception at a 45 dB SPL level. There were no statistical differences between the groups when speech perception was measured in noise.

Capability and capability constraints as inferred from interviews

Respondents appeared to be quite open and willing to share with us their reflections on their lives, in terms of achievements, but also in terms of challenges they experienced. Basically, what we did in the interviews was to ask people to tell us about their projects, the sort of activities that seemed to give shape to their lives. From this, we could identify underlying value commitments, using the basic goods, described by Finnis (2011). The interviews provided an informative basis for classifying each respondent in one of the capability classes (no or hardly capability constraints, some capability constraints, and significant capability constraints). We achieved moderate agreement in this classification task, with a kappa of 0.55 ($T = 6.4$, $n = 68$, $p < 0.001$). Full consensus was reached after discussion. The obtained distribution of research subjects across capability class was statistically significant between groups (Chi-square = 28.8, df = 6, $n = 68$; $p < 0.001$, Table 2). Summaries of our findings and illustrative citations are presented below for each of the groups separately. A larger set of citations, along with underlying value commitments is presented in Appendix 1.

Table 2. Distribution of research participants across capability class, per group, and statistical test results (Chi-Square).

		A Typical hearing adults		B Adults with CI		C Adults referred for CI, but ineligible		D Adults eligible for CI, but chose not to		Total		Pearson Chi-Square	
		N	%	N	%	N	%	N	%	N	%	χ2	p
Rating	1 (minor capability constraints)	15	75,0%	6	30,0%	0	0,0%	6	42,9%	27	39,7%	28.779	.000
	2 (moderate capability constraints)	5	25,0%	10	50,0%	5	35,7%	5	35,7%	25	36,8%		
	3 (major capability constraints)	0	0,0%	4	20,0%	9	64,3%	3	21,4%	16	23,5%		
Total		20	100,0%	20	100,0%	14	100,0%	14	100,0%	68	100,0%		

Group A: Normal hearing peers (n = 20)

All non-hearing impaired peers except one (who was retired) reported to be engaged in full-time or part-time professional activities. Additional activities included running the household, looking after the (grand)children, and volunteer work. All except two lived with their partner or family. Leisure activities included sports (e.g., soccer, tennis, sailing), hiking, preferably with friends but also on their own, cycling, gardening, listening to music, watching films, going out with friends, going on holiday, visiting places (e.g., museums), pets, cooking, and games. Very few constraints were reported, in the sense of not being able to pursue what was important to them. If there were, they mostly appeared to relate to specific health problems, e.g., prostate carcinoma (in remission), thyroid disorder, skin cancer, depression, migraine, or physical trauma. Basic goods as distinguished by Finnis could readily be inferred from the interviews, as illustrated in Box 1. Overall, 15 out of 20 (75%) were classified in capability group 1 (no or very few capability constraints), and 5 (25%) in capability group 2 (some capability constraints). None in this group were classified in group 3 (significant capability constraints) (see Table 2).

Box 1.Excerpts from interviews illustrating how the seven basic goods distinguished by Finnis transpired in the lives of normally hearing peers. SOC = sociability (friendship); AESTH = aesthetic experience; PRACT REAS = practical reasonableness; REL = religion; KNOW = knowledge.

"I've been General Practitioner, done a lot of research, too. Now I have the time to study things for which I didn't have the time then; things that I found interesting, such as immunology and everything that has to do with DNA. I try to catch up, and learn as much as possible about it." (KNOW)
"I have worked full-time until I reached the age of 62. I then developed physical problems. As a GP you can never be present just a little bit, so I had to choose between pushing on under quite extreme conditions, or quit altogether. I decided to quit. But it was okay, really. I had been doing it for a long time. Worked hard for everyone; then it's okay to start thinking about your own health." (PRACT REAS)
"I had prostate cancer. Radical resection. I had to recover, of course. Now it's back to normal, wait and see how things will go. But I think I was fully cured." (LIFE)
"I have a home trainer, weights and all that. Good stuff. Gives you a sense that you can still do everything. I now have the time for it. Only restriction being not to overload my muscles and joints." (LIFE)
"I am Rotary member. Meet weekly. Make cultural trips together. Collect money for those who need it more than we do." (SOC, AESTH)
"Once COVID restrictions are lifted, I would like to go to church again, meet friends that we haven't seen for some time, travel, that sort of thing." (REL, SOC)
"A few years back, our house burned down. You then notice what it is like to be back on square one again. It's not fun, but also a valuable experience. Because you still have each other, you start all over again, you notice that you can and that special and nice things start to happen again. You then notice that there are only a few things that really matter in life." (PRACT REAS, SOC)
(Interview number 202)

GROUP B: Individuals wearing a unilateral cochlear implant (n = 20)

In this group, 12 out of 20 reported to be engaged in full-time or part-time professional activities. Two were formally declared unfit for work, one was retired, one was out of work, two were running the household, and two were doing volunteer work. Additional activities included looking after the (grand)children, and being caregiver of elderly parents. Leisure activities included reading, crafting, sports (e.g., sailing), hiking, preferably with friends but also on their own, cycling, gardening, pets, cooking, and yoga. Constraints primarily related to being in groups, listening to music, lack of a sense of belonging, and lack of energy. Seventeen considered themselves as hard of hearing, while three considered themselves as hearing; none considered themselves deaf. The majority in this group indicated to be (very) satisfied with the CI. Health problems included osteoarthritis (hip surgery, knee surgery), arthrosis, and leukemia (in remission). Basic goods as distinguished by Finnis, within or beyond reach could readily be inferred from the interviews, as illustrated in Box 2. Overall, 6 out of 20 (30 %) were classified in capability group 1 (no or very few capability constraints), 10 (50 %) in capability group 2 (some capability constraints), and 4 (20 %) in group 3 (significant capability constraints) (see Table 2).

Box 2.Excerpts from interviews illustrating how the seven basic goods distinguished by Finnis transpired in the lives of individuals with uni-lateral CI. SOC = sociability (friendship); AESTH = aesthetic experience; PRACT REAS = practical reasonableness; REL = religion; KNOW = knowledge.

"I used to love music. But with the hearing devices, it was over at a certain time. You hear the rhythm. But a good guitar solo, or piano playing, that's missing…When I got the CI, I thought, let's try music. But they said, you do realize that it's a speech processor, don't you? But I still went to listen. And now I listen music every day. And I hear the instruments separately again. And also the voices of the singers. What they say… My experience of music is again what it used to be."(AESTH)
[Anything that you would like to do but can't?] "I wouldn't know. I think of my life as rich again. Not that it was poor before. But I said to myself, if such a CI didn't exist, then you would end up socially isolated. Lip reading, sign language, that's a lot of hassle. What good is sign language to me, others need to learn that too. Do I have to expect that from everyone?" (SOC)
Interview number 107.
"I feel super, but I'm always tired. It is very tiring. Always filling in. Unconsciously. But I do notice, when I'm having a conversation with someone, and that person says something that seems completely out of context. Then you realize that you're hearing not nearly half of what is being said. But very good in filling in. Which costs a lot of energy."(SOC, CONSTR)
(Interview number 110)
"I used to be a primary school teacher. Was great fun with those kids. With all my heart. But that was no longer possible either. I always had very nice classes. But each day we started the week with circle-time: what did you do over the weekend? I usually responded with 'Great, nice!' Then, one day, a boy told a story. And the class responded 'Miss, what are you saying? We scattered dad's ashes on the water.' And I had responded 'Oh, nice!' And then I thought: I may like doing this, but it's not right. It's the children's education. Since then I have dreamed about teaching classes, and those were the best dreams I have ever had. But now I am okay with it. Other doors have opened. Which was good." (SOC, PRACT REAS, CONSTR)
(Interview number 113)
"I can make telephone calls again. That was no longer possible with the hearing devices. That affected my social activities. Avoiding conversations. No longer making telephone calls spontaneously. You don't answer the telephone anymore. Passing everything to my partner. Now it's the other way round. Now I am the one who makes the call. That feels good for your independence. I find that important, being able to do my own things, without having to ask for help too much from others." (SOC)
(Interview 115)
"I used to watch soccer, here at the club. Now I sit apart, behind the goal, so that no one is near. Canteen is no longer an option either. What used to give me so much fun means nothing to me anymore." (PLAY, CONSTR)
(Interview number 118)

6

Group C: Individuals with hearing impairment, screened for CI, but found ineligible (n = 14)

In this group, 4 out of 14 reported to be engaged in full-time or part-time professional activities. Four were formally declared unfit for work, four were retired, one was running the household, and one was doing volunteer work. All considered themselves as being hard of hearing (that is, not deaf, nor hearing). Additional activities included cycling, travelling, cooking, pets, fitness, gardening, singing in a choir, looking after the (grand)children, jogging, board games, and drawing. Constraints were primarily reported in relation to being in groups, listening to music, feelings of loneliness, and lack of energy. Health problems included cervical cancer (in remission), backpain, visual problems, and arthrosis. Basic goods as distinguished by Finnis, within or beyond reach could readily be inferred from the interviews, as illustrated in Box 3 Overall, 5 out of 14 (35,7 %) were classified in capability group 2 (some capability constraints), and 9 (64,3 %) in group 3 (significant capability constraints). None in this group was classified in capability group 1 (no or very few capability constraints) (see Table 2).

Box 3. Excerpts from interviews illustrating how the seven basic goods distinguished by Finnis transpired in the lives of hearing-impaired adults who were screened for CI but found ineligible. SOC = sociability (friendship); AESTH = aesthetic experience; PRACT REAS = practical reasonableness; REL = religion; KNOW = knowledge.

"I usually listen to the classical radio channel. Avoids commercials. More by way of background. Otherwise, it can be very quiet in the house. The lack of someone talking to you…Neglected my friendships a bit, too. Not member of some club either." (SOC, CONSTR)
(Interview number 301)
"Hearing is a challenge, so you need people who encourage you, not people who tell you that you can't." (SOC, CONSTR)
"I don't dare to cycle anymore because of my balance and because I don't hear anything from behind. In the past, I've had to learn cycling secretly. My parents thought it was too dangerous for me. While it gave me a huge sense of freedom. And my family said that I couldn't do it, that it was too dangerous." (SOC, PRACT REAS, CONSTR)
(Interview number 302)
"I'd very much want to be able to understand my grandchildren. They are very fond of me, but it's quite obvious that they sometimes simply don't know how to deal with me." (SOC, CONSTR)
"What is important for me is, in fact, simply joining and participating. Also in society. No need to always lock yourself out because you can't cope." (SOC, CONSTR)
(Interview number 304)
"But there are many things that you stop doing. Sometimes you're dragged into it, such as birthday parties. COVID was great for me, no more birthday parties. Sitting with ten to fifteen people in a room, everybody cross-talking. Simply a matter of waiting until you can go home. I've stopped attending other meetings with large groups already for many years, it's no use. I simply can't understand what is being said." (SOC, CONSTR)
"I've stopped listening to the radio more than 15 years ago. Music, for instance. It's all a jumbled mess. Ten years ago, I started singing in a choir. I've tried until COVID. But I frequently got the notes all wrong. I could enlarge the sheet music so that I could read the text. But now I can't read it anymore because of my eyes. So, I stopped with the choir. In fact, continuing with the choir has been doubtful because of my hearing for many years." (AESTH, CONSTR)
"It takes such an effort to understand just a few things. And frequently, you get things wrong. Afterwards, my wife fills me in. And it appears that I got it all wrong. Very frustrating. Therefore, I try to avoid such situations. A shame, really, when you come to think of it." (SOC, CONSTR)
(Interview number 306)
"I do not do nearly as much as I used to do. That's a shame. Cycling, for instance, because of my problems with balance. Sports is very hard, because you need balance. I used to dive, but that's not allowed anymore either. And those things, it makes it very difficult. Walking is, in fact, very intensive. I can do it, but always at the arm of my husband… My husband and I do a lot together, by yourself gets increasingly difficult. So you give up a lot of freedom and independence." (PLAY; SOC, CONSTR)
"It's difficult, because you lose your independence. I love music. I have very specific preferences in that regard. But it has always been difficult. Start to recognize it only after listening long enough. Now, since 1,5 year, I have a hearing device that I can directly connect to my mobile phone. Now I can stream, and with YouTube on my iPad I can completely lose myself. It's wonderful that that is possible now." (AESTH)
(Interview number 309)
"Because, because of your hearing loss you are a different person. You can seem harsh. Unresponsive. Walk right past someone. Or make an improper comment, merely because you misunderstood." (SOC, CONSTR)
[Anything that you leave while you would like to do it?] "Perhaps taking some sort of course. I love needlework. I wanted to learn some new techniques. But I didn't understand at the time it was explained. I hear something, need time to process it, and only then I take it in. But then they have already moved on. Difficult to keep up with." (SOC; KNOW, CONSTR)
(Interview number 315)

Group D: Individuals with hearing impairment, screened and found eligible for CI, but decided not to proceed (n = 14)

In this group, 8 out of 14 reported to be engaged in full-time or part-time professional activities. One person was formally declared unfit for work, three were retired, and two were on sick leave. Eleven of this group considered themselves as being hard of hearing; three considered themselves as hearing person. Additional activities included outdoor activities such as mountain biking and hiking, travelling, pets, looking after the (grand)children, going to church, volunteer work, and needle work. Constraints were primarily reported in relation to lack of energy, the effort associated with listening, and tiredness. Specific devices that were mentioned included flash doorbell, hearing devices, vibrating alarm clock, and speech-to-text converter. Health problems included COPD, heart failure, hip fracture, and hypertension. Basic goods as distinguished by Finnis, within or beyond reach could readily be inferred from the interviews, as illustrated in Box 4. Overall, 6 out of 14 (42,9 %) in this group were classified in capability group 1 (no or very few capability constraints), 5 out of 14 (35,7 %) were classified in capability group 2 (some capability constraints), and 3 (21,4 %) in group 3 (significant capability constraints). (see Table 2).

Box 4. Excerpts from interviews illustrating how the seven basic goods distinguished by Finnis transpired in the lives of hearing-impaired adults who met CI criteria but who decided not to proceed with the procedure. SOC = sociability (friendship); AESTH = aesthetic experience; PRACT REAS = practical reasonableness; REL = religion; KNOW = knowledge.

