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INTEGRATED MASTER’S THESIS

Social problems of Cochlear Implant Patients explained by the Social Determinants of Health:

An extended Literature Review

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2. Abbreviations

ASL - American Sign Language
CDI - Child Development Inventory
CI - Cochlear Implants
CPG - Clinical Practical Guideline
DHH - Deaf or hard of hearing
HH - Hard of hearing
HL - Hearing Loss
HR-QOL - Hearing-related Quality of Life
HUI (3) - Health utility index (Version 3)
NAD - National Association of the Deaf
NH - Normal Hearing
LHL - Low health literacy
PEACH - Parent Evaluation of Aural/Oral Performance of Children
SCHL - Subclinical hearing loss
SDH - Social determinants of health
SDQ - Strengths and Difficulties Questionnaire
SEP - Socioeconomic position
SES - Socioeconomic status
SP - Speech perception
QUALY - Quality adjusted life years

3. Summary

Cochlear implants (CIs) represent a significant medical advancement; however, their success is heavily influenced by various social factors.

Disparities in healthcare access and its quality, particularly in low-income or rural populations, can delay treatment, limit rehabilitation opportunities, and worsen outcomes. The high cost of implants and therapy may prevent access, especially for financially constrained families, whereas insufficient follow-up care can hinder speech and auditory development.

Education access as well as quality play a crucial role in the development of CI users, especially in speech and language acquisition. However, children with CIs often face stigmatization, social isolation, and educational challenges. Parental involvement and understanding are key, but lower

educational levels or misconception can impede support, further hindering cognitive and social growth in educational environments.

Social and community support is vital for mental well-being, yet societal stigma and a limited understanding of CI technology often result in social exclusion or misperceptions. This lack of community integration affects personal and professional growth, affecting the overall quality of life of CI users.

Economic status is directly linked to access to healthcare, with families in lower socioeconomic brackets facing greater financial strain. Limited insurance coverage or access to support programs creates treatment disparities, with fewer resources for rehabilitation and follow-up care. These financial inequalities exacerbate health outcome disparities among CI users.

The neighbourhood and physical environment also significantly impact CI user outcomes. Rural or underserved areas often lack specialized care and therapy facilities, delaying CI intervention and rehabilitation. Isolated living conditions may lead to loneliness and social exclusion, compounding the challenges CI users face in their everyday lives.

Overall, the challenges faced by cochlear implant users extend beyond the technology itself, deeply influenced by healthcare and education access and quality, the social and community context, economic stability, and the neighbourhood and physical environment. These social factors often contribute to significant disparities, emphasizing the need for a holistic approach to support CI users in overcoming these obstacles and improving their quality of life.

4. Keywords

Cochlear Implant(s) (CI); social problems; social determinants.

5. Introduction

This thesis aims to enhance the understanding of otorhinolaryngologists and parents of deaf children regarding the patient’s experience of receiving a cochlear implant. By deepening this understanding, practitioners will be better equipped to address the unique challenges these patients face in their daily lives, allowing for more informed and empathetic care tailored to their specific needs. For parents, this thesis points out as well the negative aspects of wearing a cochlear implant, which could help them to make a better-informed decision pro or contra implantation or help understanding their implant-caring child because even with a CI ‘(h)earing loss has profound impacts on communication, education, socialization, cognition, and overall well-being across the lifespan’ (1).

Many Articles describe, & it seems a common sense that ‘the treatment with a cochlear implant (CI) is the gold standard in therapy of patients with (this) profound hearing loss or deafness’ (2) (3, 4, 5,6).

The massive numbers of cochlear implants in use of 1 million globally, that ‘(e)ach year, around 25,000 European citizens receive cochlear implants’ (7) and also that ‘(t)he number of cochlear implantation surgeries almost tripled during last decade’ in Lithuania (8) show how important and fundamental cochlear implants have become as a treatment.

‘Results of previous research show that cochlear implantation gives the opportunity to hear, positively affects speech and language development, improves educational achievements, employment possibilities, and quality of life. It is proven that cochlear implantation decreases expenses for the deaf children education and increases deaf people work productivity’ (9) (2, 10).

However, ‘speech perception outcomes are highly variable among (...) CI recipients’ (11). As formerly hoped for the cochlear implant is not recreating a natural hearing, ‘instead, it can give a deaf person a useful representation of sounds in the environment and help him or her to understand speech’ (6). Despite the medical discourse that shaped the CI ‘as an innovative neurotechnology’ (12) it is rather ‘an imperfect and uncompleted prothesis’ (12). And this causes problems in the daily lives of implant receivers, such as ‘difficulties of communication and social participation’ (13).

Besides all positive effects on perception and communication ability in children (14, 15), as well as self-reported benefits on top in adults (5) and stable or improved hearing in the elderly (16), the ‘access to and utilization of such devices is neither uniform nor equitable. In spite of this expanding global public health problem, the utilization of hearing devices, including cochlear implants, across the world is less than 15%’ (1).

The inequality is also reflected if an individual who received a CI, in, for example, the results of speech understanding in children that are highly dependent on their socioeconomic status and their parents (9).

This study seeks to highlight the numerous social challenges and influential factors that significantly influence the development of patients with cochlear implants. It also aims to shed light on the social and political barriers that hinder the adaptation of these patients to a predominantly hearing world. Additionally, this study proposes potential changes at the societal level to improve the integration of cochlear implant users. By addressing these three key aspects, this thesis serves as a comprehensive summary for those unfamiliar with the complex issues faced by cochlear implant patients, providing a foundational understanding without the need to consult multiple sources.

6. Research Methods

6.1 Strategy used to search for Sources & select articles

Table *1: Research strategy*

<table>
<tr><th>Database name</th><th>Key words/ Phrases</th><th>Database headings used</th><th>Search limits (in-& exclusion criteria)</th><th>No of results found</th></tr>
<tr><td>Google Scholar</td><td>Social problems AND Cochlear implants</td><td></td><td>2014-2024</td><td>17 800</td></tr>
<tr><td colspan="5">Comment: This was a global search on Google scholar only with the limitation of years the article had to be written in</td></tr>
<tr><td>Google scholar</td><td>Social problems AND “Cochlear implants”</td><td></td><td>2024</td><td>16,800</td></tr>
<tr><td colspan="5">Comment: I wanted to only include articles that included the rigid term of cochlear implants but wanted to have the term of social problems more vaguely to have a broader view on the topic</td></tr>
<tr><td>Google scholar</td><td>Social problems AND “Cochlear implants”</td><td>100 most relevant articles</td><td>2024</td><td>100</td></tr>
<tr><td colspan="5">Comment: I selected the 100 articles on Google scholar to be most relevant</td></tr>
<tr><td>Google scholar</td><td>Social problems AND “Cochlear implants”</td><td>100 most relevant articles
At least cited by 20 others</td><td>2024</td><td>44</td></tr>
<tr><td colspan="5">Comment: I selected those 44 articles because of their relevance and repeated citation number of at least 20 times and worked with them and also included sources that they contained with the aim having direct information from the original sources</td></tr>
</table>

Google Scholar was searched using the approach listed in Table 1 above.

I had to exclude one source because I could not access it.

I included three sources sent by my supervisor, Prof. Dr. Eugenijus Lesinskas, which showed the results of CI-related research in Lithuania that would have been excluded by my research methods because of their small scale and relevance globally due to the small number inhabiting this country they have been conducted in. Those are the article by Stumbrys et al. (9), Mataityte-Dirziene et al. (8) and Byckova et al. (17).

I also included numbers on cochlear Implant reinforcement written on the official website of the Ministry of Health of the Republic of Lithuania (18) and that I used in the Subchapter on Economic Stability.

Then, I went on reading until the discovery of the article by Schuh and Bush (1) and took over their categorization into social determinants of health.

From the articles collected, I was researching and reading their newer (up to 10 years old) sources and grouped them into different categories of determinants. Naturally, some articles were source for more than one subchapter.

6.4 Characteristics of the selected Research

The criteria for inclusion in this thesis were, that the studies should not be older than 10 years (not from a year before 2014) for all articles from the beginning of the search.

I made an exception to this age criterion for theories that are still valid and proven to be so with an article which was not older than 10 years itself. They help me to explain social phenomena in this thesis. These theories are as follows:

1.Bourdieu’s theory (1986) of social capital (19) → proven by Moore & Carpiano (2020) (20)

2. Bat-Chava’s deafness identity theories (Already formulated in 1993, revised 1994; I used 2000) (21)→ proven by Michael J. Carter (2015) (22)

3. Social identity theory (already formulated in 1979; I used 1986) by Tajfel and Turner (23)→ proven by Scheepers and Derks (2016) (24)

4. Meyer’s Minority Stress theory (already formulated 1995, revised 1998, 1999, 2001; I used 2003) (25) → proven by David Frost (2023) (26)

Studies often have small participant numbers when researching deaf people or Cochlear Implant users, however only studies with at least 10 participants were included.

I also only included papers written in English or were fully translated into English.

I collected data in Lithuanian about CI reimbursement practices from the official website of the Ministry of Health of the Republic of Lithuania and by informational email exchange with Ramutė Baklanova, the Chief Specialist of the Department of Centrally Reimbursed Medicines of the Ministry of Health of the Republic of Lithuania and used the help of Chat GPT to translate some of the passages into English.

7. Research Discussion & Results

7.1 Explanations for the underlaying structure of this thesis

In the subsequent discussion, I adopted the framework of social determinants of health as outlined in the work of Schuh and Bush (1). I have structured my extended literature review according to these subcategories, as they provide a well-organized approach to demonstrating the multifaceted social impact of wearing a cochlear implant (1).

The social determinants of health are organized within a widely recognized framework, which considers the environments where individuals live, work, and engage in daily activities. These settings significantly influence health outcomes and overall quality of life, either directly or indirectly (1).

This framework is divided into five key domains: ‘healthcare access and quality, education access and quality, social and community context, economic stability, and neighbourhood and physical environment’ (1).

The first domain addresses access to and use of healthcare services, as well as patients’ health knowledge. Factors include the type and extent of insurance coverage, availability and accessibility of providers, health literacy, and the standard of care provided (1).

The second domain focuses on the role of educational access and quality in shaping health outcomes. Relevant factors include educational attainment, vocational training opportunities, parental education levels, early childhood education access, and school-based rehabilitation services (1).

The third domain, social and community context, examines the social networks and conditions individuals experience and their effects on health and well-being. This includes support systems, community involvement, social integration, and cultural, racial, or ethnic identity. Discrimination based on race, ethnicity, gender, or sexual orientation is also analysed within this domain (1).

Economic stability forms the fourth domain, covering financial and material resources and their influence on health. Factors such as employment, income, poverty levels, debt, expenses, and food and housing security fall under this category (1).

Lastly, the neighbourhood and physical environment domain explores how living conditions affect health and well-being. Considerations include housing quality and safety, transportation access, water and air quality, crime rates, and the urban or rural nature of a location (1).

Together, these five domains offer a holistic framework for assessing health and healthcare disparities. They highlight factors that either enhance or hinder the health of individuals who are eligible for or who receive cochlear implants (1).

7.2 Healthcare Access & Quality

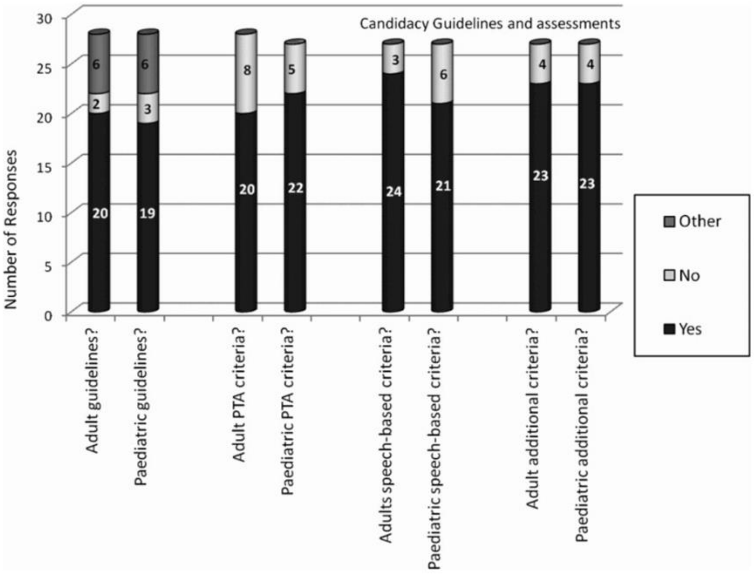
Starting with a global scope on this determinant of health, the social problems of cochlear implant patients are starting with the basic issue of unequal supply of different populations and sub-ethnicities with health insurances or, if absent, unequal economic means. Those different standards are influencing who receives a cochlear implant.

Looking at ‘(t)he average lifetime cost (of a cochlear implant) for an adult patient first implanted between the age of 20–80 is at 53,030 € (present value)’ (27), and ‘mean costs (per child from diagnosis to 3 years after first implantation) were €64,675 (range, €38,709–113,954)' (28) stresses how important reimbursement of a cochlear implant is, especially in regards of the improved Quality of Life. Crowson et al. (29) describe that even if high expenditures are existent, the cost-effectiveness threshold is meat for CI in the USA and Canada, which where around 50,000 USD and like this, incremental cost-utility is also insured (meaning additional cost that need to be paid compared to the additional quality of life it provides).

Schuh and Bush (1) emphasize the critical issue of access to care for cochlear implant (CI) patients, noting the 'global underutilization of hearing devices' (1). They highlight the complexity of CI care, which requires long-term, transdisciplinary services often provided in different locations. Access to CI care is influenced by 'different geographic and socioeconomic factors', with rural areas facing significant challenges. In these regions, access to CI treatment is particularly limited, which is concerning given the 'greater burden of age-related hearing loss' (1) (30) among rural adults compared to their urban counterparts (1, 31, 32, 33). Later in the subchapter of Neighbourhood and Physical environment I will go into further detail.

Generally, there doesn't exist a standardized criteria when to receive a cochlear implant: 'The relative success of cochlear implantation in restoring functional communication has seen an expansion of their application from the relatively small population of totally deaf individuals with little or no residual hearing, to the much larger population of people with cochlear hearing loss who have difficulties understanding speech with acoustic hearing aids in one or both ears (...). Along with advances in device technology and surgical techniques that aim to preserve residual hearing, this means that a wider population of patients can potentially benefit from cochlear implantation' (34, 29). What remains difficult to determine is a clear set of implantation candidacy criteria—that is, the point at which a cochlear implant would be expected to provide better functional hearing over acoustic hearing devices. 'Within the literature, cochlear implantation is frequently referred to as the 'standard of care' (...), 'treatment of choice' (...), or the 'gold standard' for management of patients with severe-to-profound sensorineural hearing loss (...) perhaps based on the common belief that patients with severe-to-profound hearing loss cannot derive benefit from traditional hearing aids (...). Such broad statements become problematic, however, when definitions and measures of hearing loss severity are inconsistent across studies. Even more problematic is the wide variability in the speech recognition ability of patients with severe-to-profound hearing loss when using hearing aids (...), contradicting the belief that they cannot benefit from a less invasive technology' (6).

Figure 1: Diagram by Vickers et al. (35)



Vickers et al. (35) showing that from 28 participants from 17 different countries (Argentina, Australia, Belgium, Bosnia Herzegovina, Brazil, Finland, Germany, India, Italy, The Netherlands, New Zealand, South Africa, Spain, Switzerland, Portugal, United Kingdom, and The United States of America) there are countries that do not have guidelines for adults or children in the two left columns. On the right, the criteria in those guidelines are further specified and respondents shown in the column secretions.