“I get up, start doing some exercises for my shoulder [because of a fall, ten years ago]. Then some yoga exercises. Go downstairs to feed the cat. I then go to my work, or do other things.” (REL; SOC; LIFE)

“Furthermore, I study. I just finished my training as energy therapist…Because, what I have noticed is that studying or taking courses does me a lot of good, developing myself further. If I don’t do that, life loses a bit of its colour for me. It makes me think, what am I doing? What I find most important in that respect is loving presence, to live that, put it into practice. Not pointing to others when things become uncomfortable, but to yourself. It’s about your perception, your reality. That is very much leading in how I live my life.”(KNOW; SOC; REL; PRACT REAS)

“I believe I have never felt completely at ease. Always uncomfortable. Always a weird child according to everyone. I think I communicated differently, too. Couldn’t control the use of my voice very well. And that I talked in a strange way, but also said strange things.” (SOC, CONSTR)

[Leisure:] “Listening music, singing with others, sit quietly. Working a bit on my website. I read a lot. Relaxing, lying down. Cooking, reading, hiking. That’s what I love to do. Can’t do that very well, though, since the left side of my body becomes thick when I’ve been walking for a long time as the result of that fall. But I love being outdoors. “ (AESTH; CONSTR, not related to hearing impairment)

“My neighbour helps me out with telephone calls. The vet, the hospital. That is really super. I can also ask a colleague form work. But still, I am alone quite often. My unhappy start in life has left a large hole of deep, intense loneliness in my life. It is always there, right under the surface. I occasionally recharge myself, but sometimes I feel that loneliness very deeply. I can cope with it, but it is my base feeling in life, my blueprint. Everything that I do pulls me out of it, but if that fades, I enter into my blueprint-state. Not nice.” (SOC, CONSTR)

Waived CI because:

“I wanted to be able to sing mantra with it in a group. That comes very precise. It’s about frequencies. Mantra are sounds from the universe that have been arranged in a specific way, such, that you can end up in a specific frequency. So you can start singing at a specific frequency., which makes you feel a particular way. Lovingly, strong, or powerful. It all depends at what frequency you sing. And since I am unable to correct my own voice when singing, I would very much want to be able to do just that. That’s why I considered CI. But that turned out to be an illusion, because that is something a CI cannot do for you. But I was deaf enough for it.” (SOC, REL, AESTH, PRACT REAS)
(Interview number 001)
“Initially, I wanted to become a history teacher..Then it turned out, you can’t become teacher because of your hearing and because of your voice…So that choice was in fact already made for me. So I thought, forget it.” CAP CONSTR)
[reason for not choosing CI:] “I’m pretty headstrong. I really love music. The sound should really be good. It should have a certain quality. ..And with CI, there’s no going back. Now, with hearing devices, if they don’t match my needs, I try something else. But if that were to happen with CI, you’re stuck. If it sounds tinny, it doesn’t give me pleasure. If I would have to make do with that for the rest of my life, I would have made the wrong decision. That’s what I’m afraid of. There’s no going back… In addition, I practice many sports. Soccer, tennis, swimming, skiing, wearing helmets. Those things [CI] are not very practical then. If something happens, a ball to your head, a fall. You don’t want all that. In fact, I’m too sportive to wear a thing like that. There’s no going back.”
“When I’m travelling, too. Everything new, all sort of triggers. At the end of the day, really very tired. I have to make more of an effort than you do in order to digest everything. I do like to travel. I love history. Do that with a group of friends. But at a certain time the focus is lost and then I’m done with it.” (SOC, AESTH, CONSTR)
“Disadvantage [of hearing impairment] is simply that in daily life, you run into all sorts of problems, such as making phone calls. That you are unable to do everything that you would like to do. That my hearing impairment has resulted in certain choices that I have had to make and that I would have made differently otherwise. Say, for instance, with respect to my profession. That I would have chosen a different profession. Also, for example, with respect to relations. Always this impairment that deters people, that prevents them from starting an affair with you. Never to be regarded for full. It’s a frustration that you need to learn to live with. One shouldn’t nag about it.” (SOC, CONSTR)
(Interview number 003)

Resources and conversion factors

The interviews also revealed the nature of resources and conversion factors that appeared to be specifically relevant for adults with hearing impairment. This could be both positive (i.e., awareness of the importance of specific resources or conversion factors that were present), or negative (i.e., awareness that such resources or conversion factors were not, not sufficiently, or no longer present). Examples include respondents’ awareness that the CI had resulted in return of their former experience of music (int nr 107, above), ability to make phone calls again (int nr 155, above), or ability to witness the speech development of their grandchildren (int nr 104). Other specific resources that were reported and that appeared to be critical in terms of capability protection included flash doorbell, hearing devices, vibrating alarm clock, speech-to-text converter, and hearing device in combination with streaming technology (int nr 309 above). Conversion factors that were reported and that appeared to be critical in capability protection were frequently social in nature, for instance the importance of people encouraging you to do or continue doing things (e.g., int nr 302 above) and social acceptance of hearing impairment, e.g.:

> *"I always tell people that I am hard of hearing. I also indicate when things start getting too busy for me, and that I switch off my hearing devices. I don't have a problem with that. Not with how it looks either. I grew up with it, and it should, in fact, be more visible. Commercials always claim that it can become even less visible. It makes me angry. It is simply not socially accepted." (SOC) 309 (group C, not meeting CI criteria).*

> *"In fact, I don't notice that I have a handicap. Because most people are willing to make an effort. As soon as they don't, I feel handicapped. It sometimes happens. In a town I haven't visited before. With a bus driver who doesn't know me. And then to say it still once more. That I really need to see lip movements. In fact, I am constantly creating the conditions so that the other is willing to cooperate."*

> *"But I've been really lucky that I can speak well. Then, other people also behave normally. As soon as you can't speak well, you get different behaviour. I've been lucky. It also gives me the sense of being able to lead a normal life. Because people treat me for full. When talking to deaf people, people sometimes think that there is something cognitively wrong, too. Striking. Horrible, actually."(Int nr 001; group D, waived CI)*

The following excerpt illustrates how individual characteristics (conversion factor) and resources combine in protecting capability:

> *"I think that by now, I have found my way in my auditory limitations. I hope I will be able to continue to take care of myself. Things are getting more difficult now that I'm growing old. But technology is improving. I'm simply very happy with my intelligence and with my character. That's how I have been able to make something of it. My handicap is part of me, not an obstacle, or a barrier. I don't feel it that way. But what I do think is important is the strengths with which you have come into the world. And I can imagine that there are people with hearing loss who do not have such strengths. Or the preconditions around them. To be strong, a positive attitude. Knowing deep down that it's okay. That things will be alright. That sort of things. I think that I've been lucky with who I am. I have seized opportunities. And I can appreciate the value of it."*
>
> (Int nr 001, group D, waived CI)

Health-related quality of life and capability well-being

No statistically significant differences were found in health-related quality of life, as measured with the EQ VAS, between the four groups when respondents judged their own health states (Table 3. The average tariff score of the EQ-5D-5L was higher in group A (typical hearing) compared to group C (not eligible). No other statistical differences between groups were observed. Health-related quality of life did not correlate with speech perception scores. The ICECAP-A scores showed no difference between the four groups. The ICECAP-A was not correlated to speech perception, but it did have a strong, positive correlation with the EQ-5D tariff scores ($n = 68$, $\rho = .667$, $p < .001$).

Table 3. Descriptive results of the EQ-5D-5L, EQ-VAS and ICECAP-A, and test statistics for comparisons between groups, parametric (ANOVA and Bonferroni) and non-parametric (Brown-Forsythe).

		A Typical hearing adults	B Adults with CI	C Adults referred for CI, but ineligible	D Adults eligible for CI, but chose not to	Total	Test of Homogeneity of Variances	ANOVA (between groups)		Bonferroni		Robust Tests of Equality of Means (Brown-Forsythe)	
							p	F	p	Groups	p	F	p
n		20	20	15	14	69							
EQ-5D-5L	M	.935	.887	.801	.845	.874	.494	3.213	.029	A-B	.026		
	SD	.088	.129	.177	.136	.139							
EQ-VAS	M	87.4	84.3	82.2	82.9	84.5	.567	.805	.496	NA	NA		
	SD	8.79	10.8	10.9	13.0	10.7							
ICECAP-A	M	.970	.948	.884	.916	.935	.008					2.779	.059
	SD	.033	.054	.139	.092	.087							

Note. NA = Not applicable

Discussion

The merits of the capability framework for our inquiry

We found the capability approach a helpful, unifying framework, centring around value and the preconditions that should be in place for its realization. The daily projects and activities that respondents put forward during interviews could be usefully conceived as functionings (doings and beings that people have reason to value), or different modes of participating in value. Interviews revealed how these functionings served in guiding major decisions, such as opting for, or declining CI. In this respect, it was of interest to note that individuals who were eligible for CI but who decided not to proceed with the procedure, even though having poor speech perception, appeared to do relatively well in terms of capability. An explanation for this might be that they were more in control of this decision as compared to those who were found ineligible for CI. Reasons for not proceeding with the operation clearly referred to functionings, and the perception that CI would not make a big difference in that respect, or could actually put their achievement at risk. Furthermore, the critical role of resources (e.g., CI, hearing devices, flash doorbell, streaming technology, etc) and conversion factors (e.g., how other people reckoned with the specific needs of people with hearing impairment) clearly emerged from the interviews. The interviews also showed the ambiguities involved, e.g. when reflecting about their hearing devices:

> *"I find them [hearing devices] ugly. Awful. I thought, perhaps, I'm ashamed of it. That sucks. I cannot do without, I'm thrilled with them, and yet…" (int nr 008)*

Finally, the intrinsic value of having a choice, a key element of the capability framework, was articulated by several respondents, e.g. in response to the question what really mattered:

> *[Main thing in life?] "Difficult question. Freedom. That I can control the things that I like, the things that give me energy. That keep me alive. Freedom to give direction to these things. For that reason also grateful for there being hearing devices. And perhaps I have become the sort of person who I am because of my hearing handicap." (int nr 005)*

Differences in capability between groups: interview findings vs questionnaire outcomes

In our view, the results of the interviews that we conducted indicate that the four groups in our study differ in terms of the participants' capability. Whereas in typical-hearing peers, the majority (75%) was classified as having no or only minor capability constraints (capability class 1), and none as having major capability constraints (capability class 3), the reverse was true of hearing-impaired adults who did not meet CI criteria (64.3% in capability class 3, and none in capability class 1). Individuals in the other two groups were distributed more evenly across the three capability classes, and were fairly comparable in this respect. In the group of typical-hearing adults, a wide variety of functionings could be identified, relating to various basic goods, while hardly any constraints or limitations in pursuing these functionings were mentioned. To be sure, major adverse life events were reported in this group, too, including serious illness and house burn-down. However, respondents in this group generally seemed to be able to cope with such events in a way that prevented them from becoming major capability constraints. A recurrent theme in the interviews that were held with participants in the other three groups was tiredness. The fact that listening can be exhausting for children and adults with hearing loss has been well established (Bess & Hornsby, 2014; Holman, Drummond, Hughes, & Naylor, 2019). Also in our study, respondents attributed their tiredness to the efforts they had to make in order to make sense of the sounds they were hearing, especially spoken language. This tiredness seemed to pervade most, if not all domains of their lives, notably social activities and work. Svinndall et al. (2018) found that among persons within working age with hearing loss, degree of hearing loss was associated with low workability, fatigue and work place accommodation, while sick leave was associated with fatigue. Kramer et al. (2006) found that employees with hearing impairment reported significantly more often problems with noise at work and job control as compared to their normally hearing colleagues. Respondents in our study also indicated that their hearing problems frequently made them avoid certain activities or situations, which, in turn, could lead to a sense of intense loneliness, a finding that is consistent with the results of a recent scoping review (Bott & Saunders, 2021). This seemed to be most strongly the case in individuals who had been screened for CI but who were found ineligible. Those who did meet CI criteria but who decided not to proceed with the procedure, in spite of having poorer speech perception, appeared to be largely on a par with CI-recipients in terms of capability.

The differences in capability that we inferred from the interviews did not, or only marginally, transpire in the quantitative results from our study. No statistically significant differences were found between the groups in subjects' self-rated health (EQ VAS), nor in capability as measured by the ICECAP-A. In terms of health-related quality of life (as measured with the EQ-5D-5L), only subjects who did not meet CI criteria differed significantly from their typical-hearing peers. A possible explanation of these findings is that the instruments simply measure different concepts. The EQ VAS invites users to indicate on a scale from 0 to 100 how good (or bad) their *health* is on that day. The EQ-5D-5L asks respondents to indicate which description best describes their *health* on that day. Somewhat confusingly, an influential definition of health, provided by the World Health Organization, states that health is 'a state of complete physical, mental and social well-being, and not merely the absence of disease and infirmity' (see for discussion of the concepts of health, health-related quality of life, and quality of life: Karimi et al., 2016). Although we do not really know the respondents' associations with the term ‘health’, it stands to reason that their thinking is more about medical conditions, for instance, physical trauma sustained in the past, arthrosis, COPD, cancer for which they have been treated, or mental deregulation such as depression, rather than how their hearing condition affects their daily lives. An explanation for the discrepancy with the ICECAP-A results is less straightforward. For instance, a statement like ‘I am able to feel settled and secure in a few areas of my life’ (ICECAP-A, Feeling settled and secure), could capture the sense of insecurity in traffic that was mentioned by various respondents in groups B – D. Likewise, the statement ‘I can have a little love, friendship and support’ might reflect the challenges that were experienced by respondents in functioning in larger groups. And, in a similar vein, the statement ‘I am able to be independent in a few things’ could reflect the relatively large dependence on others (e.g., partners, neighbors) when going out, or when communicating with administrative or health authorities on the phone. The ICECAP-A asks respondents to indicate which statements best describe their overall quality of life at that moment. The approach that was taken in the interviews was more indirect, asking respondents to reflect on their main activities (or functionings) and to what extent these resulted from their own choices or from external constraints. Moreover, rather than asking about their status at that moment, it took more of a life course approach, with respondents reflecting on how things had evolved in their life over time. This frequently included how hearing loss had (gradually or suddenly) changed their life, how the use of specific resources (CI, hearing devices) had brought about change, and how adaptation and ageing had impacted this. Another explanation may be that the number of participants in our study was insufficient to demonstrate relevant differences in ICECAP-A scores between groups at conventional levels of statistical significance. Indeed, the trends in the classification in capability classes on the basis of interviews and the ICECAP-A results are compatible, with typical-hearing individuals ranking highest, individuals who did not meet CI criteria lowest, and the other two groups in between. Moreover, the difference in ICECAP-A scores approached conventional levels of statistical significance.

Possible implications for instrument development

If researchers wish to develop capability instruments that are more sensitive to the specific way capability may be compromised in hearing-impaired persons, our results suggest that relevant domains would include fatigue (e.g., being able to be full of energy), education and work (e.g., being able to find and secure satisfying paid work), music (e.g., being able to enjoy making or listening to music), and being able to be comfortable and enjoy the company of larger groups of people. It should be noted, however, that our findings relate to persons with hearing impairment only. Several studies have shown that the ICECAP-A, as compared to the EQ-5D, resulted in different, complementary information, can give attention to more broader impact, and can be more sensitive to change (e.g., Goranitis et al., 2016; Keeley et al., 2016). In addition, however, we should perhaps accept that the two approaches for exploring people’s capability that were used in this study, produce disparate (not just different) results. Rating one’s health by selecting descriptions that seem to correspond best with how someone experiences his or her condition at that moment, is simply different from telling a story of one’s life in the context of an interview (Einola & Alvesson, 2021).

Limitations

Our study has several limitations. Firstly, the four groups differed in age and gender distribution. It is not unreasonable to assume that they differed in yet other respects that were not determined, for instance educational level or social-economic status, that might be related to the outcomes of interest (i.e., health-related quality of life, capability well-being). As such, our results may suffer from confounding in a way that is impossible to estimate. Secondly, candidate research participants for groups B, C and D were identified from our own clinical records, with 126 individuals being approached and 49 individuals consenting to participate (39%). We do not know whether, and if so, how and to what extent, this selection has affected the results of our study. Thirdly, the research was conducted at a time when COVID-19 restrictions were in place. These restrictions limited the daily activities of research participants in various ways, while our goal was to explore research participants’ capability under more normal conditions. This may have affected the results of our study. For instance, it was abundantly clear that COVID-19 restrictions disproportionately affected hearing-impaired people, for instance because the wearing of facial masks rendered lipreading virtually impossible. Fourthly, our goal was to gain a better understanding of the way and extent people’s capability is constrained as the result of impaired hearing. We think we succeeded in identifying what was important to the persons who participated in our study, and also in identifying the limitations that they encountered in achieving such things. What is more uncertain, however, is the extent to which such limitations result from hearing impairment, or from other causes; moreover, multiple, interdependent factors may be at play, including hearing impairment, which cannot always be easily disentangled.

Fifthly and finally, interpretation played a key role in our study. Basically, what we did in the interviews was to ask people to tell us about their projects, the sort of activities that seemed to give shape to their lives. From this, we tried to identify underlying value commitments, using the basic goods, described by Finnis (2011). Several assumptions are being made in this process. Firstly, we assume that the activities and projects that people are engaged in and told us about are, in one way or another, actually of value to them. In other words, we conceived of these activities and projects as specific ways of ‘participation-in-value’ (Finnis, 2011, p. 64), or, in the capability framework, of functionings. Secondly, we assumed that the basic goods as distinguished by Finnis could be used for this purpose; that in one way or another, the reported projects and activities can be mapped onto those basic goods. Thirdly, we assume that the underlying value commitments can be accurately gleaned from the manifold and diverse activities in which human beings engage. Indeed, Finnis suggests that such presupposed commitments can be identified by reflection not only on our own thinking but also on the words and deeds of others. In the context of our study, we have tried to render our interpretations transparent and credible by translating key parts of the interviews into English and by presenting them in this paper, alongside the basic good or goods that, in our view, were involved. In addition, the interpretative exercise was conducted by two researchers (WR and GJvdW) independently of each other; the moderate agreement that was achieved strengthens, in our view, the credibility of this this classification task. In addition, we did not merely query respondents about their doings and beings that they had reason to value (functionings). We also asked whether they experienced any facilitators or barriers in that respect, or whether things had changed in their lives, especially in relation to how their hearing impairment developed over time. This enabled us to also collect information on the other two constituents of the capability framework, resources and conversion factors, which is yet another distinction with a capability measurement instrument such as the ICECAP-A.

Conclusion

Although the literature on the capability approach is rather daunting, the main underlying idea is fairly straightforward. It has been proposed as a metric to express the relative advantages and disadvantages that people (or groups of people) have. In other words, in this framework, if one wishes to know how well people's lives go, the answer should be given in terms of their capability. Implicitly, throughout this paper, we have held that it is precisely this what policymakers should want to know: how well do the lives of people, in our case, the lives of people with hearing impairment go? And, if there is reason to believe that they do not always go that well, what are possible reasons for this, and what might be effective directions to remediate this? Measurement instruments such as the ICECAP-A may be of use here, but have some limitations that may not be easily resolved. Agencies such as the National Institute for Health and Clinical Excellence (NICE) in England and Wales and the National Healthcare Institute in the Netherlands (ZIN) should, therefore, consider to demand mixed methods research when their objective is to better understand 'how well a specific group of people's lives go.'

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Conflict of Interest Statement

The authors declare that there is no conflict of interest.

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References

1. Al-Janabi, H., Flynn, T. N., & Coast, J. (2012). Development of a self-report measure of capability wellbeing for adults: the ICECAP-A. *Quality of Life Research 21*(1), 167-176. doi:10.1007/s11136-011-9927-2
2. Alkire, S. (2002). *Valuing freedoms: Sen's capability approach and poverty reduction*. Oxford; New York: Oxford University Press.
3. Angelis, A., Lange, A., & Kanavos, P. (2018). Using health technology assessment to assess the value of new medicines: results of a systematic review and expert consultation across eight European countries. *The European Journal of Health Economics, 19*(1), 123-152. doi:10.1007/s10198-017-0871-0
4. Bess, F. H., & Hornsby, B. W. Y. (2014). Commentary: listening can be exhausting--fatigue in children and adults with hearing loss. *Ear and Hearing, 35 6*, 592-599.
5. Bosman, A. J., & Smoorenburg, G. F. (1995). Intelligibility of Dutch CVC syllables and sentences for listeners with normal hearing and with three types of hearing impairment. *Audiology 34*(5), 260-284.
6. Bott, A., & Saunders, G. (2021). A scoping review of studies investigating hearing loss, social isolation and/or loneliness in adults. *International Journal of Audiology, 60*(sup2), 30-46. doi:10.1080/14992027.2021.1915506
7. Cohen, J. (1960). A Coefficient of Agreement for Nominal Scales. *Educational and Psychological Measurement, 20*(1), 37-46. doi:10.1177/001316446002000104
8. Einola, K., & Alvesson, M. (2021). Behind the Numbers: Questioning Questionnaires. *Journal of Management Inquiry, 30*(1), 102-114. doi:10.1177/1056492620938139
9. Finnis, J. (2011). *Natural Law and Natural Rights*: OUP Oxford.
10. Flynn, T. N., Huynh, E., Peters, T. J., Al-Janabi, H., Clemens, S., Moody, A., & Coast, J. (2015). Scoring the Icecap-a capability instrument. Estimation of a UK general population tariff. *Health Economics, 24*(3), 258-269. doi:10.1002/hec.3014
11. Goranitis, I., Coast, J., Day, E., Copello, A., Freemantle, N., Seddon, J., . . . Frew, E. (2016). Measuring Health and Broader Well-Being Benefits in the Context of Opiate Dependence: The Psychometric Performance of the ICECAP-A and the EQ-5D-5L. *Value in Health 19*(6), 820-828. doi:10.1016/j.jval.2016.04.010
12. Helter, T. M., Coast, J., Łaszewska, A., Stamm, T., & Simon, J. (2020). Capability instruments in economic evaluations of health-related interventions: a comparative review of the literature. *Quality of Life Research 29*(6), 1433-1464. doi:10.1007/s11136-019-02393-5
13. Hennink, M., & Kaiser, B. N. (2022). Sample sizes for saturation in qualitative research: A systematic review of empirical tests. *Soc Sci Med, 292*, 114523. doi:10.1016/j.socscimed.2021.114523
14. Holman, J. A., Drummond, A., Hughes, S. E., & Naylor, G. (2019). Hearing impairment and daily-life fatigue: a qualitative study. *International Journal of Audiology, 58*(7), 408-416. doi:10.1080/14992027.2019.1597284
15. Karimi, M., Brazier, J., & Basarir, H. (2016). The Capability Approach: A Critical Review of Its Application in Health Economics. *Value in Health 19*(6), 795-799. doi:10.1016/j.jval.2016.05.006
16. Keeley, T., Coast, J., Nicholls, E., Foster, N. E., Jowett, S., & Al-Janabi, H. (2016). An analysis of the complementarity of ICECAP-A and EQ-5D-3 L in an adult population of patients with knee pain. *Health and Quality of Life Outcomes, 14*(1), 36. doi:10.1186/s12955-016-0430-x
17. Kramer, S. E., Kapteyn, T. S., & Houtgast, T. (2006). Occupational performance: comparing normally-hearing and hearing-impaired employees using the Amsterdam Checklist for Hearing and Work. *International Journal of Audiology, 45*(9), 503-512. doi:10.1080/14992020600754583
18. Nussbaum, M. C. (2000). *Women and human development : the capabilities approach*. Cambridge ; New York: Cambridge University Press.

19. Rijke, W. J., Meerman, J., Bloemen, B., Venkatapuram, S., Van der Klink, J. J., & Van der Wilt, G. J. (2023). Strategies For Researching Programs' Impact On Capability: A Scoping Review. *Journal of Human Development and Capabilities, X*(X), X-X. doi:10.1080/19452829.2023.2209027

20. Robeyns, I. (2003). *The Capability Approach: An Interdisciplinary Introduction.* Paper presented at the International Conference on the Capability Approach, Pavia, Italy.

21. Rohrbach, P. J., Dingemans, A. E., Essers, B. A., Van Furth, E. F., Spinhoven, P., Groothuis-Oudshoorn, C. G. M., . . . Van den Akker-Van Marle, M. E. (2022). The ICECAP-A instrument for capabilities: assessment of construct validity and test–retest reliability in a general Dutch population. *Quality of Life Research, 31*(3), 687-696. doi:10.1007/s11136-021-02980-5

22. Rohrbach, P. J., Dingemans, A. E., Groothuis-Oudshoorn, C. G. M., Van Til, J. A., Essers, B. A., Van Furth, E. F., & Van den Akker-Van Marle, M. E. (2021). The ICEpop Capability Measure for Adults Instrument for Capabilities: Development of a Tariff for the Dutch General Population. *Value in Health*. doi:https://doi.org/10.1016/j.jval.2021.07.011

23. Sen, A. (1979). *Equality of What?* Cambridge: Cambridge University Press.

24. Sen, A. (1993). Capability and Well-Being. In Nussbaum & Sen (Eds.), *The Quality of Life*. Oxford: Clarendon Press.

25. Sen, A. (1999). *Development as freedom*. New York NY: Anchor Books.

26. Summerfield, A. Q., & Barton, G. R. (2019). Sensitivity of EQ-5D-3L, HUI2, HUI3, and SF-6D to changes in speech reception and tinnitus associated with cochlear implantation. *Quality of Life Research 28*(5), 1145-1154. doi:10.1007/s11136-018-2070-6

27. Svenaeus, F. (2018). *Phenomenological Bioethics. Medical Technologies, Human Suffering, and the Meaning of Being Alive*. London: Routledge.

28. Svinndal, E. V., Solheim, J., Rise, M. B., & Jensen, C. (2018). Hearing loss and work participation: a cross-sectional study in Norway. *International Journal of Audiology, 57*(9), 646-656. doi:10.1080/14992027.2018.1464216

29. Till, M., Abu-Omar, K., Ferschl, S., Reimers, A. K., & Gelius, P. (2021). Measuring capabilities in health and physical activity promotion: a systematic review. *BMC Public Health, 21*(1), 353. doi:10.1186/s12889-020-10151-3

30. Versteegh, M. M., Vermeulen, K. M., Evers, S. M. A. A., Wit, G. A., Prenger, R., & Stolk, E. A. (2016). Dutch Tariff for the Five-Level Version of EQ-5D. *Value in Health, 19*(4), 343-352. doi:https://doi.org/10.1016/j.jval.2016.01.003

31. Yang, Y., Longworth, L., & Brazier, J. (2013). An assessment of validity and responsiveness of generic measures of health-related quality of life in hearing impairment. *Quality of Life Research 22*(10), 2813-2828. doi:10.1007/s11136-013-0417-6

Appendix 1: Excerpts from interviews

These excerpts are illustrative of how research participants appeared to participate in the various basic goods as defined by John Finnis, or reported difficulties in achieving this. The seven basic goods are life (LIFE), knowledge (KNOW), play (PLAY), aesthetic experience (AESTH), sociability / friendship (SOC), practical reasonableness (PRACT REAS), and religion (REL); for brief description of these seven goods, see main text of the paper.

'CONSTR' refers to constraints that are being reported on realizing the specific basic good

Numbers refer to the number of the interview.

Group A: Typical-hearing peers
201:

> *"I get along fine with colleagues at work; I take much pleasure in a forest walk with my partner" (SOC; AESTH)*
>
> *"I get a lot out of music; makes me relax, brings coziness" (AESTH)*
>
> *"Visiting music festivals with friends" (AESTH + SOC)*
>
> *"A day at a festival takes a lot of energy, you walk around, you danse, etc. You feel it. But it is not as though I wouldn't want it anymore. (PRACT REAS)*
>
> *"Meditation gives me energy. And it calms me down. I do it as often as I can. If you can spare a moment, even if it's once a day or every other day, you have to grab it." (REL)*
>
> *"I try to cook while using as little fat and salt as possible; I prepare smoothies, and fruit for the children" (LIFE)*
>
> *"I started to take courses in Spanish; not a big success, really, but the intention is there." (KNOW)*
>
> *"I love theatre, but I also like to make things myself, like small presents. I also enjoy it when my children can make such beautiful things" (AESTH)*

202:

> *"I've been General Practitioner, done a lot of research, too. Now I have the time to study things for which I didn't have the time then; things that I found interesting, such as immunology and everything that has to do with DNA. I try to catch up, and learn as much as possible about it." (KNOW)*
>
> *"I have worked full-time until I reached the age of 62. I then developed physical problems. As a GP you can never be present just a little bit, so I had to choose between pushing on under quite extreme conditions, or quit altogether. I decided to quit. But it was okay, really. I had been doing it for a long time. Worked hard for everyone; then it's okay to start thinking about your own health." (PRACT REAS)*
>
> *"This has been a good year. I had prostate cancer. Radical resection. I had to recover, of course. Now it's back to normal, wait and see how things will go. But I think I was fully cured." (LIFE)*
>
> *"I have a home trainer, weights and all that. Good stuff. Gives you a sense that you can still do everything. I now have the time for it. Only restriction being not to overload my muscles and joints." (LIFE)*
>
> *"I am Rotary member. Meet weekly. Make cultural trips together. Collect money for those who need it more than we do." (SOC)*
>
> *"Once COVID restrictions are lifted, I would like to go to church again, meet friends that we haven't seen for some time, travel, that sort of thing." (REL, SOC, KNOW)*
>
> *"A few years back, our house burned down. You then notice what it is like to be back on square one again. It's not fun, but also a valuable experience. Because you still have each other, you start all over again, you notice that you can and that special and nice things start to happen again. You then notice that there are only a few things that really matter in life." (PRACT REAS, SOC)*

Group B: Individuals wearing a unilateral CI

101:

> *"I have my own business; furniture upholstery. I have managed to organize my work in such a way as to divide my energy when I'm there. I can't go for it for 40 hours anymore. That's no longer possible. So I need auxiliaries to support me and get me through the day, so as to generate the sort of income that is needed to support my family and children. I slowdown from time to time. I am tutor at the technical school, so I attract pupils to the firm. They can work under my supervision. I can step down a little myself…But I do notice that as compared to prior CI, I have had to hand in a lot of energy. Due to tinnitus." (PRACT REAS)*

> *"What I miss most dearly is music. I have always heard well. I have danced at high level, Latin-American. Even won awards. The most frustrating thing is that no one can tell me why I suddenly lost hearing."(AESTH, CONSTR)*

> *"A bit more energy. I would like to have a bit more energy. Do a bit more with the children for example. Say yes more often, instead of, no, today daddy won't join you." (SOC, CONSTR)*

102:

> *"I like people, so I also like to be in touch with them. But with poor hearing that's pretty tiring."(SOC)*

> *[most important thing in life:] "My faith, in the end. That's the main thing for me. Reading Scripture, being with God. My moment of silence. Replenishing my void, my soul. It has an impact on how I experience my life. But also the community that is around you. To avoid that you are all alone." (REL)*

105:

> *"But the pleasure is gone. What I used to feel, ah, nice! I'm a people-person. Talk to him, talk to her. These are steps backward. I still can't talk about that without choking up. But I do miss that. We used to have music in the background, but nowadays I find that too busy. I can't do that anymore. I sit, watching, but unable to have a real conversation. But in such moments I can enjoy myself in a different way. Watching from my chair. It's not easy, but if you don't do it, you don't make things easy for yourself." (SOC, AESTH)*

107:

> *"I used to love music. But with the hearing devices, it was over at a certain time. You hear the rhythm. But a good guitar solo, or piano playing, that's missing…When I got the CI, I thought, let's try music. But they said, you do realize that it's a speech processor, don't you? But I still went to listen. And now I listen music every day. And I hear the instruments separately again. And also the voices of the singers. What they say… My experience of music is again what it used to be."(AESTH)*

110:

> *"I feel super, but I'm always tired. It is very tiring. Always filling in. Unconsciously. But I do notice, when I'm having a conversation with someone, and that person says something that seems completely out of context. Then you realize that you're hearing not nearly half of what is being said. But very good in filling in. Which costs a lot of energy."(SOC, CONSTR)*
>
> *"I do everything. But it is not always easy. When we are together with friends. It starts okay, they are considerate. But once more booze is at play…Then I think, I sit here, but did I have a nice evening? But I wouldn't want to miss it either. Otherwise, I would never see them again."(SOC)*
>
> *"There are nice moments, but also sad ones. Being annoyed all evening. I occasionally say something. Or I close myself off…I don't want to bother others. I bear that burden myself. That's not always okay either. But if you constantly shout NO, I don't hear. Then, at a certain time, you're no longer part of it anymore."(SOC)*
>
> *(anything that you are currently unable to do and that you would like to do?) "Talk with a group of people. Simply participating in a conversation. You often feel excluded when I'm in a group."(SOC)*
>
> *"When I became deaf, I said: no matter what or how, but I'll come back. If the tambourine were the only instrument I could play, I would play it. Returning home from hospital I started playing the trumpet by feeling. That's awkward from time to time, because sometimes I lost it. I also said, if I'm not doing okay, kick me. Then I find my way back."(AESTH, PRACT REAS)*

113:

> *"I used to be a primary school teacher. Was great fun with those kids. With all my heart. But that was no longer possible either. I always had very nice classes. But each week we started with circle-time: what did you do over the weekend? I usually responded with 'Great, nice!' Then, one day, a boy told a story. And the class responded 'Miss, what are you saying? We scattered dad's ashes on the water.' And I had responded 'Oh, nice!' And then I thought: I may like doing this, but it's not right. It's the children's education. Since then I have dreamed about teaching classes, and those were the best dreams I have ever had. But now I am okay with it. Other doors have opened. Which was good." (SOC, CONSTR, PRACT REAS)*

115:

> *"I can make telephone calls again. That was no longer possible with the hearing devices. That affected my social activities. Avoiding conversations. No longer making telephone calls spontaneously. You don't answer the telephone anymore. Passing everything to my partner. Now it's the other way round. Now I am the one who makes the call. That feels good for your independence. I find that important, being able to do my own things, without having to ask for help too much from others." (SOC)*

116:

> *"I consider myself hard of hearing. I have come to accept that. I just want to be with other people. I consider myself a normal human being. Not handicapped. But sometimes, at a firm's outing, it can be very crowded. And I still feel alone then." (SOC, CONSTR)*

> *"I have thrown away hundreds of CDs. Because that doesn't work anymore. I have tried, but it doesn't work. I loved music. It was a hobby of mine, listening music. Country and blues. Soul. I hear it, but I don't understand it. I am unable to take pleasure in it, to enjoy it. I'd very much like to, but it simply doesn't work." (AESTH, CONSTR)*

> *"I used to watch soccer, here at the club. Now I sit apart, behind the goal, so that no one is near. Canteen is no longer an option either. What used to give me so much fun means nothing to me anymore." (PLAY, CONSTR)*

Group C: Individuals with hearing impairment, referred and screened for CI but found ineligible

301:

> *"I usually listen to the classical radio channel. Avoids commercials. More by way of background. Otherwise, it can be very quiet in the house. The lack of someone talking to you…Neglected my friendships a bit, too. Not member of some club either." (SOC, CONSTR)*

302:

> *"I try to pray every day. I'm very faithful in that respect. I try to pray for everyone. It makes me feel good, calms me down. To think of other people, too." (REL)*
>
> *"I sing from early in the morning until late at night. Rehearsing texts until I can sing it well. So also training your memory. Gives me pleasure. It sometimes annoys me if the doorbell rings, so that I cannot finish the song." (AESTH)*
>
> *"I love may colours around me. I've made many beautiful paintings; bought them, too." (AESTH)*

304:

> *"I don't work anymore because of my hearing impairment." (SOC, CONSTR)*
>
> *"I need to take care not getting too tired from having to listen all the time." (SOC, CONSTR)*
>
> *"I like contact with other people, so that's difficult." (SOC, CONSTR)*
>
> *"I like to join and participate, but that's impossible." (SOC, CONSTR)*
>
> *"My husband is sometimes annoyed when I do not immediately hear what he says. But I keep emphasizing, you need to call my attention first." (SOC, CONSTR)*
>
> *[Music:] "I love it, but it doesn't sound anymore as it used to. And I know that it will stop, some time, so I am slowly saying goodbye to that." (AESTH, CONSTR)*

> *"I'd very much want to be able to understand my grandchildren. They are very fond of me, but it's quite obvious that they sometimes simply don't know how to deal with me." (SOC, CONSTR)*
>
> *"What is important for me is, in fact, simply joining and participating. Also in society. No need to always lock yourself out because you can't cope." (SOC, CONSTR)*

306:

> *"But there are many things that you stop doing. Sometimes you're dragged into it, such as birthday parties. COVID was great for me, no more birthday parties. Sitting with ten to fifteen people in a room, everybody cross-talking. Simply a matter of waiting until you can go home. I've stopped attending other meetings with large groups already for many years, it's no use. I simply can't understand what is being said." (SOC, CONSTR)*
>
> *"I've stopped listening to the radio more than 15 years ago. Music, for instance. It's all a jumbled mess. Ten years ago, I started singing in a choir. I've tried until COVID. But I frequently got the notes all wrong. I could enlarge the sheet music so that I could read the text. But now I can't read it anymore because of my eyes. So, I stopped with the choir. In fact, continuing with the choir has been doubtful because of my hearing for many years." (AESTH, CONSTR)*
>
> *"You hear a lot, but you don't understand a thing." (SOC, CONSTR)*
>
> *"When you sit with a group of people, chatting. I do try. But after an hour, I'm exhausted." (SOC, CONSTR)*
>
> *"At a certain moment you start to avoid other people. But I do miss that." (SOC, CONSTR)*
>
> *"It takes such an effort to understand just a few things. And frequently, you get things wrong. Afterwards, my wife fills me in. And it appears that I got it all wrong. Very frustrating. Therefore, I try to avoid such situations. A shame, really, when you come to think of it." (SOC, CONSTR)*

307:

> *"Now it's okay for me to say that I am hard of hearing. It no longer gives me a bad feeling. It annoys me, however, that when you're with other people, that you cannot laugh along with them. I try to go through it all, but it simply doesn't work. That's when you find out." (SOC, CONSTR)*

308:

> *"After raising the kids resuming work simply never happened. Which I've regretted. I'm not a born mother or housewife…I've tried things. But then you end up in volunteer work. And there, too, I got stuck because of my hearing problems. I didn't dare to accept everything. For instance, reception desk or phone work. So, you start to look for more simple things to do, but that gave me no satisfaction." (SOC, CONSTR)*

> *"I get easily in touch with foreign people. I teach Dutch to refugees, even with my hearing problem. So why is that not a problem for me? I think because these people have the same problem as I do: understand. You're more on a par. That's why I always felt at ease with Chinese and Syrians." (SOC)*

309:

> *"I don't do nearly as much as I used to do. That's a shame. Cycling, for instance, because of my problems with balance. Sports is very hard, because you need balance. I used to dive, but that's not allowed anymore either. And those things, it makes it very difficult. Walking is, in fact, very intensive. I can do it, but always at the arm of my husband… My husband and I do a lot together, alone gets increasingly difficult. So you give up a lot of freedom and independence." (PLAY, SOC, CONSTR)*

> *"It's difficult, because you lose your independence. I love music. I have very specific preferences in that regard. But it has always been difficult. Start to recognize it only after listening long enough. Now, since 1,5 year, I have a hearing device that I can directly connect to my mobile phone. Now I can stream, and with YouTube on my iPad I can completely lose myself. It's wonderful that it is possible now." (AESTH)*

310:

> *"To start with, I don't work anymore. Used to work in child care. But I couldn't understand the children anymore. I was also very tired. That's better now." (SOC, CONSTR)*

> *"I don't withdraw myself for anything either. I travel by train on my own. I deal with things. I go out for a walk on my own, also when my husband doesn't feel like it. I don't spare myself." (SOC)*

313:

> *"So, when I'm listening music, I turn the volume real loud, when the neighbours are out. And the best is without my hearing devices. Because the hearing device deforms, too. I love Tina Turner, Phil Collins, the blues. Modern pop music, too. I don't understand what they are saying, so it's really the melody.' (AESTH)*

315:

> *"Because, because of your hearing loss you are a different person. You can seem harsh. Unresponsive. Walk right past someone. Or make an improper comment, merely because you misunderstood." (SOC, CONSTR)*
>
> *[Anything that you leave while you would like to do it?] "Perhaps taking some sort of course. I love needlework. I wanted to learn some new techniques. But I didn't understand at the time it was explained. I hear something, need to process it, and only then I take it in. But then they have already moved on. Difficult to keep up with." (SOC, KNOW, CONSTR)*

Group D: found eligible, but waived CI
001:

> *"I get up, start doing some exercises for my shoulder [because of a fall, ten years ago]." (LIFE)*
>
> *"Then some yoga exercises." (REL)*
>
> *"Go downstairs to feed the cat." (SOC)*
>
> *"I then go to my work, or do other things."*

“Furthermore, I study. I just finished my training as energy therapist…Because, what I have noticed is that studying or taking courses does me a lot of good, developing myself further. If I don’t do that, life loses a bit of its colour for me. It makes me think, what am I doing? What I find most important in that respect is loving presence, to live that, put it into practice. Not pointing to others when things become uncomfortable, but to yourself. It’s about your perception, your reality. That is very much leading in how I live my life.”(KNOW; SOC; REL; PRACT REAS)

“I try to apply that way of life at work, too, with my colleagues. Toward the clients it is very much like: how can I help? That suits me fine. Making sure that patients can keep control over their own lives. It’s hard, though, from time to time, ‘cause some of them are semi-psychiatric.” (SOC)

“I believe I have never felt completely at ease. Always uncomfortable. Always a weird child according to everyone. I think I communicated differently, too. Couldn’t control the use of my voice very well. And that I talked in a strange way, but also said strange things.” (SOC, CONSTR)

[Leisure:] “Listening music, singing with others, sit quietly. Working a bit on my website. I read a lot. Relaxing, lying down. Cooking, reading, hiking. That’s what I love to do. Can’t do that very well, though, since the left side of my body becomes thick when I’ve been walking for a long time as the result of that fall. But I love being outdoors. “ (AESTH; CONSTR, not related to hearing impairment)

“I’m also very fond of having good conversations. So we meet form time to time and go out for a walk. I have a fellow coach. Then we coach each other. Walking and sparring, every three months.” (SOC)

“My neighbour helps me out with telephone calls. The vet, the hospital. That is really super. I can also ask a colleague form work. But still, I am alone quite often. My unhappy start in life has left a large hole of deep, intense loneliness in my life. It is always there, right under the surface. I occasionally recharge myself, but sometimes I feel that loneliness very deeply. I can cope with it, but it is my base feeling in life, my blueprint. Everything that I do pulls me out of it, but if that fades, I enter into my blueprint-state. Not nice.” (SOC, CONSTR)

002:

> *"Things became increasingly tedious. Acoustics. Ringing everywhere. I used to be foreman. Then you have to deal with executors, mostly in a hut. But that became increasingly tedious. Ever more effort, ever more strain." (SOC, CONSTR)*
>
> *"Hearing takes a lot of energy." (SOC, CONSTR)*
>
> *"It's hard to follow a conversation." (SOC, CONSTR)*

003:

> *"Initially, I wanted to become a history teacher...Then it turned out, you can't become teacher because of your hearing and because of your voice…So that choice was in fact already made for me. So I thought, forget it." SOC, CONSTR)*
>
> *"When I'm travelling, too. Everything new, all sort of triggers. At the end of the day, really very tired. I have to make more of an effort than you do in order to digest everything. I do like to travel. I love history. Do that with a group of friends. But at a certain time the focus is lost and then I'm done with it." (SOC, AESTH, CONSTR)*
>
> *"Disadvantage [of hearing impairment] is simply that in daily life, you run into all sorts of problems, such as making phone calls. That you are unable to do everything that you would like to do. That my hearing impairment has resulted in certain choices that I have had to make and that I would have made differently otherwise. Say, for instance, with respect to my profession. That I would have chosen a different profession. Also, for example, with respect to relations. Always this impairment that deters people, that prevents them from starting an affair with you. Never to be regarded for full. It's a frustration that you need to learn to live with. One shouldn't nag about it." (SOC, CONSTR)*

004:

> *"I've been to festivals. Pinkpop, Pearljam. Can't hear what is being sung, though. My experience of the music is really in the melody. And the being together. Rock, Pink Floyd. Were political texts, too. Friends were very much obsessed with that. But I was unable to follow the texts. And, therefore, not the passion of the singers either. Has a social function. Some people can lose themselves entirely in it. I've never had that. Gives me energy, though. The sounds, the melody. I do feel that. But it's like water. There's a barrier. It's not your main thing." (AESTH, PLAY, CONSTR)*