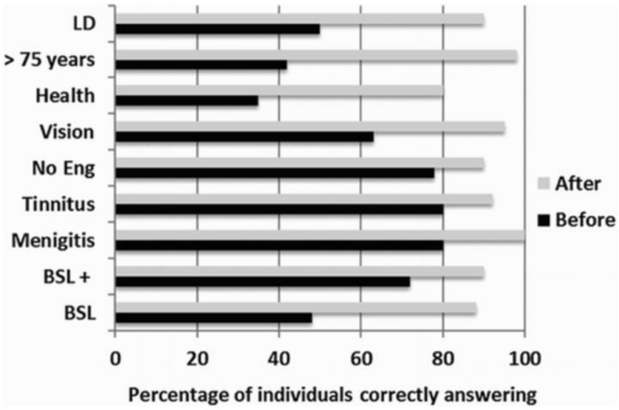
‘Cochlear implant (CI) intervention is expensive and accessed mainly by developed countries. The introduction of Universal Newborn Hearing Screening and funding via a public health service give children better access to CIs. However, for adults large disparities exist between utilization and estimated prevalence’ (36). As well, tests used to measure the “true audibility” of patients differ tremendously and make it even more difficult to compare receiver groups or create a standardized criteria when to receive a cochlear implant: there is a ‘contrast between assessing hearing using sound detection thresholds (the traditional hearing test), and the functional use of hearing for communication, generally demonstrated by measuring speech perception with various materials and under various conditions. Hearing threshold tests are useful when prescribing conventional hearing aids, but for those using cochlear implants, they provide little information about functional hearing for communication. Specifically, while audibility after implantation is restored within a relatively narrow range across the population, variability in speech perception outcomes is much broader and does not appear to relate directly to hearing thresholds. To a large extent, it is improvement in speech perception that is the primary goal of cochlear implantation, as this will in general facilitate improved communication and concomitant quality of life’ (5). And those restrictive and not clearly defined candidacy criteria in clinics is leading to that many adults that would have benefitted from a CI did not receive it. This is reflecting in the relatively low penetration of Cis in the population (5).

Also, de Magalhaes Barbosa et al. (37) confirms this and as a reason for the low CI penetration rates stresses the complexity of the process: The ‘correct selection of patients who will receive cochlear implants is essential to attain success, which requires a multidisciplinary approach, consisting of several stages and involving high costs and technology’ (37). De Magalhaes Barbosa (37) emphasizes the need for standardized, efficient, and rapid patient selection to minimize delays, as auditory deprivation impacts outcomes in paediatric patients (37) as well as in elderly in which ‘prolonged hearing deprivation (could have a) (...) downstream effects on cognitive function, general health, and quality of life’ (38).

Raine et al. (36) also detected a lack of knowledge in audiologists, which patient (or its pure tone audiogram) shows such results that this person is within candidacy for a cochlear implant, but they also demonstrated that seminars on the correct candidacy collection are clearly effective for the knowledge of this professional group (5, 39, 36)

Figure 2: Results by Raine et al. (36)

Figure 3 Percentage of individuals correctly indicating the candidacy appropriateness for nine clinical statements before and after training (*see text for horizontal axis nomenclature*)



Results by Raine et al. (36) on effectiveness of audiologists training on correct candidacy criteria. Individuals in percentage before and after audiologist training on candidacy criteria shown for 9 different statements. (LD - Deafened adults with learning difficulties; No Eng - Deafened adults with learning difficulties; BSL + - Deaf people who use British Sign Language and speech; BSL - British Sign Language Users who do not use spoken language)

In the way of better-defined candidacy criteria are also the lack of predictors of cochlear implant outcomes. Pisoni et al. (4) who is writing about the US which as a large multi-state country rather homogenous medical system with clearly defined candidacy criteria by the FDA adopted by most healthcare insurers, is reporting that as of 2017, clinicians there too rely on limited variables like demographics, hearing history, and preimplant behavioural tests for candidacy. However, no reliable preoperative behavioural or neural measures exist to predict post-implant success despite the length of CI usage and ‘intensive aural rehabilitation (AR) carried out by experienced clinical audiologists and speech-language pathologists’ (4). This gap hinders progress in understanding and improving implant efficacy for both adults and children (4).

In Europe, we have the issue that ‘numerous efforts (...are made) to standardize CI care at the national level. While most people in Europe already live in countries with a CPG (Clinical Practical Guideline), this is not the case for CI registries.’(3) Cochlear implant registries serve the function of databases that collect and maintain information about patients who have received CIs and track various aspects of CI use, for example patient demographics, surgical details, device performance, complications, and long-term outcomes. (3) ‘European-wide consensus on CPGs or registries does not yet exist. The (...) study of Loth et al. (3) thus provides a first assessment of the distribution of CI-related CPGs and registries’ (3). Europe-wide guidelines and registries would be important to achieve and assure a steady status of quality in this medical process of receiving and maintaining hearing with Cis (40, 41). ‘With their help, structural requirements and operational processes can be standardized and treatment results as well as complications can be recorded’ (3).

As shown in the maps below and table in Annex 1 in, for example in Lithuania, in 2021 CPG and CI registries are not yet established. ‘Possible explanations could be that the spread of CI treatment differs regionally. In countries where this method is used less frequently, the perceived necessity or acceptance of a CPG could possibly be less pronounced. In addition, the creation of a CPG also requires the initiative of individual stakeholders to take on the task. Therefore, in a country where fewer CI treatments are performed, there may be fewer doctors available to take on the task of creating a CPG’ (3). So, a possible explanation why there is not yet established structures in Lithuania could be that there are only few inhabitants and with that also CI patients (CI prevalence on ‘the 1’st of January 2018: (...) 377 CI patients implanted in Lithuania’ (9) and experts to create CPG and CI registries.

Figure 3: Results by Loth et al. (3), state 1st of June 2021:

Fig. 1

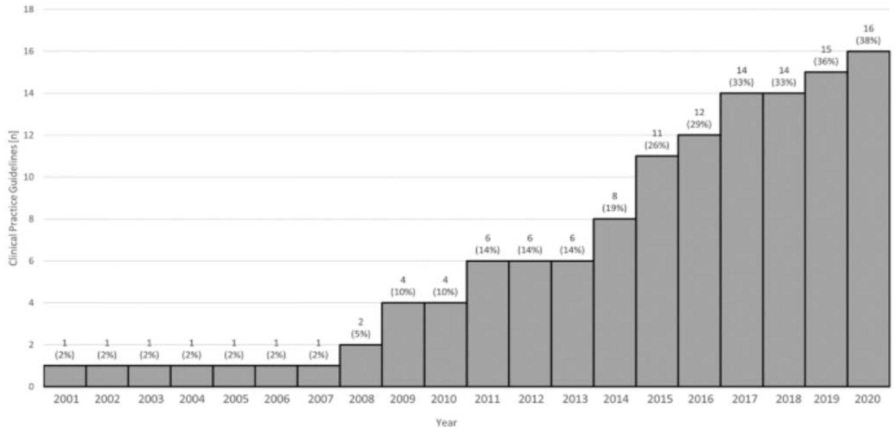
Countries analyzed on the European continent including Turkey and Russia. The numbering of the countries corresponds to the numbers in Table 1. Countries where a cochlear implant guideline or guideline-like format has been identified are shown in gray

Fig. 2

Countries surveyed in continental Europe, including Turkey and Russia. The numbering of the countries corresponds to the numbers in Table 1. Countries where a cochlear implant registry has been identified are shown in gray

on the left countries in grey that already established guidelines or guideline-like formats; on the right countries in Gray that already have established CI registries.

Figure 4: The graph about the development of CPGs by Loth et al. (3):



The graph is showing a positive trend in Europe between 2001 and 2020. The number of CPGs is shown above the column of the particular year.

An established guideline who is indicated receiving a CI is the ground for reimbursement practices. In the before demonstrated map those CPG-using countries are shown but to my best knowledge there is no European-wide description or comparison of different countries, only some articles describing reimbursement practices in single countries, like De Raeve and Wouter (42) in Belgium and Thum et al. (34) in Germany, only there is evidence that 'reimbursement policies also cause large differences in the ratio of the number of implanted children (reimbursed in most European countries) and the number of adults (reimbursed in fewer countries). Estonia, (Slovakia), Turkey, Hungary, and Italy focus on the implantation of children rather than adults' (43).

Well-established guidelines would also prevent the big inequalities in all countries until today in who receives a cochlear implant not only in between countries but also within one country or society (44). For example, that 'Insurance status and type of insurance has been used as a proxy for SEP (socioeconomic position) but may be influenced by various factors including income, employment, or race and ethnicity' (1) (30, 45). Consequently, for example in Lithuania, Stumbrys et al. (9) found that 'the benefit which deaf children gets from cochlear implantation varies between in upper and lower socioeconomic groups' (9).

To investigate the racial and ethical influence on CI distribution Tolisano et al. (47) grouped their patients into white and non- white, into different family states and different types of surgery and found out, that 'compared to White patients, non-Whites were half as likely to pursue surgery (...). Single (...) and widowed patients (...) were about half as likely to pursue surgery as compared to married patients' (47). The same is valid for children from a non-white racial background who are often experiencing delays in receiving CIs, irrespective of their insurance coverage, and are less likely to undergo implantation before the age of two compared to their white counterparts (48). Still, 'non-white patients and minority ethnic groups are more likely to have public insurance coverage instead of private insurance coverage compared with white patients' (1). Addressing this racial and ethnic disparity is essential, given the significant developmental benefits of early implantation for paediatric patients. Beyond access to care, implicit bias or racial and ethnic discrimination by healthcare providers may also influence the quality of care delivered (1). Mauldin et al. (45) 'revealed that race/ethnicity also played a role in clinician attitudes about parents. Parents' immigration status or cultural background potentially conflicted with audiologists' (45) imaginations of ideal CI candidates. 'If another language besides English was spoken at home or parents adhered to cultural norms from their home countries, this was seen as a deterrent' (30) to CI success.

These inequities in access are further exacerbated by the disparities in reimbursement practices, which vary significantly across age groups. For example, the reimbursement practices in the United States which numbers are well documented and available are showing well those inequities in reimbursement: 'while cochlear implantation is typically covered for children by Medicaid and most private insurance carriers, (...) the same is not true for adults. (...) Only approximately 60% of states offer Medicaid coverage for cochlear implantation in adults' (1), with coverage varying based on state criteria (49). 'Even when CI Medicaid coverage is available, the quality of care may be negatively impacted by barriers in obtaining upgraded or replacement equipment, poor reimbursement, limitation in locations of care, limitations in the number of covered appointments, and difficulty in authorization for care' (1). Additionally, in some states, patients who received cochlear implants as children under Medicaid may lose eligibility for necessary care once they transition to adult Medicaid coverage. According to Schuh and Bush (1) there also was a 50% lower chance to receive sequential bilateral implants as well as compliance with follow up and a five times higher risk for post-surgery complications for Medicaid patients when comparing them to privately insured individuals (1) (49). In the subchapter of Economic stability this also will be explored in more detail.

Already mentioned a few times in this subchapter are the important post-surgery follow ups. To emphasize the necessity of ongoing language and speech perception training after cochlear implantation, I would like to present the findings of some studies. Without adequate post-implantation support, patients may experience reduced quality of life or face psychological challenges. For example, (Boerrigter et al.) found, that in children with CIs, 'children with lower speech perception and language levels are more at risk of developing behavioural problems at school. Adequate speech perception and language levels are found to be protective factors for the development of behaviour' (50). This also is thematized by Mousley et al. (51) who focuses on the psychological outcomes of not understanding the surrounding world: 'Deaf individuals experience worse psychological and physical health relative to their hearing counterparts (...). For example, higher rates of impulse control disorders, depressive symptoms, and developmental disorders have been recorded in deaf populations (...). Similarly, deaf individuals report worse rates of physical well-being and are less likely to utilize health care systems than hearing individuals' (51).

Another point that I would like to make in this subchapter is, that healthcare access and quality are as well crucial in order to stop the preventable causes of neonatal deafness. The access to medical professionals is important to educate pregnant women on how to prevent getting in contact with infectious agents such as Cytomegalovirus which contributed to 9.8% of prenatal deafness causes today, 2024, in a study performed in Lithuania (17, 52, 53). Also, the research about neonatal causes of deafness is important and should be mentioned here because the 'Idiopathic aetiology of hearing loss was still the most commonly identified, which indicates a limitation in terms of diagnosis' (37). Also, in the past, etiological investigations and resulting preventive measurements lead to that 'since the beginning of vaccination against measles, epidemic parotitis, Hemophilus influenzae type b, and Streptococcus pneumoniae, proportion of postnatal HL (Hearing loss) decreased. Better perinatal and neonatal care correlates with the reduction in the number of perinatal HL cases. Lastly, immunization against rubella has been related to the lower number of rubella associated HL in the developed countries' (17). Besides infectious agents there should be genetic testing performed too, for example, 'Pathogenic variants of GJB2 gene (that) are the major cause of non-syndromic hearing loss' (17) or 'perinatal events, syndromes, postnatal infections or traumas' (17) (54, 37). The importance can only be stressed by the statement of the 'WHO (that) 50% (and even 60% in the paediatric population) of HL causes are preventable' (16) (WHO).

The final aspect I wish to address in this subchapter is, that the so-called health literacy that is defined as 'literacy and numeracy skills that enable individuals to obtain, understand, appraise, and use information to make decisions and take actions that will have an impact on health status' (55). It is noteworthy because it 'influences the cost of care, as there is a strong correlation with lower health literacy and higher medical expenses among patients with hearing loss' (1) resulting in 'a link between language barriers, patient satisfaction, care adherence, and utilization of healthcare services' (1). I would categorize this point somewhere in between Healthcare & Education Access and Quality but because Schuh and Bush (1) of whom I took over the organization into social determinants of health are mentioning it here, I will do so as well.

Levy and Janke (56) made general research about "Health Literacy and Care" that I would like to mention because it 'analysed a large, nationally representative sample of adults age(d) 50 and older to estimate the relationship between low health literacy (LHL) and self-reported difficulty obtaining care. (They) found that individuals with low health literacy were significantly more likely than individuals with adequate health literacy to delay or forgo needed care or to report difficulty finding a provider, even after controlling for other factors including health insurance coverage, employment, race/ethnicity, poverty, and general cognitive function. They were also more likely to lack a usual source of care, although this result was only marginally significant after controlling for other factors. The (study concludes that), low health literacy also reduces the probability that people get in the door of the health care system in a timely way' (56).

If we project those findings on people that are deaf or hard of hearing (DHH), like Wells et al. (57) did in their article about "Limited Health Literacy and Hearing Loss Among Older Adults", we find that 'Unaided mild, aided severe, and (especially) unaided severe hearing loss were positively associated with LHL, although the association was reduced among hearing aid users. Specifically, aided mild or severe hearing loss had lower odds of LHL, compared to unaided mild or severe hearing loss, respectively. We also observed that people with both hearing loss and LHL were more likely to have higher medical costs' (57). And again, the hearing loss has a negative impact by decreasing the health literacy of a patient itself (46), leading to a vicious circle.

Despite an extensive search for sources on the impact of parental health literacy on children's outcomes with cochlear implants, I was unable to find relevant studies. But one study conducted in Jordan by Alkhamra et al. (2) expresses the need of "parents (of cochlear-implanted children) (...) for a comprehensive multidisciplinary team approach during the different stages of the cochlear implant process. Parents' education about cochlear implants prior to the surgery can affect their post-surgical outcome expectations' (2). And '(a)although parents used a variety of information sources when considering a cochlear implant, the ear, nose and throat doctor comprised their major source of information (60%)' (2) and 'that those who choose to get a cochlear implant for their children feel that they lack "comprehensive and bias-free" information when making the decision' (2). Similar results are reported by Mauldin et al. (30). Also, Chang et al. (58) that conducted semi-structured interviews with parents about their decision-making states that parents were usually informed by doctors that were pro-implants but finally not the medical opinion but meeting with families that already decided and were now living with one or another approach had the main influence on them (58). Yorgun et al. (59) did a study in Turkey and found out that '90.1% of parents remarked that they needed more information and recommendations before the surgery' (59).