> *"Noisy environments, going out, games. Sitting with friends at a table, a lot of cross-talking. That's when things start to get complicated for me. Then I start to lean back and pass. Those are the moments that it's a shame, really. But that's how it is. And then we go skiing, and everything is okay again." (SOC, CONSTR)*

006:

> *"Currently, there's nothing that I don't do because of my hearing impairment."*

> *[music?] "No, not interested. Probably because of my hearing impairment. I don't understand what they say, so I'm not interested." (AESTH, CONSTR)*

> *[many people talking:] "I'm not sure whether it takes more energy, but I think it does. When I'm really tired, I hear less. Then you're simply too tired. But I don't know whether normal people have that too. You don't know any better." (SOC, CONSTR)*

007:

> *"Your peers can be quite harsh. Yelling at you 'deaf, deaf!" (SOC, CONSTR)*

> *"I've always had to prove myself. On the one hand, I understood that. Because they hire someone who may not be hearing things. And then they would be stuck. But on the other hand, I would not take any risks that I would not be able to deal with. So I've always had to fight for myself." (SOC, CONSTR)*

> *"Often, I've had to adapt myself to others, whereas it was them who should have adapted themselves to me. It made me angry and sad." (SOC, CONSTR)*

“The other day I thought, if my hearing were not so poor, would I then have further continued my studies? I think so. Would have pursued higher education or something. But then I think: for me, I have already achieved a lot. Why would I complicate things further? ..It may have had more impact than I sometime think. But I don’t want to think about that, because it doesn’t change anything.” (SOC, CONSTR)

“Hearing takes a lot of energy. I notice now that I’m growing older. Also at work. Remaining vigilant takes so much energy. I hear something; do I recognize the sound? If not, I go looking.” (SOC, CONSTR)

[Safety, traffic:] “I don’t hear cars coming. Motorcyclists is okay. But they do startle me.” (SOC, CONSTR)

“I’ve never liked team sports.” (PLAY, CONSTR)

008:

“I’m convinced that, if I had not been hearing impaired, I would not be working in a factory now.” (SOC, CONSTR)

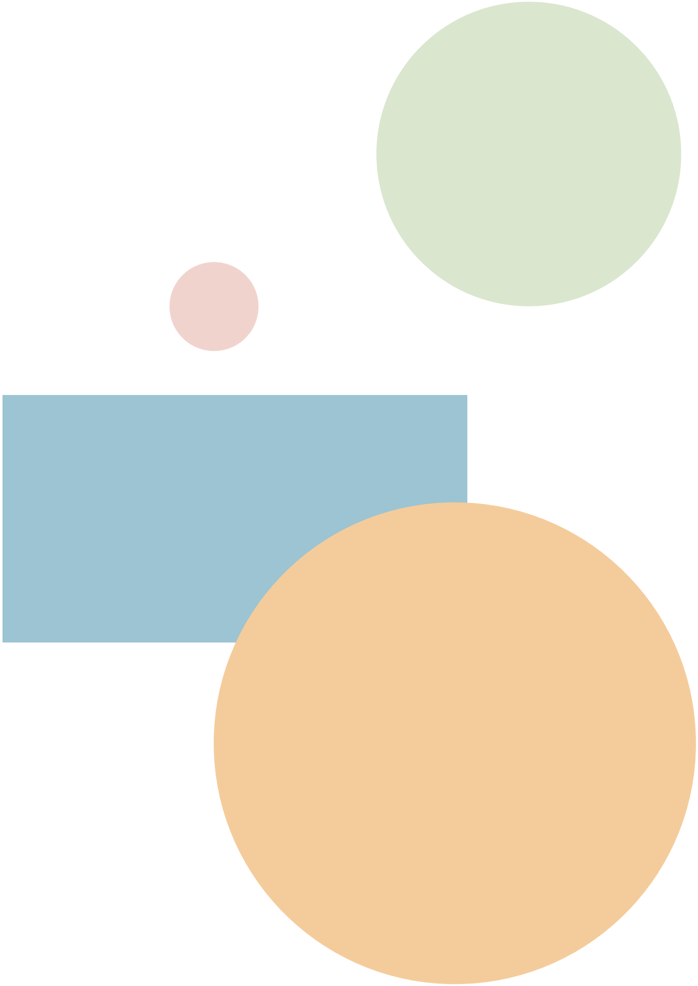
011:

“When I still worked, I took my devices off when I got home. For a few hours, I didn’t want to hear anything. I was completely exhausted from all these sounds. I am ‘on’ all day, you know. Very tiring.” (SOC, CONSTR)

“We have a grandson since half a year. So I babysit from time to time. That goes very well. It brightens you up, you know. They don’t notice; completely unprejudiced.” (SOC, CONSTR)

014:

“Really. Particularly when you don’t understand and you want to understand. That’s a huge drain.” (SOC, CONSTR)



7

GENERAL DISCUSSION

Lessons learned

We feel that, upon completion of this research, we have learned a couple of -potentially valuable- lessons, including some lessons that we had not, in fact, anticipated or were intentionally seeking to learn. In the following paragraphs we will briefly describe what these lessons were. Each of them touches upon much wider issues, and our discussion will only 'scratch the surface'. We mention them here because we think that they could be relevant for any type of evaluative research, that is, research that seeks to provide an answer to the question 'how well things are or how well things are going'. In our case, the basic question was, of course, how well the lives of people with hearing impairments are going, in our society, in 2023.

LESSON 1: Do universal values exist?

We have phrased this 'lesson' in the form of a question. It is a rather grand issue, but inevitably, any researcher who wishes to adopt the Capability Approach (CA) will run into it at some point in time. In our view, one of the appealing features of the CA is its avowedly focus on values. This focus results from the fact that functionings ('doings and beings that people have reason to value') take center stage in the CA. However, it confronts researchers with the need to articulate the nature of those functionings: what is it that may be considered so important that all members of a community should be able to achieve it if they wanted to. And, equally important, how can this be established? There seem to be two schools of thought in this respect. One is exemplified by Sen himself, who held that it is not for researchers to decide on this issue. Rather, he firmly advocated for the establishment of a deliberative process with the purpose of extracting the content or definitions of functionings from the individuals it pertains to, rather than having these definitions determined by researchers. Others, including Nussbaum, argued that some list of basic goods can, and should be drawn that may be considered universally applicable. We recognized the validity of the arguments on both sides. In some parts of our research we followed Sen, for instance when developing domains that were to be included in our capability questionnaire (**Chapter 3**). Other parts of our research were more in line with Nussbaum's approach, for instance where we used the list of basic goods from John Finnis in order to analyze interviews for evidence of (realized or constrained) capability (e.g., **Chapter 5 and 6**). From this study in particular, we learned that there may be a middle way between Nussbaum and Sen. This middle way arises because, even though we defined (and imposed, some would say) the relevant domains of value ourselves, this did not mean that we also defined the exact nature of doing and beings that represent value. This follows from the fact that the seven basic goods, as distinguished by Finnis, are highly abstract, and what follows from a commitment to these basic values in concrete situations cannot be inferred from them deductively. In other words, these basic goods are ‘open-textured’ (Brennan, 1977), and need to be *specified* with the individuals question in order to establish their practical significance (Richardson, 1990).

This message was also driven home to us because we surveyed people of different ages about their values, interests, and activities. In doing so, we observed recurring values, such as autonomy, appearing at all ages. However, the way this was specified varied significantly. For an 80-year-old man with a CI, autonomy meant being able to choose to go cycling with his wife, while for an 8-year-old girl, autonomy meant having the choice to attend a sailing camp. During puberty and adolescence, the attitudes and behaviors of the respondents towards their hearing, hearing devices, and themselves were significantly affected by others, both positively and negatively. They started to compare themselves to others in the world, which was shaped by their social environment. However, as individuals entered adulthood, personal and social changes start to decrease, and more consistent values might develop (such as time with family, work and religion). In other words, while values such as play, sociability, and aesthetic experiences recurred in all stages of the lifespan, the way these values were specified was continuously evolving.

So yes, we ‘imposed’, in some parts of our research, certain values (e.g., John Finnis’s list of seven basic goods), and no, we did not thereby specify what counts as ‘doings and beings that people have reason to value’ (because of the latitude in the way these general concepts can be specified). In that sense, we feel we have not been guilty of over-specifying the CA, a concern that led Sen to opt for an entirely procedural solution to the task. In conclusion, then, the lesson that we learned was that Richardson’s method of specifying norms seemed to offer the possibility of holding onto a set of generic values, without unduly imposing our own value commitments to the communities who participated in our research.

LESSON 2: Exploring capability = exploring freedom

Particularly during the research that was reported in **Chapter 6** of this thesis, it became increasingly clear to us that exploring a group of people’s capability is tantamount to exploring their freedom and its constituents. Semi-structured interviews had been held with individuals from four different groups and were analyzed using Finnis’s list of seven basic goods. When we had submitted our paper, one of the reviewers encouraged us to complement our study with a quantitative analysis. We decided that we would conduct such an analysis on the basis of reports of positive functionings (that is, achieved functionings), and negative functionings (doings and beings that interviewees mentioned as being of value to them, but were not or no longer able to achieve). On the basis of this analysis, we tried to obtain an indication whether important life choices were mainly made *by* those who were interviewed or rather *for* them (that is, conditions leaving them little choice). We felt that this analysis, in conjunction with the qualitative interview data, perhaps best captured how things were for the people who participated in this study in terms of their capability. However, it still relied heavily on participants' reports of what they were, and of what they were not capable of doing or being. Some form of triangulation (e.g., a further probing into resources and conversion factors, or corroboration of participants' reports with observations from others) would have strengthened our conclusions. Only in retrospect, we realized that our study might have benefited from insights derived from empirical studies of freedom, both conceptually and methodologically (see for instance McMahon, 2012). In addition, because of its multifaceted nature (i.e., resources, conversion factors, functionings, and their dynamic interplay, see Figure 1), researchers would do well in articulating which facets of the CA they aimed to bring into view (and which not), apart from how they did this.

LESSON 3: The CA can serve as a framework to integrate quantitative and qualitative data

Historically, a great divide exists between quantitative and qualitative methods in scientific research. In this thesis, we report results of both. We found that the CA presents a theoretical framework that invites to be nurtured by data that have been obtained by using both, quantitative and qualitative methods of inquiry. For instance, in **Chapter 3**, quantitative data on speech perception were collected alongside qualitative data on achievement or non-achievement of functionings. The two dimensions did not always converge: high scores on speech perception did not always translate into high levels of achievement of functionings. Similarly, low scores on speech perception did not always preclude high achievement in functioning. The CA can serve as a framework to better understand how the interplay between resources, conversion factors and functionings works out in concrete cases, leading to expanded or constrained capability. As such, we learned that the CA can serve as a framework to *integrate* data from heterogeneous sources.

In addition, as explained above, we used qualitative methods in conjunction with quantitative methods in **Chapter 6**. We learned how the quantitative methods enabled us to better summarize and obtain an overview of the data, whereas the qualitative methods considerably contributed to a better understanding of 'what was going on' and what explained wide differences in capability between research participants. Also, the qualitative data enabled us to better identify recurrent themes that were associated with specific levels of capability.

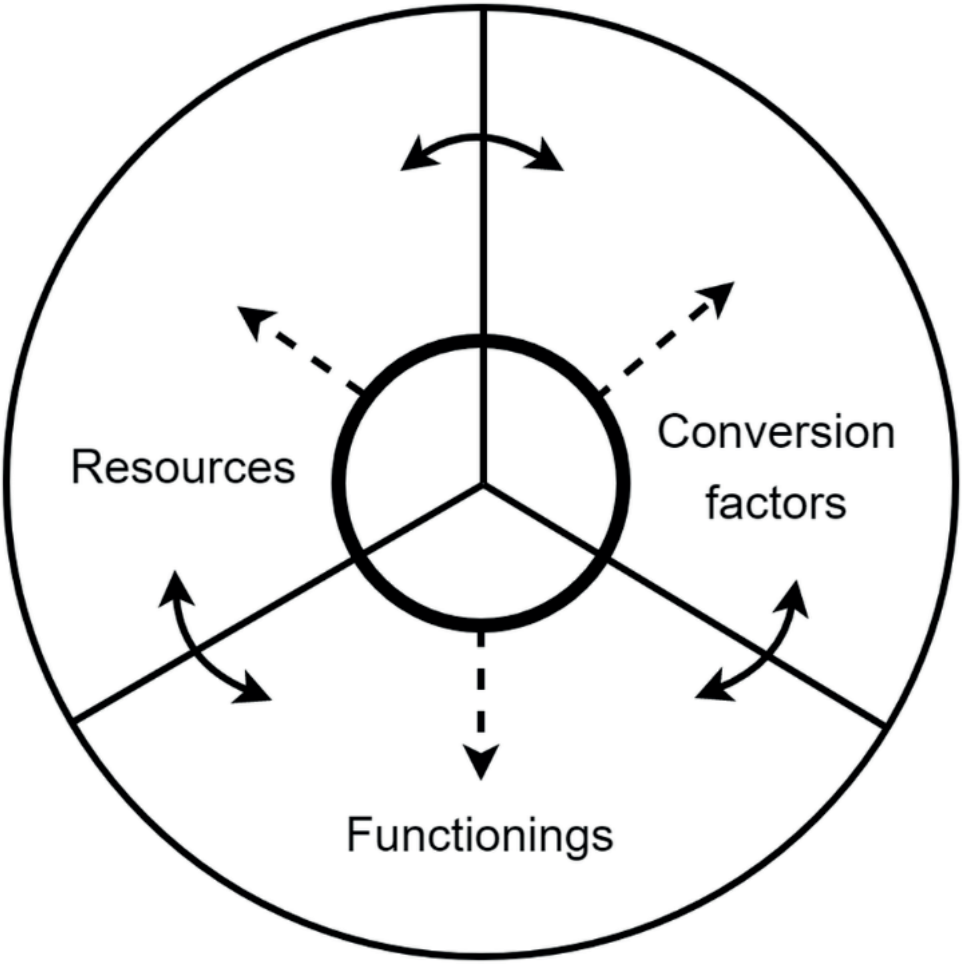


Figure 1. The interaction between resources, conversion factors, and functionings result in capability.

LESSON 4: Kierkegaard was right

In the field of HTA, prospective studies are generally rated higher than retrospective studies. And with good reason. For research in the field of capability, however, things may be somewhat different. Measuring capability prospectively would, typically, involve definition of specific moments in time relative to some sort of exposure (e.g., the start of some intervention), asking research participants to indicate whether they consider themselves capable of conducting certain tasks. To this end, instruments such as the ICECAP, OxCap, or OCAP-18 may be used (Al-Janabi et al., 2012; Lorgelly et al., 2015; Simon et al., 2013).