But even if receiving enough information beforehand, parents are biased in their view on CIs and have higher expectations for the immediate results when the CI is turned on. One mother in an interview-based study by de Souza Vieira et al. (60) gave the following quote: 'We were so desperate to do the implant that we created an erroneous expectation. (…) We went outside, and I stood there like an idiot saying over and over 'This is mommy'. It's not that the institution hadn't prepared us, they gave us the right information, it's just that the parents' expectations are so great that we end up forgetting this' (60). This brings to a point that these high parental expectations make the caregivers deaf themselves towards what the reality really is of living with a CI. It takes time until the family perceives the CI as a resource helping them instead of the ultimate cure (60, 61).

I will also reference an article by Hübner et al. (62) that provides numerous patient statements and perspectives on how health literacy and implant care are interconnected in the experience of living with such a device. This topic will not be explored further in this thesis, as it would introduce a broader discussion beyond the scope of this work.

7.3 Education Access & Quality:

Educational access and attainment impact health in multiple ways, as they intersect with other social determinants by influencing income levels, access to nutritious food, safe housing, and adequate insurance coverage (63,1). Thus, it is not a surprise that health outcomes and educational attainment are correlating with lower educational levels tied to worse outcomes in health (63, 1).

Barnett et al. (64) made research about "Factors Involved in Access and Utilization of Adult Hearing Healthcare" (64) and like the other sources confirmed that the educational level influenced the compliance of the usage of hearing devices including cochlear implants. One of the barriers they located were unrealistic expectations, which could be prevented if the patient receiving a hearing device, especially in case of a cochlear implant which means a surgery for implantation, could be prevented if the responsible doctors explain thoroughly the effects on hearing that also change within time due to neuroplasticity and how cochlear implant hearing differs from natural hearing (64,6,2). Mäki-Torkko et al. (65) found in their research that '(t)timescale and past experiences were the most important types of information desired pre-implantation by both the CI-users and the significant others. Timescale referred to the length of time required between the implantation and actually being able to differentiate between sounds, that is, the ability to hear selectively. Not having too high expectations understanding that the hearing doesn't immediately get perfect but rather develops gradually. (...) (This information) would (also) prevent others taking for granted that the CI-user would hear immediately after the implantation' (65).

In paediatric CI the parental education level, particularly the mothers, as noted by de Moura Silva et al. (9), has been linked to the use of hearing healthcare services and the speech development of their child. Lower educational attainment among parents may indicate reduced participation in speech therapy after implantation (1, 44, 10, 14). Mauldin et al. (30) writes about this from a sociological point of view: ‘Because the CI is a neuroprosthetic device, deafness has come to be redefined from a sensory (hearing) loss to a neurological (processing) problem. One result of this is that the CI is then constructed as merely a tool providing access to the brain, which is the site of the ‘real’ treatments. These ‘real’ treatments are the long-term therapeutic endeavours parents engage in, which are focused on neurological training to transform the child’s brain into one that functions as much like a hearing brain as possible’ (30).

Another reason why the parental education effects the CI use of their children, could be that not only the quality of the explanation by the responsible doctor but also the parental understanding and literacy in health matters is influencing the following time post-surgery. There is a common parental ‘misconception (that CIs restore natural hearing, which) may harm paediatric recipients. Some parents of children with cochlear implants believe their child is “hearing” like them, so they do not teach their child American Sign Language (ASL). Not learning sign language may delay their child’s language acquisition’ (67).

Nasralla et al. (68) adds to this insight: ‘Acceptance of the deafness of the child is the starting point for the development of communication (either verbal or gestural) and (with that as well) cognitive, motor, and emotional skills. (...) (For example, they) observed the association between deafness and impairments in fine motor skills’ (68).

Marschark et al. (69), as an example what impact the CI is having on communication even if ASL is taught, discovered in their research that CI-using colleague students, had inferior ASL (American sign language) expressive skills despite there being no significant difference in the age at which ASL was acquired between CI users and non-users. Additionally, the study indicated that the CI-using group tended to overestimate both their signing and speaking abilities. This highlights the consequences of elevated expectations surrounding cochlear implants, which ultimately reduced the quality of outcomes due to insufficient practice in both sign and spoken language skills.

Cooper (67) is criticizing the construct that is pushing such wrong believes built up especially in social media in, for example, first time CI activation videos with titles like “Hearing My Husband say I Love you for the First Time”; this kind of presentation is downplaying the recovery and effort that has to be made to actually comprehend speech using a CI and glamorizing the first time experiencing the new sensory input, which in fact causes fear in many individuals (67).

(For the interested reader I would like to refer to the website “Cochlear implant Brain and Behaviour Lab” of the university of Connecticut, which showcases how some sentences are sounding through a cochlear implant (70). This should help to thoroughly comprehend the results of cochlear implant hearing.)

Sharma et al. (66) is drawing a connection in between the parental educational attainment and their socioeconomic position (66). For the education of their child, the parents need to make a tremendous effort and involve themselves a lot to make going to (the right) school possible for their child. The schools must fulfil various requirements: they should offer respect from peers and teachers, a strong academic environment, safe spaces, and recreation areas free from static-inducing materials (for example not only plastic toys) that could interfere with CI processors. Once a suitable school is found, they strive to maintain enrolment, fostering trust and adaptation. Success strategies include staying actively involved in the child's education, informing staff about the CI and deafness, and involving a speech therapist to support the school (60). This effort is only possible if the parents are in a socioeconomic position to have enough time and money to aid their child's educational path with such an extent of dedication (1, 10, 14, 9, 60, 30).

Addressing the education of CI-users themselves, they also face more difficulties receiving education than normally hearing peers. Sharma et al. (14) explored the "dose-dependent association between hearing loss and various domains of cognition" (14) including memory, verbal functioning, and executive abilities, observing these effects in both adults and children (14, 71, 72). Cognitive risks often begin with mild hearing loss (26–40 dB HL) and worsen as severity increases. Research on adults revealed that subclinical hearing loss (SCHL) correlates with impairments in global cognition, verbal memory, and executive functions (73), with similar patterns suggested in children. Even minor hearing loss links to lower academic performance, particularly in reading, due to difficulties in hearing and grasping concepts in verbal formats (14). For CI-using pupils, the double burden of impaired understanding in verbal teaching environments and cognitive challenges linked to hearing deficits leaves them especially at risk of poor educational outcomes.

Additionally, to the intrinsic challenges which CI-using pupils face there are the extrinsic hurdles of education systems today. In their study evaluating mental health problems in adolescents, Huber et al. (74) let CI users and a normal hearing (NH) control group be rated in the Strength and difficulties questionnaire (SDQ) scale by themselves, their parents and their teachers. They found that 'adolescents did not differ between clusters in the analysis of parent- (...) and self-ratings (...). However, the distribution of CI adolescents and NH adolescents did differ significantly between clusters in the analysis of teacher ratings (...). CI adolescents were more frequent in the high problem cluster than in the low problem cluster' (74). This might show that teachers might have a rather negative attitude towards DHH people and evaluate them to be more problematic than they are seen by the other evaluating groups here.

Byatt et al. (75) explored how the social capital of d/Deaf adolescents is shaped by experiences in the school and what those experiences were and based their article on Bourdieu's theory of social capital (19) whereas social capital is defined as the ‘aggregate of the actual or potential resources which are linked to the possession of a durable network of more or less institutionalized relationships of mutual acquaintance and recognition - or in other words, to membership of a group which provides each of its members with the backing of the collectivity owned capital’ (19). In practical terms, this can involve belonging to social groups like families, peer circles, educational institutions, extracurricular activity groups, or specific societal classes, which may provide access to various resources such as working prospects, supportive networks, and valuable information (75). This social capital again ‘significantly correlated with individual health status and health behaviours’ (76) in many relevant studies. For example, in the research of Wong et al. (77) that drew a correlation between ‘better language skills’ (77) and the likelihood ‘to seek help and build beneficial personal networks to assist them in the educational system’ (77) making those adolescents having ‘higher feelings of empowerment/control over their family life and services’ (77).

I acknowledge that the article by Byatt et al. (75) does not specifically focus on adolescents with cochlear implants (75); however, I believe it is still relevant to include. It provides insights into the experiences of students with hearing impairments in school settings, which serve as microcosms of society. School environments are particularly significant because they play a critical role in shaping an individuals' perceptions of the external world and their own identities during formative developmental years (78). Indeed, ‘(s)schools are the most dominant extra-familial institution in childhood and adolescence’ (79).

Within the school ‘language (…abilities are…) a key component in successful social interaction. Children who have difficulty integrating the various components of language in interaction might be at risk for social problems. Competent face-to-face conversation demands that children understand the nuances of turn-taking, including the different roles of speaker and listener, and involve the ability to express their intent, respond to their partner’s initiations, provide the right amount of information and know how to initiate or maintain a topic as well as repair communication breakdown’ (81). Meaning that in schools the social capital is dependent on how much schools are including HHD students (75) so that they are having the possibility to practice such communication.

Important to note here is that not only already high schools should be obligated to provide such environment but also primary or secondary schooling institutions (82). Even by the age of 5 some conversation skills are already acquired and then need to be increasingly defined during the following years (81). In the research of Duncan et al. (83) they reported that adverse events already took place in schools’ years before high school in many of their participants and had a tremendous impact on the following social interactions (83).

Moreover, the limited understanding displayed by a subset of mainstream teachers, students, and administrators reflects reduced access to bridging social capital. Bridging social capital could be defined as someone's connectivity with its social environment, giving resources and opportunities that the bonding social capital cannot offer (75) (19). This form of social capital pertains partly to recognizing and accepting differences, such as the distinct ways in which d/Deaf adolescents communicate and engage with the curriculum (75).

It is important that there exists a 'balance between bonding ('a kind of sociological superglue' (75)) and bridging ('a sociological WD-40' (75)) capital' (75). When putting bridging social capital into the context of a (hearing) disability, it may lead to increased number of possibilities after the school, like in ones' professional career (75, 84).

Although some adolescents possessed bonding social capital, they experienced limited access to friendships and supportive networks beyond their immediate family and close friends (75). From a social capital perspective, this limitation may signify reduced bridging social capital for both the CI users and their families (85, 65, 86).

Despite all those difficulties that must be overcome, for example, Yorgun et al. (59) found in their research concerning CI patients that possessing an implant over 18 months and attending a regular school had a positive impact on the participants social relationships and their self-confidence (59). Johnston et al. (87) found out, that if high school students were placed in segregated educational institutions, they experienced stigma through placement. The authors regarded this process of stigmatization as resulting in the young disabled participants being "excluded from access to usable (bridging) social capital resources" (Johnston) (75) This again could lead to the formation of a marginal identity (88).

Later in the subchapter of social and community context I will elaborate more about the different identities that DDH and CI users can acquire and how those identities are impacted by different environments but also wanted to shortly mention it here because the type of school attended is having a great impact. Chapman et al. (89) parted their research participant's identity into d/Deaf, bicultural, hearing and marginal. They found that 'those claiming deaf identity were significantly more likely to have attended deaf education than the other three groups. Those with a bicultural identity were significantly more likely than those with a hearing and marginal identity to have attended deaf education. Finally, those with a marginal identity were significantly more likely to have attended deaf education than those with a hearing identity' (89). They also found out that a lower educational attainment correlated with both bicultural and deaf identity in comparison to a better attainment with a hearing identity (89). (For more detailed research results see Annex 2.) This suggests that better hearing ability (or as good as being identifying as hearing) is linked to higher educational attainment (14, 90).

Since successful hearing with a cochlear implant (CI) heavily relies on participation in post-surgical programs, which themselves are influenced by the educational background of the patient or their parents. This highlights significant inequities among different patient groups.

7.4 Social and Community Context

Support derived from formal networks, interpersonal relationships, and community interactions significantly influences health outcomes. Strong relational support promotes overall well-being and reduces mortality, whereas a lack of social ties and connectedness is linked to adverse health effects (1).

The outcomes regarding auditory perception and speaking language skills development of cochlear implants, especially if implanted within young age, are widely proven, yet research also has indicated the 'difficulties of communication and social participation' (13) that those paediatric or adolescent CI patients are experiencing (13, 77, 74). Additionally, policies that encouraged integrated schooling have led to fewer schools specializing in deaf education and with that also the bicultural approach of using both spoken and signed language (80). 'The spread of CI technology therefore raises questions about its implications for deaf identity, social participation, and general well-being' (13).

Because of the higher number of articles and broader information that I could find for this social determinant of health I further subcategorized it into social participation, identity, psychological well-being and d/Deaf as disability versus culture.

7.4.1 Social Participation

To come to the point in social participation, 'a large body of research suggests that language ability plays an important role in developing social skills and competence, and consequently (school-aged) children who are DHH (deaf or hard of hearing) have higher rates of peer and social problems' (91) (77, 45) For example, a study conducted in Turkey came to the results that '94% of parents stated that speaking was easier than sign language during communication (with their CI-implanted children) (...) (but) 71.5% of parents stated that communication was still a problem with people with normal hearing, even though they were aware of their child's disability' (59) (45) while also the same group of parents in another study was expecting pre-intervention that their off-springs would 'receive education in mainstream schools (92%)' (2) when implanted. Those children or adolescents possibly 'face challenges in developing close relationships with their peers (even if wearing a CI) and this may predispose them to mental health problems' (1) because they 'may experience dissonance in defining their social identity when coexisting among hearing peers and family members' (1) (79). As a result, Hoffmann et al.

(93) and Sarant et al. (92) found in both of their studies, that ‘parent data indicated that children with CIs were delayed in comparison to their hearing peers on the social competence latent variable across all time points’ (93). Hoffmann et al. (93) investigated further and discovered that during their study there ‘was minimal evidence of “catch-up” growth over this 5-year period’ (93).

Ketelaar et al. (94) researched the role of moral emotions like shame, guilt, and pride directly evoked in their performed interview in children, defining these as responses to evaluating one's own behaviour as morally wrong or right. They note that these emotions are essential for guiding socially appropriate behaviour. Their study compared children with CIs to NH peers, focusing on the expression of moral emotions and links to social functioning and language skills. Findings indicated that CI children showed fewer moral emotions than NH peers, and while NH children showed a connection between moral emotions and social functioning, this was absent in CI children. Although general language skills weren't linked to moral emotions in the CI group, emotion vocabulary correlated with social functioning in both groups. They concluded that enhancing emotional language skills could improve social functioning and reduce behavioural issues in children with Cis (94) (See Annex 3 for comparative results). In contrast to Katelaar et al.’s (94) findings, Wong et al. (77) obtained the results that language abilities had an influence on social skills: ‘Children whose parents rated them as being able to listen and communicate well in a range of different quiet and noisy environments, as measured on the Parent Evaluation of Aural/Oral Performance of Children (PEACH) scale, also had more highly developed social skills on the Child Development Inventory (CDI)’ (77). Here should be noted that in contrast to Katelaars’ experiential interview study Wong et al. (77) used questionnaires with preformulated closed questions and preformulated ‘assessments of nonverbal cognitive ability (Wechsler Non-verbal Scale of Ability) and language (Preschool Language Scale - fourth edition)’ (77).

Chapman et al. (13) report ‘that children with CIs often have hearing and communication difficulties in group settings or other situations in which the optimal conditions for hearing or speechreading are absent’ (13). Byatt et al. (75) confirms those findings for ‘adolescents with cochlear implants (...) (that still) experienced difficulties with social awareness and communicating in groups’ (75). Michael et al. (95) termed this phenomenon as “social deafness” and that it is ‘not used in any audiological or cultural sense and refers to difficulties in social interactions involving groups of people or noisy environments (...). In children, social deafness can impede social interactions such as play and conversation with peers. Potential barriers to easy social interactions with hearing peers include not only dhh children’s communication difficulties in challenging listening environments but also a misunderstanding on the part of hearing children of these difficulties, and the sometimes-inadequate social skills (such as difficulty forming friendships) of children who are dhh' (95). This is also expressed in the feedback of naturally hearing children towards their DHH peers: '(H)earing peers' attitudes about deaf children's personal qualities (e.g., likeability, intelligence, confidence, extroversion) were closely related to deaf children's speech intelligibility: as intelligibility improved, so did peers' attitudes, particularly those of peers with little experience with deaf speakers. These findings establish the importance of speech intelligibility as an integral link between linguistic and psychosocial abilities' (96). This again might lead to lesser popularity or in other terms bridging social capital (97, 75, 77, 79, 1).

Those findings are especially concerning regarding Wolters et al.'s (97)' findings that d/Deaf adolescents are risking a diminished acceptance among same-aged pupils if they behave in a withdrawn manner (97), which may happen if such CI user in not comprehending the group conversation and are therefore not enabled participating in the common conversation (97, 51). 'In short, if a child's speech articulation is difficult to understand, frustrated peers may avoid social contact, and with less social interaction, the child has fewer opportunities to learn appropriate social behaviours' (96).

(A detailed and well-structured analysis of conversation of children with CI and hearing peers was conducted by Church et al. (81). Unfortunately, the extent of their work is too large and specific to include it in detail into my thesis, but for the interested reader I would highly recommend reading their paper (81).

For adult CI users the overall psychological well-being was most strongly predicted by the variables of 'other people's attitudes to their hearing difficulties, degree to which social participation was restricted (for example, by the stigmatization of a placement in a deaf educational facility (87), level of perceived social support, and age' (13) (96).

Those 'Social support systems (also) influence adherence with wearing hearing devices' (1). The age doesn't play an important role but it might change the support settings, for example children are more adherent wearing their devices if they experience support and reinforcement both by their family and in the school (87). Zaidman-Zait et al. (98) describe that '(p)parents (...) spoke of an adjustment period in which their children resisted the CI at first but then came to use it more regularly' (98). Adolescents have higher adherence if they are supported by their peers mostly in the educational facility (88, 99, 83, 82) and in adults it is equally friends and partners or the working environment (64, 5, 100, 86) as well as in elderly for which increased number of social interactions are crucial (33, 16, 38). And wearing the CI frequently is of major importance - general outcomes (101, 60) and working memory are improved (102) by influencing the neural plasticity (103) with the duration or frequency the CI is in use.

Especially in the case of CI-wearing children the social support can be quite demanding on the relatives of the CI-patient: Families realize they must actively advocate for their child's progress, committing to formal rehabilitation and home-based stimulation. They come to see themselves as central to the child's development, as daily involvement drives success. This ongoing effort includes overcoming obstacles, seeking support, and persistently working toward the child's ability to hear, communicate, and thrive socially and academically (60). Nasralla et al. (68) pursued a study on factors influencing CI-children's development and cognition and found that 'a good child–mother relationship is a positive factor for development and for overcoming the consequences of these impairments' (68). This impact of maternal bonding is further underscored by Mauldin et al. (30), who explain that 'in the past forty years (...), responsibility for the care of children with disabilities has shifted from institutions to the home' (30). Living as a family with a CI could introduce more difficulties in the family dynamics due to 'limitations and restrictions imposed by the device, the child's questions regarding her disability, parental fear regarding the child's future, jealous siblings, overload and lack of family support for the main caregiver, parental overprotection and dependence of the child for self-care (...) and difficulties at school' (60). And those 'problems in family dynamics, including overprotection, accompanied by poor sociability led to lack of independence, low self-esteem, and poor overall development in children with hearing impairment' (68).

Mäki-Torkko et al. (65) investigated adult cochlear implant (CI) users and their partners, focusing on the shift in expectations pre-implantation and experiences post-surgery. They found that receiving a CI brought a sense of "normality" for users, reducing feelings of being 'different from everyone else' (65) and helping them feel more integrated in social and work environments. The implant also benefited family, friends, and colleagues, who no longer had to serve as "interpreters" or adjust to communication limitations. Many CI users described increased self-value, empowerment, and clearer communication due to better voice control, which helped them participate on equal terms with hearing people. However, adjusting to a "hearing life" was challenging, as users had to relearn sound differentiation and manage others' assumptions about them hearing from the beginning on as everyone else.

As a consequence of changed possibilities in connections, the CI is influencing who an individual is engaging with or befriended. Chapman et al. (13) analysed that individuals with a CI are significantly more likely to socialize with hearing friends than those without a CI, and vice versa, those without, with deaf friends and to participate in Deaf cultural events (13).

Nowadays CI users also have the additional possibility to connect to others online. On this matter, the authors Wong et al. (91) investigated what impact online social interactions as a new form of communication or even social capital has on DHH individuals. 'Online participation may increase (bridging) social capital and be particularly beneficial for individuals (especially adolescents) who are deaf or hard-of-hearing (DHH), as it provides an alternative method to communicate, interact with others and access information. However, reduced levels of literacy may be a barrier to participate and benefit from online activities' (91). They found a positive correlation in between internet use daily and increased bridging social capital (BSC) online and vice versa lower BSC in less internet use daily (91). But online bridging capital was the only positive correlation because this increased online time didn't have an influence on online bonding or even offline social capital as well, they could not establish a connection between increased time spend online and increased literacy.

In their investigations on the analogue world, Duncan et al. (99) found that real human contact would increase adolescents' social capital before and after attending a deafness-specific camp and compared how their on- and offline social capital changed by the attendance. They detected an increased face-to-face social capital after the camp (99). In a following study performed, by a similar team, about social capital, peer relations, and loneliness and how they are related, again in relation to before and after a camp, they discovered a correlation between common good and decreased loneliness at three points of time post-camp (83). The findings of Duncan et al. (83) suggest that in this deaf-specific camp the DHH adolescents might transformed their attitudes towards their deaf identity by perceiving it as something positive in a greater group with a similar usually disabling handicap that could understand and support one another.

Further in this chapter I would like to discuss which different identities might form in the group of CI patients and what influences they have in many aspects of their lives.

7.4.2 Identity:

The social identity has a big impact on an individual's life: 'Related to social identity, stigma around deafness and hearing loss heavily influences hearing health behaviours and outcomes. Stigma regarding hearing loss stemming from social contexts has been associated with poor mental health and overall decreased quality of life' (1).

Already emphasized in quite some points in this thesis, I finally want to come to the explanation how different identities of DHH or individuals with a CI have an impact in many aspects of their life. The underlying concept is the Deafness Identity Theory by Bat-Chava (21) that distinguishes in between four different identity groups (21, 22).

The first one is the hearing identity of which individuals that define as such, regard themselves as belonging to the hearing world. They might have the opinion that being deaf is a disability (21, 22, 89).

The second group is the marginal identity (also “negative identity”). Those individuals regard themselves as neither belonging to the deaf nor the hearing identity groups and perceive themselves therefore as someone that is marginal and not belonging to any society (21, 22, 89).

The third group is the group of Deaf identity which views being Deaf as its own culture and sign language as a language as any other and eventually has a negative view on the hearing society (21, 22, 89). Individuals with a Deaf identity feel like they also experience advantages by being Deaf, the so-called Deaf gain, for example increased visual acuity (104). Deaf with capital D is describing this view of this identity group while deaf with an uncapitalized d is the inability to listen to what is said in words (12).

The fourth group is the bicultural identity in which individuals that feel themselves belonging to this group, regard themselves as being part of hearing and deaf culture and estimates none of them better or worse (21, 22, 89).

Chapman et al. (13) made a big-scale survey, which ‘constituted 25% of the adult population with moderate to severe hearing loss in Denmark’ (13) with ‘about one in three (...) having at least one CI’ (13). In Denmark the bicultural/bilingual approach in deaf education, emphasizing sign language and Deaf culture, was prevalent from the 1980s until the mid-2000s. Since then, cochlear implants and a greater focus on spoken language in education have led to a decline in this model (80). The historical shift influenced the study's interest in examining how age, and thus generational differences, as well as the age of CI surgery, affect identity. Participants were divided into age groups: those older than 25 years, who experienced the bilingual/bicultural period, and those 25 and younger, who have grown up in a time focused more on spoken language. Additionally, cochlear implantation performed at age 12 or younger was categorized as “young childhood implantation” whereas implantation after age 12 was considered “late childhood implantation”. Because the youngest CI surgery age for those over 25 was 17, this group was not compared concerning the age of cochlear implantation.

Chapman et al. (13) discovered that participants without CIs were significantly more likely to identify as deaf, while those with CIs were more likely to adopt a hearing identity. ‘Those with a bicultural identity were significantly less likely to have a cochlear implant compared to the hearing identity group’. These differences remained significant even when focusing on participants over 25 years of age. In this age group, individuals with a CI were more likely to report a hearing identity and less likely to identify as deaf compared to those without a CI. However, no significant identity differences were found among participants under the age of 26 (13).

Within the same study they also performed a survey for researching how cochlear implants are affecting the well-being of patients, and placed questions examining discrimination, challenges and the feeling of limitation: ‘participants above age 25 years with a CI reported significantly higher levels of feeling limited than those without a CI (...). However, there were no significant differences among those under age 26, neither with respect to age of CI surgery nor to having a CI or not’ (13). ‘(But) significant differences were found between the identity groups with regard to feeling limited (Table Annex 4). Those with hearing and marginal identities reported significantly higher levels of feeling limited than those with deaf and bicultural identity’ (13). ‘It may be, therefore, that this finding reflects the greater difficulties with spoken communication skills that are associated with getting a CI at an older age. (...) These findings point to a risk that individuals with CIs who develop a hearing identity come not to experience being deaf as culturally positive but to perceive it more in terms of limitation and disability. This may not have negative psychosocial implications for those with a CI who can fully socially participate and identify with the hearing community, but it may for those who have enduring difficulties with spoken communication and participation’ (13). And there are ‘young people with CIs who demonstrate ambiguity about identity and have ongoing communication difficulties (13). Goldblat and Most (105) grouped their participants into one well-signing, one well-speaking and one neither-nor group and detected that ‘(a)adolescents and young adults who were proficient in one of the modes of communication developed well-established bicultural identities. Adolescents and young adults who were not proficient in one of the modes of communication did not develop a distinguished cultural identity. These results suggest that communication proficiencies are crucial for developing defined identities’ (105). And vice versa, the identity as well as the degree of hearing loss have an influence on the languages used by the participants: Chapman et al. (89) found out that Individuals with a ‘deaf identity reported having significantly better sign language abilities and greater hearing loss’ (89) than those in the other three identity groups. ‘Those with a bicultural identity reported significantly greater hearing loss than those with a hearing identity and better sign language abilities than those with a marginal and hearing identity’ (89).

But ‘sign language and cochlear implants (don’t need to) be mutually exclusive’ (69) and that a single approach, whether language modality or cultural orientation, does not guarantee solutions to the psychosocial challenges faced by adolescents and young adults with hearing loss. Research highlights the diversity within the deaf community, with differences in educational settings, language proficiency, family support, and other variables, emphasizing that each young deaf adult must ’find their own way ‘(69), rather than rely on a universal method for achieving personal, social, and academic success (69). This could be unveiled in several studies conducting research on communication modes and levels of CI users. For example, Chapman et al. (13) as well as Cooper et al. (67) found out that parents generally perceived an advantage for their CI using children spending time with other deaf children and even some of them, despite opposition from early intervention centres, viewed the use of signed communication as advantageous for children's social and identity development (13, 67).

One barrier to this success could be increased by a certain type of identity formed, for example, those identifying as Deaf were significantly more likely to report cultural differences when asked about what challenges they faced when 'working with hearing people' (13) than those from the three other identity groups. Those with a hearing or bicultural identity were even significantly less likely to report such problems than individuals from the marginal group. In general, those with a CI were less likely to report differences in culture than those without such device in the context of 'working with hearing people' (13). But ultimately those findings were only significant for the group over 25 years and 'not for those below' (13).

Marschark et al. (69) implemented similar research about differences in CI users and non-users in the acculturation of deaf students entering college: The CI group was worse acculturated in the deaf culture than the group without devices, but both exhibited 'similar levels of hearing acculturation' (69). In the CI group were 54% bicultural, 25% deaf and 8% hearing acculturated people. Among this group there was a correlation found between learning signing earlier and lower hearing acculturation (69). Marschark et al.'s (69) findings can be found in Annex 5)

Another theory, that could explain those different acculturation levels is the social identity theory by Tajfel and Turner (23) which suggests that individuals with threatened or minority identities may adopt "social mobility" strategies by dissociating from their lower-status group and identifying with a higher-status or majority group (23, 24). This can be seen in some individuals with hearing loss who, using new hearing aid technologies like CIs, may identify more with the hearing community rather than the deaf community (13). In the study about the HrQoL by Duarte et al. (90) using Kidscreen-52 the results presented that 'Cochlear implantation appears to favour the perception of a good QoL in children and adolescents' (90) (61, 106).

This supports the idea that well-being is tied to group status, where some achieve higher well-being by distancing themselves from a stigmatized identity and aligning with a higher-status group (23, 13, 51, 1).

However, existing research on the psychological impact of cochlear implants is inconsistent. In both studies by Duarte et al. (90) and Haukedal et al. (107) for example, they report that the HrQoL of CI children is higher than other DHH children (90) but still lower than of NH children (90, 107). Some studies report high psychological well-being and few identity problems among children with cochlear implants (108). Other studies indicate that adolescents with cochlear implants may face identity challenges, feeling torn between the hearing and deaf worlds (13) (107).

This “double identity” can complicate their social identification processes, which are crucial for their psychological well-being, regardless of their hearing loss level or hearing aid technology. Chapman et al. (13) for example, describes that many children with cochlear implants occupy a space between - they may see themselves as not deaf in an audiological sense but still want to explore Deaf culture and signed language, particularly during adolescence or young adulthood (13, 51,1).

Chapman et al. (13) surprisingly found, that the ‘age of cochlear implantation was not significant for (forming an) identity, friendships, and social activity. No significant differences were found between those having CI surgery at an age younger than 13 years and those having CI surgery at an age older than 12’ (13) this may ‘speak to the possibility that significant patterns of deaf identification will emerge as young people with and without CIs grow older. This would accord with previous research indicating that children and young adults with a CI are ambiguous about their deaf identity’ (13). But also, I would like to remind at this point that even if other studies would come to another conclusion that age of implantation is indeed having an influence on the identity ‘that severe and profound hearing losses are usually detected at a very early age. Thus, children who are identified with a hearing loss when they are older (,) tend to have more mild or moderate hearing losses or to have developed a hearing loss later in life. Consequently, it is unclear how and to what extent age of hearing loss identification may impact children’s functioning, including in social and emotional areas’ (95).

Chapman et al. (89) and Dammeyer et al. (88) summarize from several studies performed, the life outcome, according to identity, which was the worst in those individuals associating themselves as a marginalized group and the best in a bicultural group. This bicultural group again had the highest outcomes of ‘measures of social relations, self-evaluation, academic achievement, and perceived family acceptance of their disability’ (89), whereas ‘deaf identity demonstrated an outcome at a level between those with a hearing and bicultural identity’ (89). Dammeyer et al. (88) yet found out that the difference in Well-being in the other three groups except the marginal group was not significantly different but when they measured the subjective feeling of being discriminated the marginal (the most likely to report a feeling of discrimination) as well as the Deaf identity (the second most likely to report a feeling of discrimination) felt the most this way. ’This finding resonates with theory and research in the field of social identity on the links between social group status and self-esteem’ (88) (13, 23).