Such a procedure is associated with two sources of uncertainty: firstly, we don't know how important the selected tasks are to the respondents; secondly, respondents may over- or underestimate their capabilities, and the resulting information may reveal something about respondents' self-efficacy, rather than their capability. When adopting a retrospective design, things might be somewhat different, especially when research participants are encouraged to reflect, in the course of an interview, on how their ability to do certain things or be in certain ways changed over time. What we suggest, here, is that research participants are likely to mention doings and beings that matter to them (after all, why would they, in such a context, start talking about things that are of little importance to them?). Also, they may be better able to indicate how things have changed in this respect over time, rather than how things are at any given moment in time. What we obtained were narratives; stories of the lives of these people, focusing on events and developments that, in their mind, had had impact on their ability to 'do and be things they had reason to value'. These findings reminded us of an observation by the Danish philosopher Soren Kierkegaard, stating that *"Life can only be understood backwards; but it must be lived forwards."* Our lesson was, then, that Kierkegaard may have been right in this respect (Kierkegaard, 1843).

LESSON 5: In HTA, the approach matters

One of the key lessons that we learned was that the CA was developed as an alternative to the utilitarian concept of justice, involving completely different informational requirements and associated instruments for inquiry. Currently, the utilitarian concept of justice is dominant in HTA, as reflected in the central position of cost-effectiveness analysis in this field. Also, a sharp distinction is being made in HTA between assessment and appraisal. Assessment, here, refers to an allegedly value-neutral stage of collecting facts. Appraisal refers to the subsequent stage, drawing on values to arrive at a judgment of the value of the technology under study. Cost-effectiveness analysis is thought to be part of the first, assessment phase of HTA. Sen's work clearly demonstrates that this is completely misguided. It also points to the many implausible assumptions associated with utilitarianism. However, by developing the CA as an alternative framework, it also shows how such frameworks and the empirical data collection are intertwined. With Sen's strong criticism of utilitarianism in mind, the HTA community would need to rethink its normative commitments and start to reflect on what HTA might look like when adopting Sen's CA as a normative framework.

LESSON 6: The pragmatic nature of the CA

In HTA, the focus is usually on assessing the comparative value of a specific health technology in resolving a specific health problem. By adopting the CA, this focus was broadened in two ways. Firstly, the problem was not confined to a medical problem but redefined as problems with achieving ‘doings and beings that people have reason to value’ (functionings). Secondly, the solution (e.g., hearing devices or cochlear implants) was broadened by taking account of conversion factors: the set of conditions and circumstances that are critical for turning resources into something of value. Another way of putting this is that our study transformed from a summative evaluation to a formative evaluation (Wholey, 1996). As such, it brought into view a range of ways in which the capability of people with hearing impairment might be expanded.

For instance, many of the participants in our studies who wear hearing aids or cochlear implants reported to experience a range of negative emotions such as loss, overestimation of their ability to communicate effectively, lack of energy, and a sense of exclusion. The respondents from our study described in **Chapter 6** expressed the crucial need to raise awareness and educate society that not responding, for example, does not equate to arrogance, and saying "never mind" is unhelpful. It is important to acknowledge that these individuals do not hear like typical hearing individuals and must work hard for what others take for granted. One approach to achieving this goal is through national campaigns, as exemplified by the Dutch National Association De Zonnebloem (Sunflower), which initiated a campaign in the summer of 2023 to raise awareness about individuals with physical disabilities. As part of this campaign, a traffic sign was introduced to symbolize the idea that people with physical disabilities face widespread inaccessibility.

Figure 2. "THIS SIGN DOESN'T EXIST. BUT IT IS ALMOST EVERYWHERE." The national campaign by De Zonnebloem, Summer 2023, the Netherlands.

The success of hearing aids and cochlear implants can be impacted by a variety of challenges. Findings in **Chapter 4** suggest that expectations, from both parents and children, can affect the success of cochlear implants. Additionally, there were teenagers and adolescents (**Chapter 5**) who explained how they started to experience the lack of inclusivity within both deaf and hearing cultures. Some respondents suggested that this could lead to a lack of acceptance and isolation for individuals who wear cochlear implants.

One challenge is informing parents about the available resources for their children. We found from interviews described in **Chapter 4** that treatment coordinators may not be aware of support programs like sign language interpreters or outpatient guidance, which can make it difficult to provide necessary resources. Additionally, parents may still be in the grieving process for their child's hearing loss, leading them to reject information or not fully understand its value.

It is crucial to set realistic goals when striving for inclusivity in society for both deaf and hearing cultures. In **Chapters 4, 5, and 6**, an apparent paradox was observed in the support needs of children, teenagers, and adults with hearing aids and cochlear implants. On one hand, most express a desire not to be treated differently from individuals with typical hearing abilities, while on the other hand, they do require assistance and consideration from others. Therefore, our focus should encompass both acceptance and adaptation, emphasizing the importance of fostering acceptance alongside making necessary adjustments. It is important to acknowledge that individuals with cochlear implants, particularly those with a single implant, still experience hearing impairment, leading to limitations in speech understanding and directional hearing. By maintaining realistic expectations, providing accurate information, and fostering inclusivity, we aim to enhance the success and acceptance of individuals with a hearing impairment in society.

In sum, we feel that adopting the CA as a framework for our research resulted in a much stronger focus on the context in which people with hearing impairments find themselves. The question how CI improves hearing is an important, but not the sole question that needs to be answered if the goal is to find ways of strengthening the capability of people with severe hearing impairment.

LESSON 7: Capability, whose responsibility?

An issue that we have repeatedly discussed throughout the course of our investigation was: is it, or is it not, within the remit of healthcare to also seek to protect, restore or expand the capability of citizens? The question was discussed first-and-foremost with clinicians. The positions were divided. For some, it was a no-brainer: of course it is! Others were less certain: ‘we are here to solve medical problems to the best of our ability’. Would Sen himself have anything to say on the matter? Probably yes, but, to the best of our knowledge, he did not explicitly address it in any of his (extensive) writings. However, responsibility is one of the key issues in the CA, and the issue could be framed as such: do healthcare professionals have a responsibility to help their patients in (re)gaining their capability? In The Idea of Justice, Sen writes:

…if someone has the power to make a difference that he or she can see will reduce injustice in the world, then there is a strong and reasoned argument for doing just that…Freedom in general and agency freedom in particular are parts of an effective power that a person has, and it would be a mistake to see capability, linked with these ideas of freedom, only as a notion of human advantage: it is also a central concern in understanding our obligations. This consideration yields a major contrast between happiness and capability as basic informational ingredients in a theory of justice, since happiness does not generate obligations in the way that capability inescapably must do…'(Sen, 2009, p. 271)

Sen seems to have primarily basic human relations in mind here, and what humans owe to each other and why. It is not immediately clear whether this would translate into any obligations that healthcare professionals have toward their patients, but it might be an inspiring element of the professional ethos. The lesson learned, here, can perhaps best be described as that it should not be taken for granted that capability protection and expansion are an appropriate objective for healthcare. More argumentative and discursive work is needed here.

Main goal of the thesis

We aimed to investigate how the CA could enhance our understanding of the well-being of severely hearing-impaired individuals. The CA broadened our investigative scope, moving beyond conventional metrics like clinical assessments, such as speech perception. This expansion prompted a thorough exploration into the various influences on the lives of hearing-impaired individuals, encompassing broader dimensions of their well-being.

The CA played a guiding role in shaping targeted research instruments, including a context-specific questionnaire and interviews. It promoted a mixed-methods design, facilitating the incorporation of both quantitative and qualitative insights to capture the nuanced experiences of the individuals. Through the application of the CA, we identified disparities between clinical scores and capability scores, emphasizing that well-being extends beyond clinical measures.

Additionally, the CA facilitated an examination of well-being across different life stages, from childhood to adolescence and adulthood. Recognizing the evolving nature of capability content during puberty and adolescence, it provided a dynamic understanding of changes in well-being over time. Qualitative insights, subjected to CA analysis, enhanced our comprehension of individuals' lives by considering factors such as resources, conversion factors, and functionings.

Particularly valuable in the healthcare context, the CA advocated for a formative assessment of well-being post-interventions, concentrating on identifying areas for improvement and enhancing the interplay between resources, conversion factors, and functionings, rather than solely pursuing a summative evaluation. It underscored the challenges associated with quantifying well-being, emphasizing the importance of considering context and the limitations of exclusively quantitative measures.

Finally, the CA guided recommendations for future research, stressing the need for explicit reporting, integration of qualitative elements, and recognition of the retrospective nature of capability impact assessments. What truly set the capability concept apart was its immediate invitation to contemplate questions about what makes life worthwhile. Though these were complex inquiries, engaging in dialogue and reflection on them was still valuable.

Conclusion

Taking an interest in the CA means taking an interest in assessing the well-being of people, with the term "people" encompassing various definitions. In this context, it predominantly involves individuals whose ability to function optimally may be compromised, either knowingly or unknowingly. In our case, this group consists of individuals with impaired hearing who face numerous challenges in their daily lives, particularly in societies oriented toward those with normal hearing. The CA provides a framework to investigate the nature and extent of these challenges and their root causes.

The motivation behind such an inquiry lies in the notion that societies should take measures to alleviate the impact of impaired hearing on an individual's capabilities. The findings from these investigations are relevant to those in positions of authority and resources who are responsible for implementing such measures. In the realm of healthcare, Health Technology Assessment (HTA) serves as a means to provide policymakers with information about the impact of health technologies on a broad scale (O'Rourke et al., 2020). In HTA, the CA has not been widely adopted so far (López Barreda et al., 2019; Mitchell et al., 2017; Ubels et al., 2022). Instead, a utilitarian framework serves to inform policymakers about implications of adopting specific health technologies on resource use and the production of Quality Adjusted Life Years (QALYs).

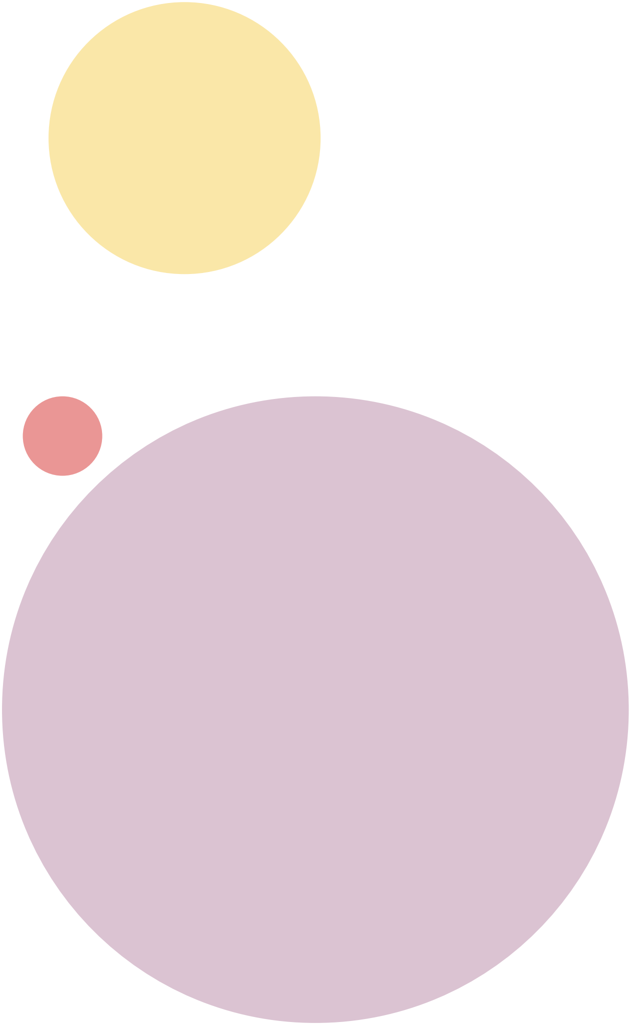
The differences between the two frameworks (CA and the costs per QALY model) are considerable and have been partly discussed in this thesis. Conceivably, a next step could be to explore how the two frameworks could complement each other in HTA. Typically, in the costs per QALY model, a specific health technology is compared with an alternative mode of managing a specific disease condition. A health-economic model is built, and populated with data from controlled situations (e.g., clinical trials).

In contrast, the CA focuses less on a specific technology and more on assessing the extent and nature of limitations in an individual's capabilities associated with a specific condition. In this framework, technologies are viewed as one of the resources and conversion factors that play a crucial role in determining the actual opportunities available to people to pursue things they value. The key research question is whether, with these technologies in place, there are still signs of unnecessarily restricted capabilities among the recipients, and if so, what potential underlying causes exist. As such, the CA can be particularly useful in the context of Health Services Research (Payakachat et al., 2016; Van der Wilt et al., 2017; Velasco Garrido et al., 2010).

To realize this potential, policy makers should begin to appreciate the relevance and added value of the CA in defining policy problems and feasible policy options. We hope that this thesis has made some contribution in this respect.