7.4.3 Psychological Well-Being:

In the aforementioned large-scale survey by Chapman et al. (13) about the psychological well-being, which demonstrated that the group above 25 with a CI reported significantly higher levels of feeling limited than those without a CI. For those under 26, there was no significant increase in feelings of limitations weather they were young or old-childhood implantation (13).

Even though due to the large number this study is well representative, there are many studies with different approaches and results or further breakdown into a more detailed picture of psychological well-being and therefore I would like to mention those others too that appeared in my literature research.

For example, Huber et al. (74) assessed mental health problems of a CI group in comparison to a demographically matched group of NH group using the Strengths and Difficulties Questionnaire (SDQ), which evaluates social, emotional and behavioural issues in the age group of three to 17 years. In their study they continued with the approach that CI users (and the NH control group) would be rated by themselves, their parents and their teachers. The results draw a picture that 'mental health problems were rated significantly higher in CI adolescents compared to NH adolescents. Subsequent univariate analyses (...) revealed that these differences were attributable to (...peer problems), which were rated significantly higher in (all three rating groups)' (74). The significance in this domain was rated higher by teachers and lower by parents and adolescent (74). Regarding the issue of peer problems, the authors Duarte et al. (90) even concluded in their study, that bullying was expected in all those rating groups that were also used by Huber et al. (74) (90).

In comparison, the results of those three rating groups did not display a significant difference in the other areas assessed and even 'prosocial behaviour (PBS) ratings of any rater did also not differ between CI children and NH children' (74). Michael et al. (95) found that CI-using children had diminished levels of hyperactivity or inattention as well as less conduct problems in comparison to a DHH group using HAs (95). Also, Sarant et al. (92) came to the same conclusion as Michael et al. (95) but added the dimension of unilateral or bilateral CI implantation and found that those with two CIs had a better and less delayed psychosocial development (92).

An effect discovered by Duarte et al. (90) which could be influencing the results of Huber et al. (74), Michael et al. (95) and Sarant et al. (92) is 'that parents of normal-hearing children perceive that their children far worse in the Psychological Well-Being dimension than parents of deaf children with implants' (90).

Chao et al. (109) found both internalizing problems as depression and anxiety and externalizations for example aggression or rule-breaking diminished in CI users in comparison to the non-CI DHH control group. In comparison to Huber et al. (74), who observed externalizing behaviour (especially attention-related problems) and emotional problems to be still prevalent for implanted children (109). Also, Castellanos et al. (110) came to a similar conclusion but revealed as well in a '(r)egression analyses (...) that language, visual–spatial working memory, and inhibition–concentration skills predicted psychosocial outcomes. (...Those) findings suggest that underlying delays and deficits in language and executive functioning may place some CI users at a risk for difficulties in psychosocial adjustment' (110).

In a study on post-lingual deaf CI-recipients, their psychological state and the factors influencing it, Kobosko et al. (111) found that '(t)he majority of post lingually deaf subjects rated their CI satisfaction as high or very high, and this was at similar levels in younger and older subjects, as well as in those who had used CIs for either a short or a long time' (111). Haukedal et al. (106) found that, in general, an older age had a positive effect on the HR-QoL (106). As factors influencing the satisfaction with outcomes which Kobosko et al. (111) detected were a 'positive self-esteem, having less severe symptoms of depression, and the use of humour or self-distraction were conducive to CI satisfaction. Using a coping strategy of denial had a negative association with CI satisfaction. Coping strategies and symptoms of mental distress varied between younger and older subjects. For younger subjects, higher CI satisfaction was associated with lower severity of depressive symptoms, whereas for the elderly, higher CI satisfaction was associated with less severe social dysfunction symptoms' (111).

Another study indicating social dysfunction affecting young adults too is the one by Terlektsi et al. (112) which found that d/Deaf adolescents in the United Kingdom experienced positive and negative friendships. Several parent participants expressed concern about their adolescent children spending time alone and occasionally experiencing loneliness. This could be 'because speech communication is essential to friendship and peer interactions, a poorly intelligible deaf child with few friends or poor-quality social interactions may become lonely and experience other negative emotions that may impact both psychological development and quality of life' (96). Dammeyer et al. (88) even found that 20% of Danish adolescents with cochlear implants felt lonely often, or always. Exhibiting withdrawn behaviours may put d/Deaf adolescents at risk for diminished peer popularity or even acceptance (97, 75).

Those issues could cause the already aforementioned stigma, which again can be classified into internalized, enacted and anticipated types. Internalized stigma is if a CI user would have feelings of shame for himself or his identity as such. Enacted stigma is the experience of stigma and discrimination in past times. Anticipated stigma, on the other hand, is the expectation for the future to be discriminated (again). All three types can have a negative effect on the mental health, for example can facilitate depressive symptoms (89, 51) and could also lead to worse physical health as well as health compromising behaviours (113).

Mousley et al. (51) discussed the unique experiences of the deaf community regarding stigma, suggesting that they may exhibit different patterns of anticipated and enacted stigma compared to other marginalized groups. The study revealed that deaf-identity individuals experience significantly more enacted stigma than those with other concealable identities yet show only slightly higher anticipated stigma. This disparity may indicate that the burden of anticipating future discrimination is lessened for the deaf community due to their cultural pride and identity. In their study only low rates of internalized stigma reported by most of the deaf-identity participants, which could reflect a "floor effect" influenced by the prevalence of positive attitudes within the deaf community (51). To explain this phenomenon the social identity theory by Tjafel & Turner could be used again, to understand how a sense of oneself is correlating with the evaluation and relative status of an individual in the context of the social group it is belonging to. (23, 13). Chapman et al. (89) found that this effect could also have an influence on the mental health in CI users: 'Both the deaf and marginal identity groups reported high levels of feeling discriminated against (significantly higher than the other two groups) yet only marginal identity was associated with low levels of well-being' (89).

The same researchers found in another study in the same year, that there was not a significant difference detectable in well-being in the general group of CI users compared to the general population regarding well-being and self-esteem (13). In the research of Marschark et al. (69) again, that studied deaf college students, so CI users and non-users in young adulthood, they found that, there weren't significant differences in self-acceptance, perception of stigmatization or social participation between the two groups.

The last point I want to mention in this subchapter discussing the psychological well-being is that marginal groups such as those with additional disabilities, LGB members and people of non-white races are especially vulnerable to a worse psychological outcome due to the experience of "collateral discrimination" (1) (51, 74).

An indicator for that is, for example, that the highest number of those with additional disabilities can be found in the marginal identity group (13). (Annex 2) According to Archbold et al. (114) in centres in the UK and the Netherlands the rate of additional disabilities among CI children 'ranged from under 10% to between 40 and 60%' (114). This number is high and so the finding of Zaidman-Zait et al. (115) is concerning: they revealed that based on parent's proxy reports those children using CIs with additional disabilities tend to also have a significantly lower Quality of life than those only wearing CIs in all subdomains that were 'self-esteem, friend, school, and family HRQoL' (115) and they also experience mental health problems (74).

Mousley et al. (51) found that 'LGB and non-white participants reported greater depressive symptoms than heterosexual and white participants' (51). (For comparison see Annex 6)

Already mentioning, what effect a marginal identity, and a perceived stigma could impact the well-being of a CI user, I would like to discuss in the next subcategory of this subchapter the different views on being D/deaf and their influence on an individual's life.

7.4.4 Deaf as Disability versus Culture:

I would like to start this subchapter from a more philosophical point of view, like it is represented by Ochsner et al. (12), according to who the CI functions as a “boundary object” or a “quasi-object”, meaning it serves as a ‘meta(-)stabilized medium of translation’ (12) that bridges and coordinates the social, cultural, and technological realms. While the CI is designed to help individuals with hearing impairments “transform” into competent, “normal hearing subjects” (12), it also plays a crucial role in reinforcing the asymmetrical structures inherent in the discourse surrounding disability. The CI, in this sense, is not merely a medical tool but a symbol that mediates between intersecting social worlds, particularly those of the deaf and hearing communities (12).

Given the prominence and impact of the CI in both medical and social contexts, it is essential to critically examine its role in the ongoing debate which often hinges between the two extremes of whether deafness should be understood as a medical condition that requires intervention or as a cultural identity that should be respected and preserved. The CI, as a transformative yet controversial technology, occupies a central place in this debate. It challenges traditional notions of disability while simultaneously perpetuating the idea that deafness must be ‘normalized’ through medical intervention. Thus, it is crucial to discuss the implications of the CI not only as a medical advancement but also as a cultural and social artifact that shapes and is shaped by the broader discourse on deafness and disability.

Mauldin et al. (30) tried to explain the “meaning of deafness” (30) by using the “sociological concept of medicalization” (30): ‘Conceptualized medicalization (...) (is) the expansion of powerful medical knowledge into ever more areas of life. Labelling something as medical problem is also a key feature of medicalization (...) (of which a working definition is) defining in medical terms (...and) language to describe a problem, adopting a medical framework to understand a problem, or using a medical intervention to treat it. (...)(T)he essence of medicalization is definitional, although this does not mean it is static. For example, (...) a variety of conditions that were once seen as medical problems but have now largely been de-medicalized, such as homosexuality. This is mainly because of the gay and lesbian movement’s fights to remove homosexuality from the purview of medicine’ (30). ‘This also applies for concepts of dis/abilities, which cannot be considered as being prefabricated then applied and attributed to humans regardless of the socio-technical context. (...Being) disabled [and normal] is not something one is, but something one becomes and, further, that disability is ordered and enacted in situated and quite specific ways’ (12).

Deaf activists have protested viewing not-hearing as a disability that induces isolation and hardship but instead that deafness is a unique culture that brings the opportunity of personal growth and solidarity with other similar individuals (89, 51). Deaf Critics distinguish between 'deaf' (with a lowercase 'd'), which refers to the 'audiologic lack of hearing' (12) and 'Deaf' (with an uppercase 'D'), which denotes a cultural identity. Members of the Deaf community share essential cultural elements, including a common language, history, and institutions such as schools, clubs, and media. Due to these shared cultural establishments, many Deaf individuals primarily socialize within their own community, often having 'limited social interactions with people from the majority culture' (12). This cultural cohesion is reflected in personal relationships, with 'ninety-five percent of Deaf marriages involve two deaf partners' (12). For many in the Deaf community, their deafness enables membership in this supportive environment. While stigma can pose significant challenges to the well-being, it also provides an 'opportunity to cultivate new and stronger coping skills, a deeper sense of purpose, and stronger bonds with similarly marginalized others' (51). Research on Deaf Gain described by Bauman and Murray (104) suggests that, although deafness involves a loss of hearing it can enhance linguistic dexterity, sensory perception and cultural connections (104). From a Deaf Gain perspective, being deaf is celebrated as a cultural and social identity rather than viewed as an impairment or a disability (104, 51, 65). Indeed, according to the NAD (National Association of the Deaf), many Deaf people want, like to be and are proud to be Deaf (12).

The perspective of the Deaf community is that oral speech and hearing 'should (...) be considered mere constructions of specific hearing communities' (12) and 'are not necessarily the natural and normal conditions of human communication' (12). 'In this conceptualization, the medical construction of deafness as a disability (is) to be overcome (by) a social construction of deafness as a characteristic way of life' (12). Cooper et al. (67) is elaborating their view of the Deaf community on the implants further: 'Not only do many Deaf culturalists find the assumption that they need to be "fixed" or "cured" insulting, but some also contend that cochlear implant technology threatens to destroy their culture' (67).

The feeling of being inferior or incomplete is strengthened by the issue that d/Deaf individuals frequently face marginalization in various aspects of life. In the workplace, they experience significantly higher rates of being 'fired (…) or not hired in the first place' (51) compared to their hearing counterparts.

Additionally, while much stigmatization comes from strangers, also in the closer relations deaf individuals face mistreatment by friends and family. Deaf children with hearing, non-signing parents often struggle to understand or engage in spoken conversations, leading to exclusion from family discussions. This exclusion is so prevalent that deaf individuals refer to it as "dinner table syndrome" (51) describing the isolation they feel when unable to join family conversations due to the lack of accessibility to spoken language (51).

Indeed, the prevalence of Deaf individuals feeling this way also could be explained by the high number of about 90% of deaf born children that are born into a family of hearing parents (30, 67, 51). Those parents again, are having an increased ‘desire for their child to develop spoken language. And that desire for the acquisition of spoken language has been documented as the most significant factor in the decision to implant’ (30). The higher rate of hearing parents of d/Deaf children also means that the ‘cultural transmission of Deaf culture does not occur within families, but rather, through Deaf institutions’ (67), for example of hearing parents 80% never learn Signs language (51). So, cochlear implants will, with high probability, lead to a decline in people possessing the ability to communicate via sign language, causing a fear within the D/deaf community that the culture will disappear with less and less people also participating in Deaf institutions (67).

On the other hand, there is the argument that it is selfish and immoral of parents to hold back the CI for their offspring solely because they would like to preserve a culture (67).

Generally, many parents have problems deciding and then being contend with their decision. ‘Because parents cannot predict the outcomes of their child's life and the effect the implant has on their identity, many parents at least once in their decision-making process question whether their child would blame the parent for deciding whether they belong in one community or not’ (58). Also, for hearing parents, they never can fully understand being deaf, making it difficult to be part of the deaf community for/ with their child. ‘There seems to be a clear division between those who belong to both the ‘d’eaf community and the ‘D’eaf community. Several parents (in their studies interviews) discussed (with the researchers) how it is difficult to be part of both communities simultaneously. They feel as though they must choose which community they want their child to be a part of indefinitely. Many parents who are hearing and have a d/Deaf child expressed that they sometimes feel ostracized from the Deaf community and culture no matter how hard they try to learn American Sign Language (ASL) and to be involved with the culture’ (58).

The ethical implications of implanting CIs in deaf infants, have sparked debate, with some viewing it as a form of “forced implantation” (12) also could influence the parents’ decision making. Critics argue that this procedure contributes to a form of “sociocultural genocide” (12), where the CI becomes a tool of power that “normalizes” deaf individuals and forces them to assimilate into the hearing majority. This process, as critics claim, shifts the child away from natural forms of communication, such as sign language, to an “artificial hearing status” (12) that does not guarantee full acceptance in the hearing community. Instead of fostering integration, the forced use of CIs can reinforce the perception of deaf people as ‘“other”, “different” or “disabled” ‘(12). Visual portrayals of successful communication with the implant, especially in parental guides, paradoxically highlight the CI as a visible marker of deafness, suggesting that the individual is not a D/deaf person anymore once implanted. (12)

But not only in something as specific to CI-users and deaf-people as parental guidelines also the general media and Pop-culture draw a negatively-connotated picture of the typical deaf person as a lonely, embarrassing and sometimes comical individual that reduces them to their hearing impairment instead of viewing them in all dimensions of their humanity (51).

A new phenomenon, especially occurring with social media, are cochlear implantation videos. ‘While many people object to cochlear implant activation videos on the basis that they are sensationalizing and reductive, others oppose them for being oppressive and offensive’ (67). Under many of those videos the comment section is filled with angry comments of Deaf members that dislike the view on repairing Deafness (67). The anger is stemming from that first-time activation videos serve as a standardization procedure, demonstrating how a “non-hearing patient” (12) can be transformed into an individual with “normal auditory perception” (12) and, by extension, a person with “normal capacities” (12). This process is framed as an act of “normalizing (re-)humanization” (12), grounded in the assumption that “specific human and therefore natural (or normal) hearing” (12) is a fundamental aspect of subjectivity. The CI, therefore, offers the potential for individuals to integrate into the “hearing world” which is differentiated from the “non (-) hearing or deaf world” (12). This transformation creates new biosocial identities and necessitates the establishment of new boundaries between the hearing, non-hearing, and CI-hearing world (12, 29).

Ochsner et al. (12) is presenting “Little Drake’s Cochlear Implant Activation” video which illustrates a typical example of CI activation video. In the video, the audiologist remains mostly off-screen while the child sits on the mother's lap playing with a toy. When the CI is switched on, eye contact is made first between the sound source (the audiologist or computer) and the child, then between the mother and the child, and finally between the camera (representing the father or spectator) and the child. The moment is often accompanied by emotional music, emphasizing the significance of the event. Notably, as with many similar videos, there are no subtitles or sign language translations, commented by the authors that ‘deaf people are obviously not addressed’ (12).

Figure 5 by Ochsner et al. (12): Drake’s CI activation video:

“Little Drake’s Cochlear Implant Activation” is illustrating a typical example of CI activation video. In the video, the audiologist remains mostly off-screen while the child sits on the mother's lap playing with a toy. When the CI is switched on, eye contact is made first between the sound source (the audiologist or computer) and the child, then between the mother and the child, and finally between the camera (representing the father or spectator) and the child. The moment is often accompanied by emotional music, emphasizing the significance of the event.

According to Cooper (67) which is using the approach of the bioethicist Wildes, we are not able to categorize any perspective on CI as “right” or “wrong” due to our ‘morally pluralistic society’ (67). They recommend to ‘accept moral ambiguity and cultivate open-mindedness and empathy’ (67).

7.5 Economic Stability

‘Economic stability can influence health outcomes both individually and within a household. Elements of economic stability include employment and income, SEP, as well as food and housing security. These elements can impact one's health through various avenues. First, employment directly affects a household's economic stability by providing not only income but also insurance coverage and other benefits. An employed individual or household could still have a low SEP and thereby limited access and availability of information and resources to manage health conditions, such as hearing loss’ (1).

Individuals or families with limited financial resources often deprioritize healthcare, even when it is financially accessible (116, 1). Families near the poverty line utilize fewer medical services, including hearing care for deaf or hard-of-hearing children (64, 1).

‘In a national electronic survey of paediatric CI audiologists, low SES (socioeconomic status) was identified as a contributing factor to decreased speech and language outcomes by 78% of responders’ (44). The limited access is evident in the lower rates of CI surgeries among children from low-income families, despite their higher prevalence of hearing loss (117).

SEP is also linked to delayed implantation and subsequent disparities. Children from low-income families experience more post-surgical complications, are less likely to follow up on appointments, and often only receive unilateral implants, which limits their auditory development compared to peers from higher SEP backgrounds (64, 1). This trend also extends to adults, who show poorer speech perception post-implant if they are from lower SEP backgrounds (64).

The high costs associated with cochlear implants and their maintenance place an additional financial burden on families. For many users, the short battery life and replacement costs of CIs can be stressful, as sudden battery failure leaves users temporarily deaf, creating a sense of vulnerability (65). Beyond batteries, other costs include rehabilitation, speech therapy, school accommodations, and insurance, leading some families to accrue significant debt to cover these needs (60). Accessories for CIs, such as cables to connect the CIs to media players or remote controls, come with a high price tag, which some patients feel is unnecessarily inflated by manufacturers (12).

Another advantage of a higher SES, and, with it, typically better health literacy, is that it provides CI users or the parents of CI-wearing children with social capital in the form of an increased number of available resources, facilitating positive outcomes (79). For example, socioeconomic advantages enable proactive rehabilitation approaches, by providing time and money, ultimately benefiting hearing-impaired children (77, 1, 10, 44, 30).

As I already described the reimbursement issues in in the subchapter of Healthcare access and quality, I now would like to specify more into the cost itself and if the expenditure that must be made to receive and maintain a CI.

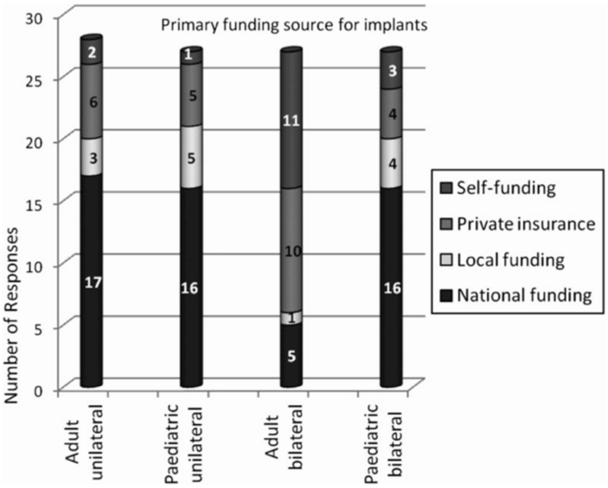
Cost-utility varies significantly across countries due to differences in criteria, coverage, and threshold valuations for Quality-Adjusted Life Years (QALY) (118).

Crowson et al. (29) in their research about cost effectiveness of CIs in the Us and Gatto et al. (119) in Europe both found that unilateral cochlear implantation shows consistent health utility gains and is deemed cost-effective, but bilateral CI interventions offer only moderate utility increases relative to their doubled cost (29, 119). For them it was challenging to explain why a technology widely regarded by patients and some researchers (92) as transformative CI have like bilateral CI, does not lead to notable increases in utility scores. One possible reason is that the tools used for assessment do not fully reflect the communication benefits provided. Even specialized measures for certain conditions may overlook the subtle yet significant ways in which binaural hearing enhances social interactions and connectivity (29).

Different to the other countries analysed, Gatto et al. (119) reported of one country, Switzerland, for which a more detailed analysis was performed for unilateral vs. bilateral implantation. In this analysis they found that ‘considering the age variations’ (119), ‘performing unilateral CI is cost-effective up to the age of 90, while sequential CI remains cost-effective up to ages 87–85’ (119) (120).

Vickers et al. (35) conducted an international survey in 17 countries including ‘Argentina, Australia, Belgium, Bosnia Herzegovina, Brazil, Finland, Germany, India, Italy, The Netherlands, New Zealand, South Africa, Spain, Switzerland, Portugal, United Kingdom, and The United States of America’ (35.). They found out that ‘(r)results showed differences in the funding model between countries. Unilateral implants for both adults and children and bilateral implants for children were covered by national funding in approximately 60% of countries (30% used medical insurance, and 10% self-funding). Fewer countries provided bilateral implants routinely for adults: national funding was available in only 22% (37% used medical insurance and 41% self-funding). Main evolving candidacy areas are asymmetric losses, auditory neuropathy spectrum disorders and electro-acoustic stimulation. For countries using speech-based adult candidacy assessments, the majority (40%) used word tests, 24% used sentence tests, and 36% used a mixture of both. For countries using audiometry for candidacy (70–80% of countries), the majority used levels of 75–85 dB HL at frequencies above 1 kHz. The United Kingdom and Belgium had the most conservative audiometric criteria, and countries such as Australia, Germany, and Italy were the most lenient. Countries with a purely self-funding model had greater flexibility in candidacy requirements’ (35).

Figure 6: chart by Vickers et al. (35) on unilateral or bilateral CIs are funded in paediatric or adult population:

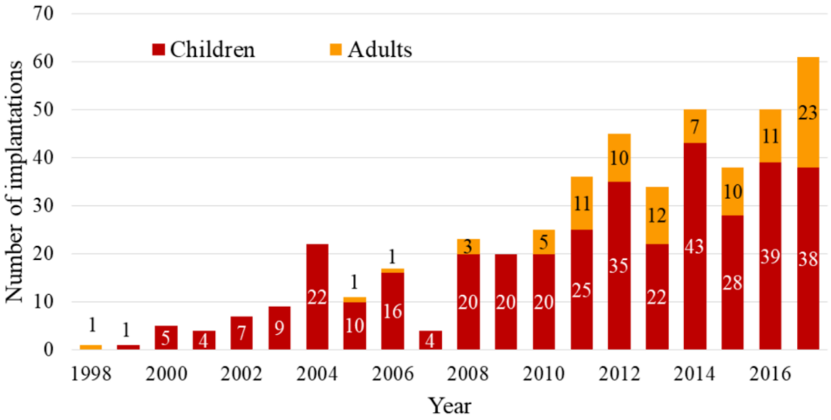


This chart is representing the numbers of countries that are funding weather one or two CIs in weather adults or children when calculating together the number in one column. The manner of funding corresponding to the number of countries is shown in the column sections.

In Lithuania, for example to describe one country more particularly, the accessibility of cochlear implants is high, with relaxed criteria for implantation and full reimbursement by the Compulsory Health Insurance Fund. For instance, the audiometric hearing threshold for both children and adults must be at least 55 dB within the 500–4000 Hz frequency range, along with the proven ineffectiveness of conventional hearing aids. In contrast, patients in Austria, Belgium, Japan, Spain, the United States, and several other nations must meet a minimum threshold of 70 dB (18). And in Lithuania this support is steadily increasing (Status 2019) to meet growing demand (18, 8). This is also showing that the choice who is receiving a CI is highly dependent on what nationality a patient is.

Figure 7: by Mataitytė-Diržienė et al. (8) on CI- implantation numbers in Vilnius and Kaunas:

Figure 2. CI prevalence in Lithuania



Data source: Kaunas and Santara Clinics, 2018

The graph above shows the published Numbers (Status 2018) by Vilnius and Kaunas university clinics showing increasing numbers of cochlear implants in both paediatric and adult populations from 1998 to 2017 (8).

The base price in Lithuania for a cochlear implant is ranging from 21,945.09 € (Type II) to 25,486.56 € (Type I) and is fully reimbursed including implantation set used during surgery and taxes coming along with it. The devices must be sourced from companies contracted with the National Health Insurance Fund (VLK) to ensure compliance with quality and pricing regulations. (18, translated by Chat GPT)

If a patient or their legal guardians choose a hearing implant or spare processor that exceeds these base prices due to enhanced technological features, they are required to pay the price difference directly to the supplier. (18, translated by Chat GPT) This could lead to that a person with a higher SEP can afford a certain model that can give him advantages over the reimbursed model while still using the money in the height of the regularly reimbursed CIs. Yet, the patient must take the risk of receiving not nationally quality-approved model.

The implantation procedure can only be carried out by healthcare institutions authorized by the Ministry of Health located in Kaunas and Vilnius. (18, translated by Chat GPT) This again could be an additional barrier for families in a lower socioeconomic position or those living in more rural areas because the travel to such a CI centre is demanding time and money.

Spare processors can be replaced with reimbursement after a minimum of five years. However, under specific conditions, an earlier replacement is possible if the originally provided processor is no longer functional and cannot be repaired, or if a medical necessity requires switching to a different model. In such cases, the patient must apply to a registered institution with the required documentation, which will then assess compliance with the original criteria established when the first implant was received. (18, translated by Chat GPT) A lower SEP and a mostly decreased health literacy connected with that carries the risk of incompliance of CI usage and documentation in CI parents or adults could lead to a higher malfunction rate in socioeconomically disadvantaged individuals.

The implant package provided after surgery includes components besides the cochlear implant kit and CI sound processor such as a protective processor holder, a storage box, a test rod, six batteries, a processor maintenance kit, left and right-side marking stickers, and a full documentation set. (Informational exchange via email with Ramutė Baklanova, Chief Specialist of Department of Centrally Reimbursed Medicines of the Ministry of Health of the Republic of Lithuania, translated by Chat GPT.) For example, the quite low number of batteries could lead to the already mentioned threat to lower SEP-individuals of not being able to afford enough batteries.

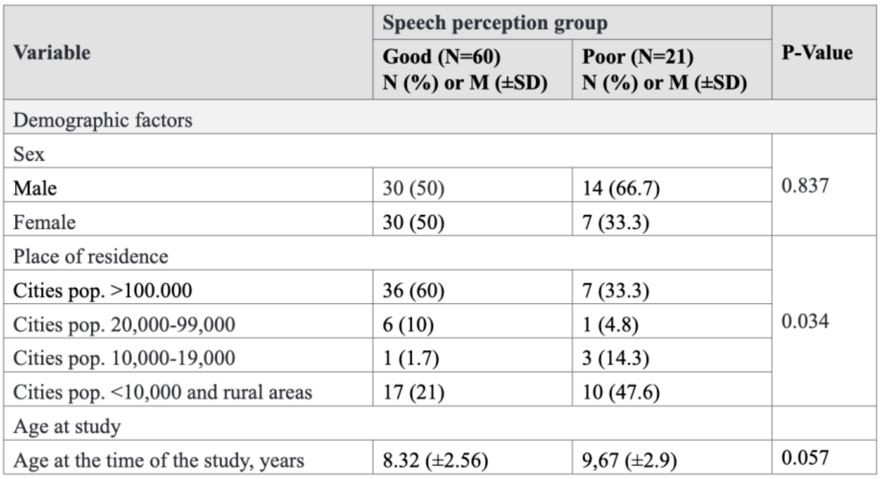
All those findings present the inequality in reimbursement rates of CIs among different countries and SEP-groups due to local, social, financial, and political differences (43, 121). Generally, the statement could be made that CI interventions have shown a positive return, particularly when implanted unilaterally in working-age individuals, as they contribute to societal and economic productivity. For children, early intervention is especially cost-effective due to the long-term benefits in speech, language development, and potential future earnings (29, 118). Yet, it is questionable, to what extent economic considerations should affect the medical decision-making.

7.6 Neighbourhood and Physical Environment

Neighbourhood characteristics, including access to education, job prospects, crime levels, food availability, and the quality of medical services, shape the environments in which cochlear implant patients reside. Each element is influencing their overall health (1).

As shown in the study of Vilnius University by Stumbrys et al. (9) the '(d)descriptive statistics results showed that the speech perception level differed significantly by place of residence (p=0.034). The majority (60%) of children in the good speech perception group lived in five largest cities, whereas 47.6% of children from the poor speech perception group resided in small cities and the rural areas' (9).

Table 2: by Stumbrys et al. (9) showing the correlation of place of residence and good or poor speech perception:



Variable	Speech perception group		P-Value
	Good (N=60) N (%) or M (±SD)	Poor (N=21) N (%) or M (±SD)	
Demographic factors			
Sex			0.837
Male	30 (50)	14 (66.7)	
Female	30 (50)	7 (33.3)	
Place of residence			0.034
Cities pop. >100.000	36 (60)	7 (33.3)	
Cities pop. 20,000-99,000	6 (10)	1 (4.8)	
Cities pop. 10,000-19,000	1 (1.7)	3 (14.3)	
Cities pop. <10,000 and rural areas	17 (21)	10 (47.6)	
Age at study			
Age at the time of the study, years	8.32 (±2.56)	9,67 (±2.9)	0.057

Stumbrys et al. (9) parted their participants into the place of residence by different city sizes and their distribution into the good and poor perception groups.

Moreover, children seemed to be influenced by the frequency they had to use speech regularly, so that children with a poorer speech perception tended to visit specialized facilities such as kindergarten and schools and used more often total communication meaning ‘spoken, signed, and written’ (9) ‘modalities of communication’ (9). On the other hand, children visiting regular facilities and participating more often in speech and language therapy, meaning having a regular and prepared access to speech had better perception of speech (9, 22, 44). For example, Noblitt et al. (44) came to the results in their research that rural children only received in 10% therapy services at the time of diagnosis compared to 42% of urban children while for 86% of rural children school-based therapy was the only option available compared to half of the children living in cities that had the possibility to access speech services through various means. Due to those disparities Noblitt et al. (44) concluded that ‘rural children overall are often delayed in receipt of cochlear implant rehabilitation services’ (44).

Noblitt et al. (44) found that ‘distance was a significant barrier to audiology services for rural participants compared to urban participants’ (44), with 71% of rural participants reporting over an hour of travel to their CI audiologist versus 23% of urban participants. Yorgun et al. (59) is even mentioning that in their study in Turkey ‘81.3% of parents had problems with transportation to the implantation centre’ (59).