References

1. Al-Janabi, H., Flynn, T. N., & Coast, J. (2012). Development of a self-report measure of capability wellbeing for adults: the ICECAP-A. *Quality of Life Research 21*(1), 167-176. https://doi.org/10.1007/s11136-011-9927-2
2. Brennan, J. M. (1977). The open-texture of moral concepts. In. London :: Macmillan.
3. Kierkegaard, S. (1843). Søren Kierkegaards Skrifter. *Journalen JJ: 167*, *18*, 306.
4. López Barreda, R., Robertson-Preidler, J., & Bedregal García, P. (2019). Health assessment and the capability approach. *Glob Bioeth*, *30*(1), 19-27. https://doi.org/10.1080/11287462.2019.1673028
5. Lorgelly, P. K., Lorimer, K., Fenwick, E. A., Briggs, A. H., & Anand, P. (2015). Operationalising the capability approach as an outcome measure in public health: The development of the OCAP-18. *Soc Sci Med*, *142*, 68-81. https://doi.org/10.1016/j.socscimed.2015.08.002
6. McMahon, F. (ed.) (2012). *Towards a worldwide index of human freedom*. Fraser Institute.
7. Mitchell, P. M., Roberts, T. E., Barton, P. M., & Coast, J. (2017). Applications of the Capability Approach in the Health Field: A Literature Review. *Social indicators Research*, *133*(1), 345-371. https://doi.org/10.1007/s11205-016-1356-8
8. O'Rourke, B., Oortwijn, W., & Schuller, T. (2020). The new definition of health technology assessment: A milestone in international collaboration. *International Journal of Technology Assessment in Health Care*, *36*(3), 187-190. https://doi.org/10.1017/s0266462320000215
9. Payakachat, N., Tilford, J. M., & Ungar, W. J. (2016). National Database for Autism Research (NDAR): Big Data Opportunities for Health Services Research and Health Technology Assessment. *Pharmacoeconomics*, *34*(2), 127-138. https://doi.org/10.1007/s40273-015-0331-6
10. Richardson, H. S. (1990). Specifying Norms as a Way to Resolve Concrete Ethical Problems. *Philosophy & Public Affairs*, *19*(4), 279-310. http://www.jstor.org/stable/2265316
11. Sen, A. (2009). *The idea of justice*. Allen Lane.
12. Simon, J., Anand, P., Gray, A., Rugkasa, J., Yeeles, K., & Burns, T. (2013). Operationalising the capability approach for outcome measurement in mental health research. *Social Science & Medicine*, *98*, 187-196. https://doi.org/10.1016/j.socscimed.2013.09.019
13. Ubels, J., Hernandez-Villafuerte, K., & Schlander, M. (2022). The Value of Freedom: A Review of the Current Developments and Conceptual Issues in the Measurement of Capability. *Journal of Human Development and Capabilities*, *23*(3), 327-353. https://doi.org/10.1080/19452829.2022.2053506
14. Van der Wilt, G. J., Kievit, W., & Oortwijn, W. (2017). THE ADDED VALUE OF INTEGRATE-HTA GUIDANCE IN THE WORK PROCESSES OF HEALTH TECHNOLOGY ASSESSMENT AGENCIES. *International Journal of Technology Assessment in Health Care*, *33*(5), 597-598. https://doi.org/10.1017/s0266462317001027
15. Velasco Garrido, M., Gerhardus, A., Røttingen, J. A., & Busse, R. (2010). Developing Health Technology Assessment to address health care system needs. *Health Policy*, *94*(3), 196-202. https://doi.org/10.1016/j.healthpol.2009.10.002
16. Wholey, J. S. (1996). Formative and summative evaluation: Related issues in performance measurement. *Evaluation Practice*, *17*(2), 145-149. https://doi.org/https://doi.org/10.1016/S0886-1633(96)90019-7



APPENDIX

SAMENVATTING
DANKWOORD
ABOUT THE AUTHOR
PORTFOLIO
DATA MANAGEMENT

Samenvatting

Als mensen bij een zorgverlener komen omdat ze minder horen, probeert de zorgverlener daar wat aan te doen. Dat kan bijvoorbeeld met een hoortoestel of, grotendeels afhankelijk van de mate van gehoorverlies, met een cochleair implantaat (CI). Het doel van de zorgverlener is dus om de betreffende persoon meer te laten horen dan zonder hulpmiddel mogelijk was. Maar, het echte doel van de zorg is natuurlijk niet om mensen weer meer te laten horen. Dat is een middel. Een middel om te kunnen participeren in de samenleving, om naar school te kunnen, om te kunnen werken, om relaties te kunnen hebben. Een middel om autonoom te kunnen zijn, om zelf keuzes te kunnen maken, om gezond te zijn. De mogelijkheid hebben om zulke dingen te doen en zijn, heet *capability*. Het is een manier om welzijn uit te drukken.

In **hoofdstuk 1** introduceren we de capability benadering en leggen we uit waar het vandaan komt. Om erachter te komen hoe het met mensen gaat, proberen wetenschappers welzijn te meten. Dit is een breed begrip die op verschillende manieren te interpreteren is. Zo is er een stroming die kijkt hoe gelukkig of tevreden mensen zijn en probeert zoveel mogelijk geluk voor zoveel mogelijk mensen te realiseren (utiliteit). Daarnaast was er een belangrijke stroming in de jaren 70 van de vorige eeuw die zei dat welzijn voortkomt uit een rechtvaardige en gelijke verdeling van middelen in een samenleving, ongeacht de achtergrond of omstandigheden van mensen. Econoom en filosoof Amartya Sen kon zich meer vinden in de tweede benadering, maar vond het belangrijk dat de nadruk niet ligt op een gelijke verdeling van middelen, maar op de vrijheid die mensen krijgen door die middelen om dingen te doen of te zijn die voor hun waarde hebben. Dat noemde hij capability. Het gaat bij capability dus niet om hoe tevreden je bent met je eigen situatie of hoe goed je denkt in staat te zijn iets uit te voeren. Het gaat om het antwoord op de vraag: *als je het zou willen, zou je het dan kunnen?*

Het doel van dit proefschrift is om erachter te komen wat we te weten kunnen komen als je met de capability benadering gaat kijken hoe het met mensen gaat. Een situatie waarin het moeilijk vast te stellen blijkt hoe goed het met iemand gaat, is wanneer iemand ernstig gehoorverlies heeft en hoortoestellen of een CI draagt. Dat komt doordat de apparaten niet altijd goed zichtbaar zijn en de meeste apparaten (gelukkig) zo goed werken dat het gehoor dicht in de buurt van normaalhorende mensen komt. Dit betekent echter niet dat er geen grote impact op het leven kan zijn. De taalontwikkeling kan gestoord zijn, iemand kan zich geïsoleerd voelen, of iemand kan minder goed aan werk komen. Het doel en de verantwoordelijkheid van zorg is om de capability van deze mensen te waarborgen. In dit proefschrift zijn kinderen en (jong)volwassenen met hoortoestellen en CI’s de mensen waar we de capability van proberen te meten.

In **hoofdstuk 2** hebben we gekeken naar 71 andere studies: hoe hebben zij de uitdagingen aangepakt die komen kijken bij het evalueren van de impact van een interventie op capability? Hierbij leerden we dat belangrijke elementen van de capability benadering niet structureel werden onderzocht, zoals de middelen die iemand tot zijn beschikking heeft, de omstandigheden of factoren die bepalen hoe de beschikbare middelen tot capability leiden, en de daadwerkelijke activiteiten die gerealiseerd worden door een persoon. Daarnaast werd er zelden ingegaan op wat mensen nou precies zouden moeten kunnen (de inhoud van capability) of hoe causaliteit tussen interventies en capability kan worden bepaald. Ondanks deze beperkingen hebben we ook sterke voorbeelden gevonden van effectieve benaderingen om de impact van interventies op capability vast te stellen. Hier zijn onze eigen studies ook door geïnspireerd.

Onze eerste eigen poging om capability te meten (**hoofdstuk 3**) was bij dove kinderen met CI's. Hiervoor hebben we een vragenlijst ontwikkeld, specifiek voor deze doelgroep. De meeste kinderen die het goed deden op gebruikelijke klinische maten, zoals spraakverstaan, hadden ook hoge capability scores, en vice versa. Er waren echter ook kinderen die lage capability scores hadden, ondanks goed spraakverstaan. En andersom waren er ook kinderen die lage spraakverstaan-scores hadden, maar hoge capability scores. Hieruit leerden we twee belangrijke dingen. Ten eerste zijn de klinische spraakverstaan-scores een belangrijke voorwaarde voor capability. Maar nog belangrijker; met capability kan je inderdaad unieke perspectieven in kaart brengen, die verder onderzocht moeten worden.

De interessante resultaten riepen ook nieuwe vragen op. We wilden eigenlijk veel meer weten van de kinderen met CI dan we met een vragenlijst konden ophalen. Wat waren belangrijke dingen om te doen voor deze kinderen? Verschilt dat van kinderen met hoortoestellen of kinderen die geen gehoorverlies hebben? Wat is er nodig voor kinderen met gehoorverlies om te doen wat voor hun belangrijk is? Om deze vragen te beantwoorden hebben we onze onderzoeksaanpak uitgebreid in **hoofdstuk 4**. In plaats van vragenlijsten af te nemen, hielden we interviews met 34 kinderen met CI of hoortoestel tussen de 8 en 12 jaar van zowel speciaal als regulier onderwijs, en 30 leeftijdsgenoten zonder gehoorverlies. Hieruit bleek dat de daadwerkelijke activiteiten tussen de groepen weinig verschilden, maar dat er een heel andere context omheen speelde. Waar het naar school gaan, sporten, met vrienden afspreken of op vakantie gaan voor kinderen zonder gehoorverlies vanzelfsprekend lijkt, zijn kinderen met hoortoestellen of CI's erg afhankelijk van en bezig met hun gehoor. Ze kunnen dus bijna alles doen wat kinderen zonder gehoorverlies doen, maar er moeten wel constant de voorwaarden geschept worden. Deze kwetsbaarheid werd niet altijd gezien door kinderen (of volwassenen) in hun omgeving, wat soms leidde tot onwetendheid en frustratie.

De complexiteit van de levens van kinderen met hoortoestellen en CI's wordt alleen maar groter naarmate ze in de puberteit en adolescentie komen. Er spelen meer factoren mee in het bepalen van capability, zoals autonomie, de sociale omgeving en identiteitsvorming. Tegelijkertijd kunnen jongeren in deze levensfase ook steeds beter reflecteren op deze factoren, hun eigen handelen en de voorwaarden om te doen wat belangrijk is. **Hoofdstuk 5** beschrijft het onderzoek waar we 59 jongeren met hoortoestellen of CI tussen de 13 en 25 jaar interviewden over hun leven, wederom van zowel speciaal als regulier onderwijs. Hier zagen we dat de hoortoestellen en CI's erg goed werkten om de jongeren in staat te stellen mee te doen in de horende samenleving. Hierin waren er weinig verschillen tussen jongeren met hoortoestellen of CI. Ze konden echter ook de uitdagingen goed benoemen. Ze hebben last van (voor)oordelen, te hoge of juist te lage verwachtingen en het gevoel dat ze niet goed begrepen worden. Ze worstelen ook met de tweestrijd dat ze niet anders willen zijn dan mensen zonder gehoorverlies, maar het wel nodig hebben om soms ondersteuning te krijgen. Deze studie liet zien hoe de capability benadering erg waardevol is om aanknopingspunten te vinden voor gepersonaliseerde zorg, maatschappelijke actiepunten, en bespreekpunten voor stakeholders die ook bezig zijn met het welzijn van deze doelgroep.

Waar de hoofdstukken tot nu toe gingen over kinderen of jongeren die al hun hele leven met gehoorverlies te maken hadden, gaat **hoofdstuk 6** over volwassenen die daar pas op latere leeftijd mee te maken kregen. We noemden in hoofdstuk 1 dat utiliteit een populaire manier is om welzijn in kaart te brengen. Daarnaast zeiden we dat bestaande capability maten nog moeite lijken te hebben om iets anders te meten dan utiliteit. In dit hoofdstuk namen we de EQ-5D (utiliteit) en de ICECAP-A (bestaande capability maat) mee in ons onderzoek naar capability, in aanvulling op de interviews. Dit deden we bij 69 volwassenen in vier groepen: volwassenen die onlangs een CI hebben gekregen, volwassenen die in aanmerking kwamen voor een CI, maar er van afzagen, volwassenen die waren doorverwezen maar toch nog niet in aanmerking kwamen voor CI, en volwassenen zonder gehoorverlies. Daaruit bleek dat er wel degelijk verschillen worden ervaren in capability tussen mensen met en zonder gehoorverlies. Vermoeidheid kwam als een terugkerend thema naar voren bij de drie groepen met gehoorverlies. De vermoeidheid kwam vooral door de inspanning die geleverd moest worden om geluiden te begrijpen, zoals gesproken taal. Dit leek impact te hebben op andere aspecten in hun leven, met name sociale activiteiten en werk. Sommigen vermijden ook bepaalde situaties, wat eenzaamheid tot gevolg kon hebben. Hoewel deze verschillen wel naar voren kwamen bij de interviews, werden deze niet gevonden bij de ingezette vragenlijsten.

De implicaties van deze bevindingen worden besproken in **hoofdstuk 7**, de discussie van het proefschrift. We hebben veel geleerd over de manieren waarop je capability kunt meten. Als het doel is om daadwerkelijk capability te meten, komen wij uit op een combinatie van kwalitatieve en kwantitatieve methoden om de belangrijke elementen van capability in kaart te brengen. Er is daarbij ook een verschil tussen het vaststellen van het niveau van capability (kwantitatief) en begrijpen waarom iemands capability is zoals die is (kwalitatief). De capability benadering kan helpen bij het concreet maken van moeilijke vragen, zoals de verantwoordelijkheid en grenzen van de zorg.

De capability benadering heeft in dit proefschrift belangrijke onderwerpen belicht voor dove en slechthorende mensen. Het is belangrijk om bewustzijn in de samenleving te creëren voor betere verwachtingen, inclusiviteit en acceptatie voor deze doelgroep. Capability leert ons niet alleen naar de uitkomsten te kijken, maar ook naar het voorafgaande proces en de vrijheid om daarna zelf keuzes te maken. Voor zorgmedewerkers is het cruciaal om met elkaar het gesprek aan te gaan over de verantwoordelijkheid om patiënten te helpen met hun capability, juist als volledig herstel niet mogelijk is. Dit kan door actief te luisteren naar patiënten, hun leven en waarden te begrijpen, en behandelingen af te stemmen op wat voor hen belangrijk is.

Dankwoord

Toen ik in 2017 begon aan dit avontuur kon ik niet voorzien wat een promotietraject van me zou vragen. Nu ben ik zeven jaar, twee werkgevers, drie afdelingen, tientallen collega's, 234 respondenten, drie subsidieaanvragen, zeven cursussen, zeven congressen en een pandemie verder en één ding is zeker: dit had ik nooit alleen gekund. Daarom is dit hoofdstuk gewijd aan iedereen die mij door deze bizarre tijd heeft geloodst.

Gert Jan. Van alle goede voorbeelden die ik in de academie heb gezien zijn er weinig die zo integer en behulpzaam zijn als jij. Ondanks dat je werkzaam bent in een wereld die constant jouw aandacht vraagt, voelde het nooit alsof je geen tijd had. Inhoudelijk is dit net zoveel jouw proefschrift als de mijne, dus ik hoop dat ik er recht aan heb gedaan. Bedankt voor de enorme capability *expansion* de afgelopen jaren.

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Emmanuel. Voor iemand met zoveel taken, ambities en promovendi ben je altijd ontzettend behulpzaam geweest. Ik was soms een beetje een vreemde eend in de bijt vanwege mijn affiliaties bij de Health Evidence en Kentalis, maar je hebt me altijd behandeld als een eigen promovendus. Dank daarvoor.

Maar liefst vijf personen hebben mijn manuscript beoordeeld: **Prof. Dr. Baziel van Engelen, Prof. Dr. Maria van den Muijsenbergh, Prof. Dr. Loes Wauters, dr. Femke Abma** en **dr. Erik Jansen**. Dank voor de tijd, energie en feedback die jullie mij gegeven hebben.

Op de afdeling Health Evidence bracht ik veel tijd door. Met kamergenoten **Daniëlle** en **Tessel**, maar ook de rest van de collega's op de gang: **Bram**, **Maarten**, **Scott**, **Anne**, **Tamara**, **Anouck**, **Romy**, **Sander**, **Rana**, **Michael**, **Rene**, **Martilord** en **Martien**. Daarnaast leerde ik veel van de (nog meer) ervaren onderzoekers: **Rob** en **Rob**, **Peep**, **Eddy**, **Leon**, **Marcia** en **Wietske**. **Anneke**, bedankt voor je secretariële ondersteuning. En nog vele andere collega's. Dank allemaal voor het zijn van mijn collega's.

Twee collega's noem ik nog even apart. **Jan**. We waren slechts een jaar officieel collega's, maar in die tijd hebben we veel gedaan. Veel over capability gelezen, gediscussieerd en geschreven. Daarnaast praatten we ook over het leven en hebben we een vriendschap opgebouwd. Dank daarvoor.

Bart. Collega, co-auteur en paranimf. Je bent één van de slimste personen die ik ken. Jouw kennis deed me soms duizelen: over filosofie, economie, bioinformatica, de gezondheidszorg… Daar deed ik graag mijn voordeel mee. Gelukkig ben je ook nog eens een ontzettend fijne vent om tijd mee door te brengen. Bedankt voor de wijsheid, gezelligheid en steun.

In het Radboudumc was ik ook veel te vinden bij mijn collega's van de KNO. In kamer 0.16 was het een ware stoelendans, waarbij we met zijn zessen vier stoelen verdeelden. **Esther, Marloes, Daniëlle, Hugo** en **Merle**: bedankt voor de intervisie, therapie, wandelingetjes, cadeautjes, versierde stoelen en steun tijdens deze bizarre jaren.

Merle in het bijzonder: mijn andere paranimf! We deelden onze begeleiders, doelgroepen, bureau, volgende werkgever en natuurlijk onze humor. Je maakte me wegwijs op een voor mij totaal onbekende plek en staat nog steeds klaar om te helpen waar je kunt. Dat maakt jou zo'n geweldige collega en mens. Merle, bedankt!

Naast mijn kamergenoten hebben ontzettend veel KNO-collega's mij geholpen mijn onderzoeken tot een goed eind te brengen. **Wendy**, bedankt voor alle tijd en hulp om samen geschikte deelnemers te vinden. **Sarah**, jij en de rest van het secretariaat bedankt! **Jan-Willem**, **Cilia** en iedereen die ik nog vergeten ben: dank!

Na de eerste twee jaar in het Radboudumc kon ik mijn onderzoek vervolgen als werknemer van Koninklijke Kentalis in Sint-Michielsgestel. **Krista**. Als mijn insider bij Kentalis al voordat ik officieel in dienst kwam, heb ik veel aan je gehad. Je maakte tijd (en prioriteit) voor mijn onderzoeken en opende deuren om bij Kentalis bij de juiste personen te komen. We schreven twee artikelen samen en daarbij was je van onmisbare waarde. Bedankt!

Harry. Ik heb het genoegen gehad om jou een tijdje officieel als leidinggevende bij Kentalis te hebben én samen een artikel te schrijven. Ik heb jouw inzichten altijd als ontzettend waardevol beschouwd. Bedankt voor je behulpzame houding en fijne samenwerking.

Het was van korte duur, maar ik heb me erg welkom gevoeld bij de collega's van Kentalis. Zodanig dat ik daar nog gesolliciteerd heb op een baan die eigenlijk niet goed bij me paste. Dus bedankt: **Loes, Daan, Corrie, Helen, Peia, Hille** en mijn andere collega's van korte duur bij team DSH.

Jac, Sridhar, Karine. Zonder jullie rol als co-auteur waren onze artikelen niet mogelijk geweest. Dank voor het maken van mijn proefschrift tot wat het nu is. For Sridhar: Thank you for working together on the scoping review. It's been a privilege collaborating with an international expert on the capability approach.

Als ik iets geleerd heb tijdens mijn promotieonderzoek, is het wel dat geen enkel onderzoek mogelijk is zonder dat iemand daarvoor betaalt. Een open deur misschien, maar zonder de financiering van de afdeling **Health Evidence (Radboudumc), KNO (Radboudumc), Audiologisch Centrum (Kentalis)**, **de Programmaraad Auditief - Communicatief** en **Cochlear Benelux** was dit proefschrift niet tot stand gekomen. Bedankt!

Specifiek wil ik hier ook de **234 deelnemers** van mijn studies bedanken. Alle kinderen (de jongste was 8 jaar!), pubers, adolescenten, studenten, werkenden en gepensioneerden die tijd wilden maken zodat we konden leren over het welzijn van dove en slechthorende mensen: bedankt!

De afgelopen twee jaar ben ik werkzaam bij de Hogeschool van Arnhem en Nijmegen als onderzoeker. Ik heb hier een geweldig team waar ik mee samenwerk; het **iXperium Centre of Expertise Leren met ict**. De laatste loodjes wogen best zwaar, maar door af en toe wat kwijt te kunnen bij mijn collega's hier, werd mijn last aanzienlijk verlicht. Bedankt allemaal!

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In mijn interviews met deelnemers kwam vrijwel altijd de waarde van familieleden terug. (Groot)ouders, broers, zussen en (klein)kinderen. Ik heb naast mijn eigen familie ook een schoonfamilie, waar ik het, gezien de reputatie van schoonfamilies, enorm mee getroffen heb. **Antoon, Marieke, Esther, Jasper, Nicolaas, Shirley**: dank voor het meeleven met mijn ervaringen onder het genot van een pot thee. Ik kijk nu al uit naar het kerstgedicht van dit jaar.

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Zoals Gert Jan ooit mooi verwoordde: de capability benadering is uniek omdat het uitnodigt om na te denken over wat het leven de moeite waard maakt. **Harmke** en **Liva**, voor mij zijn jullie het antwoord op die vraag. **Ham**, zonder jou had ik niet eens gesolliciteerd op dit promotieonderzoek. Jij opent mijn ogen voor de mogelijkheden in ons leven. Dank voor alles, maar vooral dank dat je bent wie je bent. Ik hou van je. **Liva**, bedankt dat je in ons leven bent gelopen. Met zijn drieën zijn we nu een team. Samen sterk. Ik geniet elke dag van de sterke vrouw die je nu al bent. Ik hou van jou.

About the author

Wouter Rijke is geboren op 22 januari 1992 in Apeldoorn. Hij groeide op als de jongste met twee oudere broers. Nadat hij zijn atheneumdiploma behaalde in 2010, studeerde Wouter Toegepaste Psychologie aan Saxion Hogeschool in Deventer. Hierna volgde hij de master Psychologie *Learning Sciences* aan de Universiteit Twente. In zijn afstudeeronderzoeken richtte hij zich op thema's als programmeren in het basisonderwijs, computational thinking en 21e-eeuwse vaardigheden.

In 2017 solliciteerde Wouter op een samenwerkingsproject van afdeling KNO en afdeling Health Evidence van het Radboudumc, getiteld: 'Ontwikkeling methode om effect van cochleair implantaat op capability van dove kinderen te meten'. Hij werd aangenomen.

Tijdens zijn aanstelling werkte Wouter onder leiding van prof. dr. Gert Jan van der Wilt, dr. Anneke Vermeulen, dr. Margreet Langereis en prof. dr. Emmanuel Mylanus. In deze periode leerde hij over doofheid en slechthorendheid, ontwikkelde hij kwantitatieve en kwalitatieve methoden om capability te meten en wierf hij subsidies. Tijdens zijn promotieonderzoek was hij in dienst bij de afdelingen Health Evidence en KNO van het Radboudumc en bij Koninklijke Kentalis, een organisatie voor mensen die slechthorend, doof of doofblind zijn of een taalontwikkelingsstoornis of communicatief meervoudige beperking hebben. Ook volgde hij trainingen en cursussen, waaronder een basiscursus gebarentaal.

Sinds 2022 werkt Wouter bij de Hogeschool van Arnhem en Nijmegen als onderzoeker in het iXperium Centre of Expertise Leren met ict. In zijn vrije tijd brengt hij tijd door met zijn vrouw Harmke en dochter Liva. Daarnaast volgt hij NBA basketbal, zwemt hij en illustreert hij zijn eigen kinderboeken.

Portfolio

PhD student: Wouter Rijke	**PhD Period**: April 2017 – December 2021
Department: Health Evidence (Radboudumc) Otorhinolaryngology (Radboudumc) Programmalijn doof en slechthorend (Kentalis)	**Promotors**: Prof. dr. Gert Jan van der Wilt Prof. dr. Emmanuel Mylanus
Graduate School: Donders Graduate School	**Co-promotors**: Dr. Anneke Vermeulen, Dr. Margreet Langereis

	Location	**Year**	**Workload (ECTS)**
General courses			
Introduction day DGS	Nijmegen, The Netherlands	2019	0
Scientific Integrity course	Nijmegen, The Netherlands	2019	0.3
2x attendance at Graduate School Day	Nijmegen, The Netherlands	2019, 2021	0.7
Scientific Writing	Nijmegen, The Netherlands	2018	3
Grant Writing and Presenting for Funding Committees	Nijmegen, The Netherlands	2018	1
Statistics and R (HarvardX)	Online	2018	1
Qualitative Research Methods and Analysis	Nijmegen, The Netherlands	2018	3
Nederlandse Gebarentaal A1	Nijmegen, The Netherlands	2018	3
Structural Equation Modeling (Statistical Horizons)	Ghent, Belgium	2018	2
Basiscursus Regelgeving en Organisatie voor Klinisch onderzoekers (BROK)	Nijmegen, The Netherlands	2019	1.5
			15.5
Conferences			
15th International Conference on Cochlear Implants (Oral)	Antwerp, Belgium	2018	1.0
Siméacongres (Oral)	Lunteren, The Netherlands	2019	0.5
Health Technology Assessment International (HTAi) Annual Meeting (Vignette)	Keulen, Germany	2019	0.5
14th European Symposium on Pediatric Cochlear Implantation (ESPCI) (Oral)	Bucharest, Romania	2019	1.0

	Location	Year	Workload (ECTS)
Human Development & Capability Association Conference (HDCA) (Oral)	Auckland, New Zealand (online)	2020	0.5
Health Technology Assessment International Annual Meeting (HTAi) (Panel, oral)	Manchester, United Kingdom (online)	2021	0.5
15th European Symposium on Pediatric Cochlear Implantation (ESPCI) (Oral)	Budapest, Hungary (online)	2021	0.5
Hearing Across the Lifespan (HEAL) Conference (Oral)	Cernobbio, Lake Como, Italy	2022	0.5
Oral presentations			
The capability approach: an update from theory and practice (with Jan Meerman)	HTA, Radboudumc, Nijmegen, The Netherlands	2017	0.1
Qualitative Capability Assessment in Deaf Children: Methods and Preliminary Findings	Research in Progress meeting, Radboudumc, Nijmegen, The Netherlands	2018	0.1
De impact van een CI op de capabilities van dove kinderen	Bijeenkomst expertise-ontwikkeling Hoor- en Taalgedrag, Radboudumc, Nijmegen, The Netherlands	2018	0.1
Assessment of Capability in Children with a Cochlear Implant: Can you do what you value?	CI Conference, Antwerp, Belgium	2018	0.1
Capability van dove kinderen met CI	Siméacongres, Lunteren, The Netherlands	2019	0.1
Capability in Healthcare	HEV congress, Radboudumc, Nijmegen, The Netherlands	2019	0.1
Capability van dove en slechthorende kinderen	Kentalis, Sint-Michielsgestel, The Netherlands	2019	0.1
Choosing Relevant Endpoints: The Capability Approach	HTAi Annual Meeting, Cologne, Germany	2019	0.1
Pursuing valuable lives with cochlear implants. The capability approach	Hearing & Implants meeting, Radboudumc, Nijmegen, The Netherlands	2019	0.1
Assessment of Capability in Children with Cochlear Implants	ESPCI, Bucharest, Romania	2019	0.1
Capability van dove en slechthorende kinderen	Kentalis, Sint-Michielsgestel, The Netherlands	2019	0.1
Capability bij dove kinderen	Programmalijn DSH, Kentalis, Sint-Michielsgestel, The Netherlands	2020	0.1

	Location	Year	Workload (ECTS)
Measuring capability: theoretical and empirical insights	Mirror Sessions, Radboud University, Nijmegen, The Netherlands	2020	0.1
Mogelijkheden voor slechthorenden Een nieuwe benadering vanuit het capability begrip	CI Team Kentalis, Sint-Michielsgestel, The Netherlands	2020	0.1
Impact van doofheid en slechthorendheid op capability	Programmalijnen DSH Kentalis, Sint-Michielsgestel, The Netherlands	2020	0.1
Impact of CI on Capability in Adults	CI Team Radboudumc, Nijmegen, The Netherlands	2021	0.1
Evidence for HTA: The Capability Approach	HTAi Annual Meeting, Manchester, United Kingdom (online)	2021	0.1
(1) Assessing the Impact of Deafness on Children's Capability (2) How to assess the impact of interventions on capability? A Scoping Review	HDCA conference, Auckland, New Zealand (online)	2021	0.2
Capability in hard-of-hearing and deaf children: A mixed methods study	ESPCI conference, Budapest, Hungary (online)	2021	0.1
HTA research meeting	Online	2021	0.1
(1) Assessing the Impact of Deafness on Capability (2) Underspecified Phonological Representations in Teenagers with Cochlear Implants	Cernobbio, Lake Como, Italy	2022	0.2
Teaching			
Master Molecular Mechanisms of Disease cursus 'Science & Society', beoordelen van Journal Club presentaties en het geven van een college over de capability approach en human enhancement.	Radboudumc, Nijmegen, The Netherlands	2018-2021	1.0

Data management

Ethics and privacy

This thesis is based on the results of medical-scientific research with human participants. The studies described in chapter 3, 4, 5 and 6 were subject to the Medical Research Involving Human Subjects Act (WMO) and were conducted in accordance with the ICH-GCP guidelines (Good Clinical Practice). The medical ethical review committee 'CMO Radboudumc' has given approval to conduct these studies (file numbers: 2016-2845, 2017-3684, 2019-5672). Informed consent was obtained from research participant, or, when necessary, from their parent(s) or guardian(s). Technical and organizational measures were followed to safeguard the availability, integrity and confidentiality of the data (these measures include the use of independent monitoring, pseudonymization, access authorization and secure data storage).

Data collection and storage

All patient file data of chapter 3, 4, 5 and 6 were directly entered into SPSS, which thereby served as both source document and database. The anonymized data was entered into Castor EDC. After acceptation of the final manuscript the Caster EDC database will be closed and archived. The SPSS datafiles of all chapters are protected with a password and only accessible by the PhD student and promotors. Data used in this thesis is stored on the Radboudumc, Otorhinolaryngology department server: (\\Umcfs023\knodata$\Onderzoek\Capability). Paper (hardcopy) data is stored in cabinets on the department.

Availability of data

All studies are published open access. The data will be archived for 15 years after termination of the study. Reusing the data for future research is only possible after a renewed permission by the participants. The anonymous datasets that were used for analysis are available from the corresponding author upon reasonable request.