Factors which had an influence on the service utilization, and which were potentially affecting language development too, besides the increased travel and cost, were the socioeconomic status, insurance type, and parental education that made the two groups differ from one another (44, 115, 123).

Cities give more possibilities of choices among paediatric care facilities as kindergartens or schools and the parents can choose which one fits their CI-using child by the amount of non-electrostatic toys, the understanding of teachers of their situations or even by their experience with other children using hearing devices as well (66). But also choosing the right care facility requires time and money, meaning that the socioeconomic status of the parents is having a strong influence on the surrounding of their CI-wearing child.

An influence of the educational difference between the urban and the rural group of parents could be reflected in that the rural group of children experienced more frequent mechanical complications with their implants, 70% vs. 33% (44). In general, a less educated population is more likely to live in rural areas (122). The influence on parental education or Health Literacy was discussed before in the subchapter of Education Access and Quality.

Similar results to children could also be found in the adult population, in which CI interventions are also delayed due to decreased access in rural areas when comparing them to their urban peers. I wanted to mention them here separately because especially in rural areas the age average is increasing and with that also age-related hearing loss (1, 32, 31, 123).

Supposedly it could be too that CI citizens, both children and adults are forced to speak with a greater variety of conversation partners in more variable environments, hence are more adapted to different speech perceptions.

CI users living in non-urban areas are also less connected to other HH/ CI individuals as generally there is lower numbers of individuals residing there. Already mentioned before, in the identity subcategory of the social and community subchapter, this being alone with this obstacle in the everyday with “normally” hearing people could lead to feelings of isolation both, for the affected person itself as well as for its relatives (123).

A group that shouldn’t be forgot to be mentioned are adolescents, that are especially vulnerable to this subjective isolation because in their age usually experiencing increasing independence from their families with also enhances the self-identification with groups exterior to their circle of relatives. Parents face difficulties finding extracurricular activities in which their children could take part in (98). Wong et al. (79) is mentioning that it is necessary in their age to form social bonds outside of their daily life of family and school and that’s why the neighbourhood and community is so important for them. Often teenagers feel like their contributions to society are invisible to others. As before already mentioned this subjective exclusion from society is also manifesting in many objective forms of violence, for example bullying (79).

For all ages of CI patients, despite their location in an urban or rural area, the quality of housing is detrimental as environmental factors such as a steady high noise state, infections or chronic diseases are enhanced in poorer living conditions, especially in cities in lower income countries. Those factors named could be the reason for a hearing loss itself or the worsening of such (124).

Areas of poorer living conditions also frequently lack adequate hearing healthcare professionals. Additionally, transportation options to healthcare facilities are often insufficient in such underresourced neighbourhoods. Especially communities with higher proportions of non-white residents often have fewer resources that support health (1, 125, 126).

8. Conclusions

This literature review presents both strengths and limitations in its analysis of the social determinants of health affecting cochlear implant patients. One limitation is that the scope was not narrowly defined by a specific topic, leading to a broad approach rather than a focused investigation. Additionally, many of the sources used, particularly those discussing the social and community context, rely on older literature. This is because much of the foundational research on social phenomena, including identity formation within marginalized communities, was conducted between the 1980s and 2010. Movements that shaped collective identities, such as the Black civil rights movement beginning in 1954 and the Deaf cultural minority movement emerging in the 1970s, prompted significant academic exploration during this period. As a result, many of the theories referenced in this review stem from that time frame.

Despite these limitations, this literature review offers a comprehensive understanding of the social challenges faced by cochlear implant patients. It explores the factors contributing to these challenges and highlights the inequalities that exist between different patient groups as well as within the broader deaf community navigating a predominantly hearing world. By analysing disparities in access, utilization, and outcomes, this review underscores the importance of considering social determinants of health in cochlear implant care.

The five domains of social determinants of health influence hearing health and healthcare access through various mechanisms over the lifespan. These factors impact when and how patients receive cochlear implants and play a role in explaining differences in post-implantation outcomes. Currently, the collection of social determinants of health data has not been a standard part of cochlear implant candidacy assessments or postoperative evaluations. However, there is a critical need to better understand how these determinants affect access and utilization of CI-related services. This knowledge can guide CI teams in designing targeted interventions, programs, and policies aimed at reducing disparities. The use of validated tools to systematically assess health-influencing factors within these five domains can support a more equitable approach to cochlear implantation. Achieving equity in access, utilization, and outcomes depends on whether this information is effectively integrated into clinical practice and healthcare policies.

9. Recommendations

To ensure equitable access to cochlear implants (CIs) and improve patient outcomes, Europe-wide candidacy criteria should be implemented, incorporating speech perception tests in various sound environments along with quality-of-life measurements post-implantation. Establishing European-wide CI registries will allow continuous quality control and the identification of factors influencing long-term CI outcomes. Additionally, a detailed comparison of reimbursement practices across European countries is essential to address disparities in access to CIs. Standardized psychosocial assessments and clinical interventions should be developed to support CI users, especially children, in managing psychosocial challenges post-implantation. Further, social factors influencing CI access and outcomes must be investigated, with a focus on discrimination and healthcare inequities. Research on the etiological profile of paediatric CI users can refine treatment strategies, while machine learning-based CI referral algorithms could enhance candidacy selection and bridge existing care gaps. Health literacy interventions should be strengthened to improve communication between professionals and patients, ensuring accessibility to critical health information. Parental health literacy also plays a key role in paediatric CI patient outcomes, necessitating targeted educational programs. Additionally, cognitive research should be encouraged to explore factors influencing speech perception in CI users to enhance rehabilitation strategies.

Educational access for CI users must also be improved. Studies examining the correlation between parental education levels and CI outcomes in children can help refine educational support strategies. Support programs focusing on spoken language development and sound optimization are crucial for school integration and peer interaction. Inclusive educational practices should be established to encourage classroom participation and extracurricular involvement for CI users. Addressing bullying and discrimination against deaf and hard-of-hearing students, including those with CIs, through targeted anti-bullying initiatives is essential. Further research into cognitive factors influencing speech perception in adult CI users can optimize rehabilitation and counselling methods. Additionally, educating teachers on effective teaching strategies for CI students and ensuring training in special education for all teacher candidates will enhance learning outcomes.

Economic stability plays a vital role in equitable hearing healthcare. Ensuring affordable access to hearing healthcare services, particularly for marginalized and socioeconomically disadvantaged groups, is crucial. Economic losses resulting from health inequities in CI access and rehabilitation should be quantified to advocate for necessary policy changes. Furthermore, using CI prevalence data for cost-benefit analyses can highlight the value of investing in equitable CI care.

The social and community context significantly impacts CI users’ experiences. Public awareness efforts should be strengthened to promote social inclusion and prevent misconceptions about deaf and hard-of-hearing individuals and CI users. Community-building initiatives, such as CI camps, can facilitate social bonding. Additionally, enhancing emotional language skill development in CI children can improve their social functioning and reduce behavioural challenges. Supporting young CI users in identity development is key to preventing social isolation and marginalization, and fostering social inclusion initiatives can provide positive social identification opportunities. Routine CI evaluations should integrate psychosocial adjustment assessments, especially for children with speech intelligibility difficulties, and intervention programs should address both speech intelligibility and psychosocial well-being. Social inclusion programs aimed at reducing loneliness among CI users, drawing from successful deaf-specific camps, should also be implemented. Recognizing deaf culture and sign language in medical and psychology education curricula can enhance societal understanding of DHH experiences. Expanding specialized services for CI users with additional disabilities will ensure access to communication, social, and academic support. Additionally, structured peer networks and professional counselling should be provided to support families of CI users emotionally and informationally.

Improving the neighbourhood and physical environment is equally important. Addressing hearing healthcare disparities in rural areas requires enhanced access to CI services and speech therapy. Mobile or telehealth services should be developed to reduce barriers for rural CI users, and families in these areas should receive compensation for travel costs associated with CI services and rehabilitation. Disability awareness, including DHH experiences, should be incorporated into teacher training programs to foster inclusive education. The availability of sign language interpreters in schools should be increased to ensure accessibility. Adhering to WHO Housing and Health Guidelines can help improve the living conditions of CI users worldwide. Additionally, public spaces and institutions should enhance accessibility by providing assistive listening technology and visual alert systems for CI users.

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11. Annexes

Annex 1: from Loth et al. (3): table presenting countries of Europe and indicating in which ones Guidelines or CI registries are present

Number	Country	Population	Guideline (G)/Registry (R)	
1	Albania	2,875,000	–	–
2	Austria	9,041,000	–	–
3	Belgium	11,623,000	G	–
4	Bosnia	3,367,000	–	–
5	Bulgaria	9,613,000	–	–
6	Byelorussia	9,447,000	–	–
7	Croatia	4,088,000	–	–
8	Cyprus	1,213,000	–	–
9	Czech Republic	10,722,000	–	–
10	Denmark	5,805,000	G	–
11	Estonia	1,327,000	–	–
12	Finland	5,546,000	–	–
13	France	65,370,000	G	R
14	Germany	83,964,000	G	–
15	Great Britain	68,127,000	G	–
16	Greece	10,389,000	–	–
17	Hungary	9,643,000	–	–
18	Iceland	342,000	–	–

continued

19	Ireland	4,975,000	G*	–
20	Italy	60,402,000	G	–
21	Kosovo	1,768,000	–	–
22	Latvia	1,872,000	–	–
23	Lithuania	2,697,000	–	–
24	Luxembourg	632,000	–	–
25	Macedonia	2,083,000	–	–
26	Malta	442,000	–	–
27	Moldova	4,027,000	–	–
28	Montenegro	628,000	–	–
29	Netherlands	17,160,000	G	R
30	Norway	5,450,000	–	–
31	Poland	37,818,000	–	–
32	Portugal	10,176,000	G	–
33	Romania	19,152,000	G	–
34	Russia	145,976,000	G	–
35	Serbia	8,713,000	–	–
36	Slovakia	5,461,000	–	–
37	Slovenia	2,079,000	G*	–
38	Spain	46,766,000	G	–
39	Sweden	10,141,000	G	R⁺
40	Switzerland	8,697,000	G	R
41	Turkey	84,958,000	G	–
42	Ukraine	43,559,000	–	–

From 42 countries only 16 had established CI criteria Guidelines and only 4 had registries.

(- countries where only one hospital with a CI program could be identified and the CPG was published for this hospital; + - registry for children only)*

Annex 2: research results by Chapman et al. (89) Correlation of identity group with other parameters

Table 1. Descriptive analysis of the psychological well-being score and the other variables for each of the identity groups

	Identity group			
	Deaf (*n* = 246)	**Hearing (*n* = 189)**	**Bicultural (*n* = 256)**	**Marginal (*n* = 51)**
Psychological well-being (range 0–100, 0 = low) *M*(*SD*)	65.5 (18.4)	66.0 (18.1)	66.9 (18.6)	46.9 (16.9)[a]
Gender (male) *n*(%)	120 (48.8)	94 (49.7)	122 (47.7)	17 (33.3)
Age (years) *M*(*SD*)	38.9 (13.8)[b]	47.0 (14.4)	45.1 (13.4)	40.2 (13.7)[c]
Type of school attended (range 1–5, 1 = Deaf school) *M*(*SD*)	1.5 (1.0)[a]	4.4 (1.2)	2.4 (1.7)[b]	3.1 (1.7)[c]
Additional disability (yes) *n*(%)	67 (27.2)	69 (36.5)	87 (34.0)	27 (52.9)[c]
Sign language (range 1–5, 1 = very good) *M*(*SD*)	1.4 (0.6)[a]	2.4 (0.8)	1.8 (0.7)[b]	2.1 (0.7)
Hearing loss (range 1–4, 1 = profound) *M*(*SD*)	1.5 (0.7)[a]	2.0 (0.8)	1.8 (0.8)[c]	1.8 (0.8)
Education level (range 1–8, 1 = lowest) *M*(*SD*)	4.6 (2.1)[c]	5.2 (2.2)	4.4 (2.2)[c]	4.8 (2.1)
Parents' hearing loss (yes) *n*(%)	48 (19.5)	47 (24.9)	40 (15.7)	9 (17.6)
Feel discriminated (range 1–4, 1 = always) *M*(*SD*)	2.3 (0.8)[b]	2.8 (0.9)	2.6 (0.9)[c]	2.0 (0.7)[b]
Cochlear implant (yes) *n*(%)	41 (16.7)[a]	99 (52.4)	81 (31.6)[c]	20 (39.2)

[a]Significant lower/different than all other three groups, by *t*-test, Kolmogorov–Smirnov, or χ^2.

[b]Significant lower/different than two other groups, by *t*-test, Kolmogorov–Smirnov, or χ^2.

[c]Significant lower/different than one other group, by *t*-test, Kolmogorov–Smirnov, or χ^2.

Here it is shown what educational level each identity group had in average & that the marginal group contains the most participants with an additional disability (89).

Annex 3: Table from Ketelaar et al. (94) results of research about Moral emotions and their correlation with language abilities and social functioning.

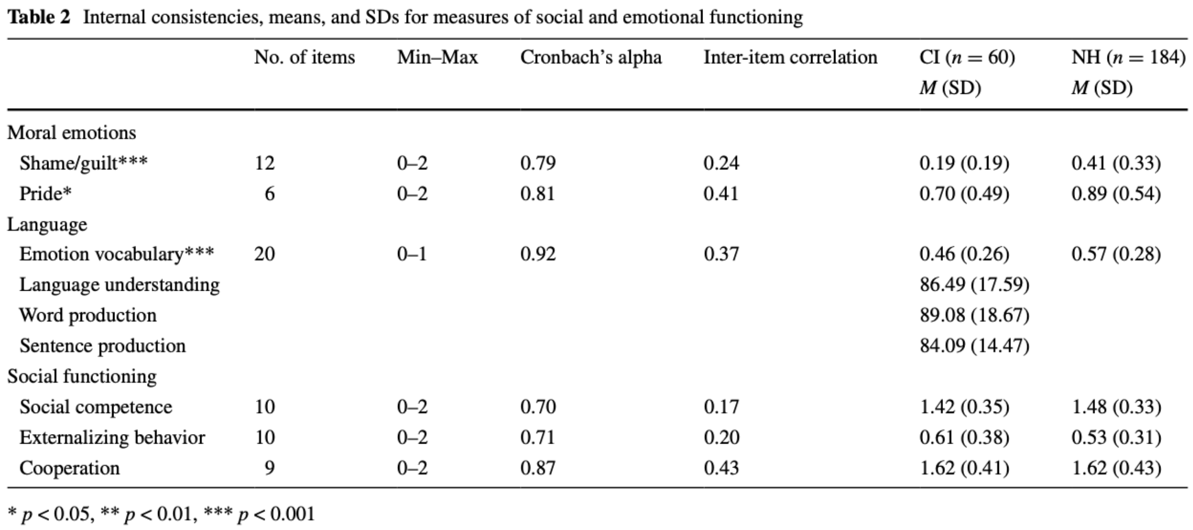


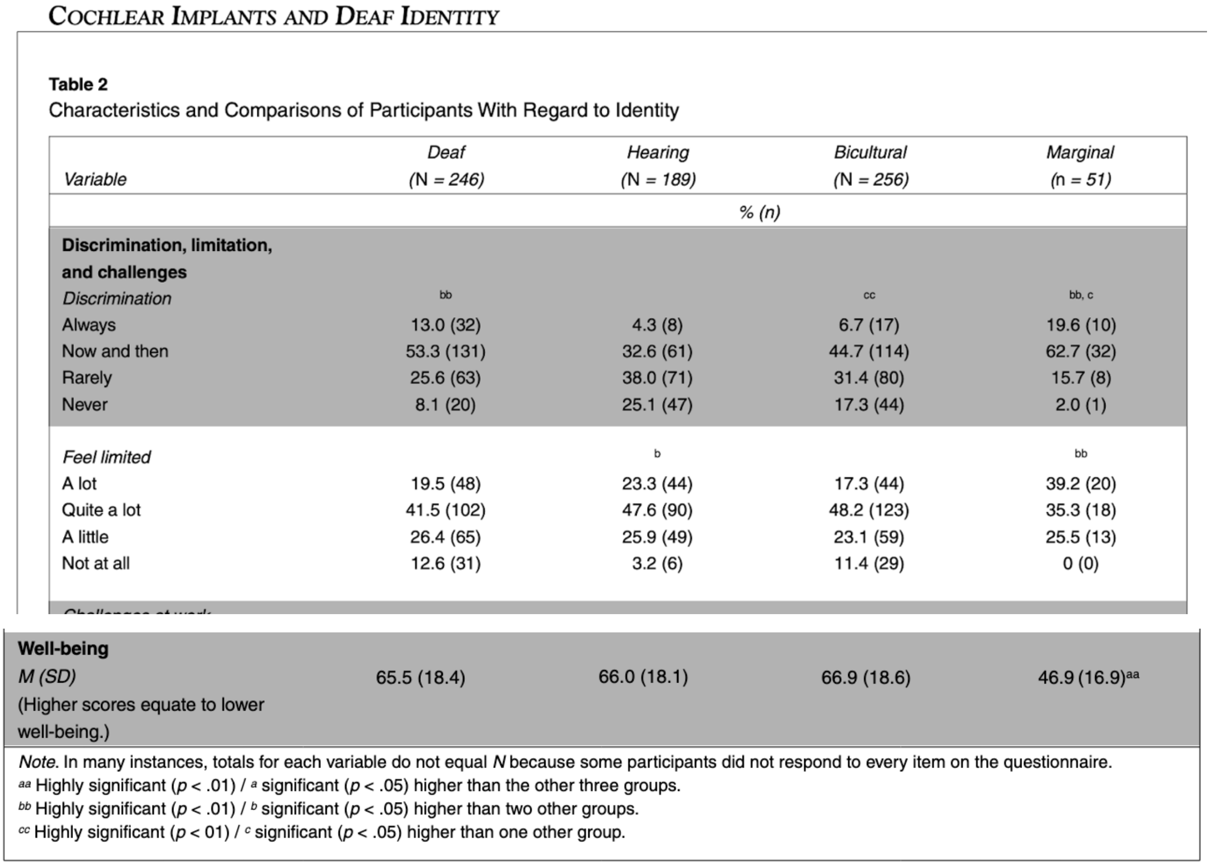
Table 2 Internal consistencies, means, and SDs for measures of social and emotional functioning

	No. of items	Min–Max	Cronbach's alpha	Inter-item correlation	CI ($n = 60$) *M* (SD)	NH ($n = 184$) *M* (SD)
Moral emotions						
Shame/guilt***	12	0–2	0.79	0.24	0.19 (0.19)	0.41 (0.33)
Pride*	6	0–2	0.81	0.41	0.70 (0.49)	0.89 (0.54)
Language						
Emotion vocabulary***	20	0–1	0.92	0.37	0.46 (0.26)	0.57 (0.28)
Language understanding					86.49 (17.59)	
Word production					89.08 (18.67)	
Sentence production					84.09 (14.47)	
Social functioning						
Social competence	10	0–2	0.70	0.17	1.42 (0.35)	1.48 (0.33)
Externalizing behavior	10	0–2	0.71	0.20	0.61 (0.38)	0.53 (0.31)
Cooperation	9	0–2	0.87	0.43	1.62 (0.41)	1.62 (0.43)

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

Here is shown that moral emotions and emotional vocabulary are significantly better in NH children compared to CI-using ones. Moral emotions are correlated to better social functioning in the NH group but not in the CI- group. Better emotional vocabulary is correlating in both groups with better social functioning.

Annex 4: Identity and feeling limited as well as Well-being correlations in DHH patients- Results by Chapman et al. (13):



COCHLEAR IMPLANTS AND DEAF IDENTITY

Table 2
Characteristics and Comparisons of Participants With Regard to Identity

Variable	*Deaf* (N = 246)	*Hearing* (N = 189)	*Bicultural* (N = 256)	*Marginal* (n = 51)
	% (n)			
Discrimination, limitation, and challenges				
Discrimination	^{bb}		^{cc}	$^{bb, c}$
Always	13.0 (32)	4.3 (8)	6.7 (17)	19.6 (10)
Now and then	53.3 (131)	32.6 (61)	44.7 (114)	62.7 (32)
Rarely	25.6 (63)	38.0 (71)	31.4 (80)	15.7 (8)
Never	8.1 (20)	25.1 (47)	17.3 (44)	2.0 (1)
Feel limited		^{b}		^{bb}
A lot	19.5 (48)	23.3 (44)	17.3 (44)	39.2 (20)
Quite a lot	41.5 (102)	47.6 (90)	48.2 (123)	35.3 (18)
A little	26.4 (65)	25.9 (49)	23.1 (59)	25.5 (13)
Not at all	12.6 (31)	3.2 (6)	11.4 (29)	0 (0)
Well-being				
M (SD) (Higher scores equate to lower well-being.)	65.5 (18.4)	66.0 (18.1)	66.9 (18.6)	46.9 (16.9)^{aa}

Note. In many instances, totals for each variable do not equal *N* because some participants did not respond to every item on the questionnaire.
^{aa} Highly significant (p < .01) / ^{a} significant (p < .05) higher than the other three groups.
^{bb} Highly significant (p < .01) / ^{b} significant (p < .05) higher than two other groups.
^{cc} Highly significant (p < 01) / ^{c} significant (p < .05) higher than one other group.

Significant differences were found in between the different identity groups and the feelings of limitations with the most feeling so was the marginal group and the second most the Deaf identity but the well-being of the marginal group was the only significantly affected by the feelings.

Annex 5: Table by Marschark et al. (69) on their research on deaf or hearing acculturation among different identity groups with and without CIs (also the perceiving of unspecified stigma):

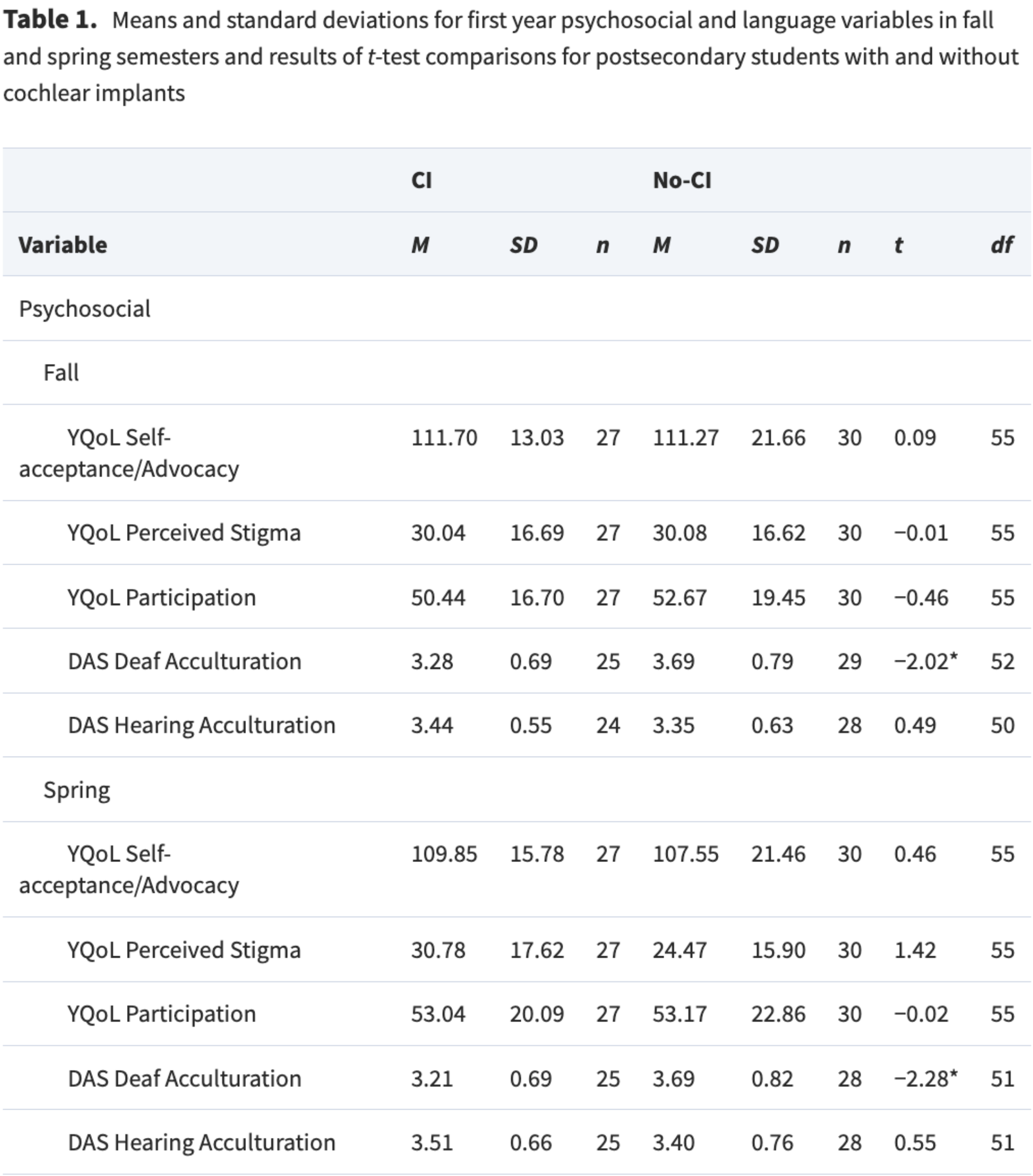


Table 1. Means and standard deviations for first year psychosocial and language variables in fall and spring semesters and results of *t*-test comparisons for postsecondary students with and without cochlear implants

	CI			**No-CI**				
Variable	***M***	***SD***	***n***	***M***	***SD***	***n***	***t***	***df***
Psychosocial								
Fall								
YQoL Self-acceptance/Advocacy	111.70	13.03	27	111.27	21.66	30	0.09	55
YQoL Perceived Stigma	30.04	16.69	27	30.08	16.62	30	−0.01	55
YQoL Participation	50.44	16.70	27	52.67	19.45	30	−0.46	55
DAS Deaf Acculturation	3.28	0.69	25	3.69	0.79	29	−2.02*	52
DAS Hearing Acculturation	3.44	0.55	24	3.35	0.63	28	0.49	50
Spring								
YQoL Self-acceptance/Advocacy	109.85	15.78	27	107.55	21.46	30	0.46	55
YQoL Perceived Stigma	30.78	17.62	27	24.47	15.90	30	1.42	55
YQoL Participation	53.04	20.09	27	53.17	22.86	30	−0.02	55
DAS Deaf Acculturation	3.21	0.69	25	3.69	0.82	28	−2.28*	51
DAS Hearing Acculturation	3.51	0.66	25	3.40	0.76	28	0.55	51

A correlation between learning signing earlier and lower hearing acculturation was found.

(YQoL - Youth Quality of Life (Research instrument used here); M - Means; SD - Standard deviation; n - numbers; t =-results of t tests)

Annex 6: regression analysis of predicting depressive symptoms by Mousley et al. (51) what correlation in between sexual orientation, race and stigma had on the development of depressions:

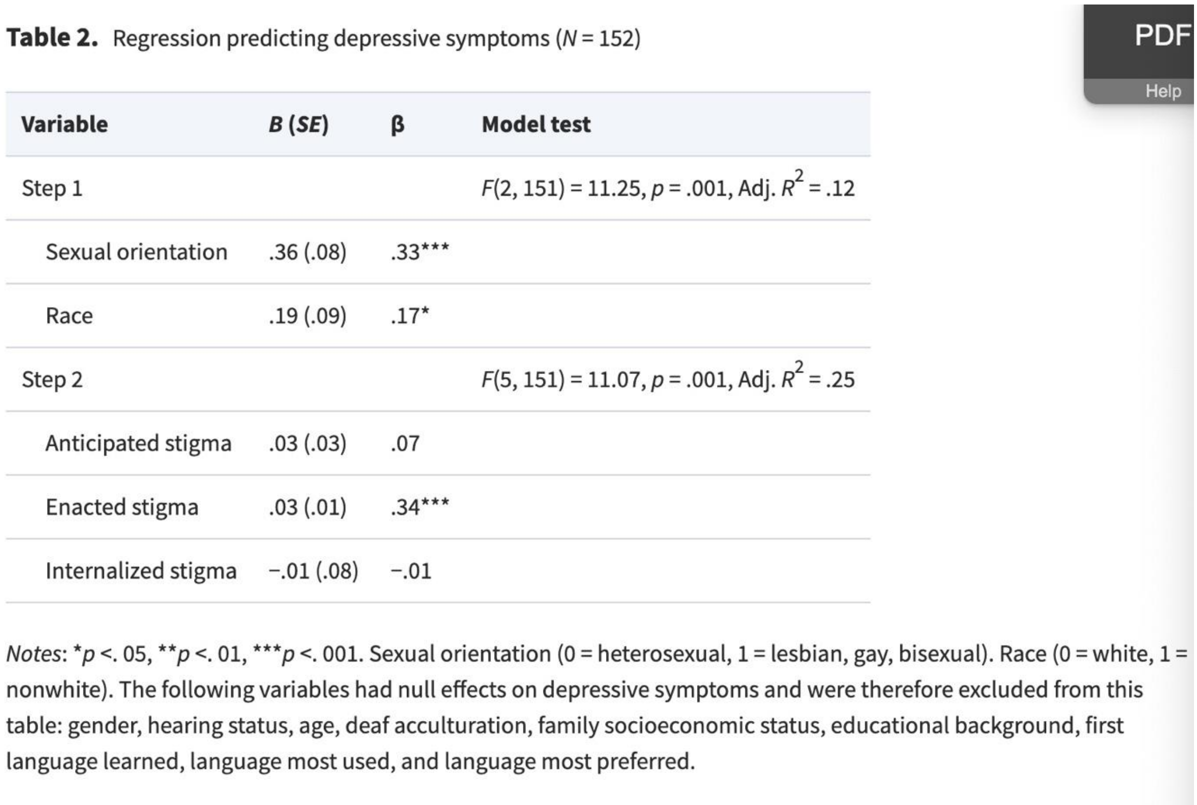


Table 2. Regression predicting depressive symptoms ($N = 152$)

Variable	B (SE)	β	Model test
Step 1			$F(2, 151) = 11.25$, $p = .001$, Adj. $R^2 = .12$
Sexual orientation	.36 (.08)	.33***	
Race	.19 (.09)	.17*	
Step 2			$F(5, 151) = 11.07$, $p = .001$, Adj. $R^2 = .25$
Anticipated stigma	.03 (.03)	.07	
Enacted stigma	.03 (.01)	.34***	
Internalized stigma	−.01 (.08)	−.01	

Notes: *p <. 05, **p <. 01, ***p <. 001. Sexual orientation (0 = heterosexual, 1 = lesbian, gay, bisexual). Race (0 = white, 1 = nonwhite). The following variables had null effects on depressive symptoms and were therefore excluded from this table: gender, hearing status, age, deaf acculturation, family socioeconomic status, educational background, first language learned, language most used, and language most preferred.

In regard to anticipated stigma, enacted stigma, and internalized stigma on depressive symptoms: LGB and non-white participants reported greater depressive symptoms than heterosexual and white participants.

Neither anticipated stigma nor internalized stigma was significantly related to depressive symptoms.

(sexual orientation (0 = heterosexual, 1 = lesbian, gay, bisexual; LGB); race/ethnicity (0 = White, 1 = Non-white)