LONGING TO BELONG
Deaf and hard of hearing young adults’ social interactions, social relationships, and identity

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DEAF AND HARD OF HEARING YOUNG ADULTS’ SOCIAL INTERACTION, SOCIAL RELATIONSHIPS, AND IDENTITY

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Abstract

This thesis gives an insight into what it is like to have hearing that you are dependent on being able to read lips and use a hearing aid to be able to communicate with others. Young adults with hearing loss included in the thesis can convey a very central perspective that can have an impact on a change in interventions and treatment in school life, working life and even in their leisure time. The overall aim of the thesis is to study the living conditions and life experiences of young men and women who are deaf or hard of hearing (DHH). Despite the increased proportion of people with hearing loss, there still seem to be challenges in the face of inclusive environments for people with hearing loss. This thesis hopes to shed some light on the experiences of people with hearing loss and also to explain the link between hearing loss, social inclusion and social exclusion.

The thesis is based on four different sub-studies. In Studies I and IV, a survey study with material collected from the web-based survey Liv och Hälsa Ung (Life and Health of Young People) was used. Pupils attending grades 7 and 9 in compulsory schools and year 2 in upper-secondary schools in all municipalities of the county of Örebro in Sweden. Life and Health of Young People survey examines young people's living conditions, lifestyles and health. The results of Study I showed that people with (DHH) experienced lower levels of well-being than those who had no disability. The results also showed that those who went to special school felt that they had more friends and were more socially included than those who went to mainstream schools. The results of Study IV showed that students with hearing loss felt worse about well-being, somatic disorders and mental health. The results showed that boys had higher well-being, lower mental ill-health and somatic problems than girls. These patterns were the same regardless of whether the adolescents had a disability and regardless of their year in school.

In Studies II and III, interviews were conducted with 16 participants (10 male, 6 female), aged 24 to 31 years, and all had severe-to-profound hearing loss. The results of that analysis in Study II showed that they longed to be included, to be accepted, to create an inclusive social environment, to find friends and partners, and to communicate effectively so that they could be understood. In other words, they desired to feel a sense of belonging. Study III showed that most HH people experience communication barriers in higher education, at work and in leisure time. These barriers lead to feelings of loneliness and make it difficult to achieve social inclusion. Another result in study III revealed how important technology is for social interactions and social relationships. The technology has helped reduce several barriers when it comes to communicating with others. Both Assistant Technology (AT) and Information and Communication Technology (ICT) are important tools for maintaining social activities with friends and partners and creating inclusive arenas.
This dissertation is dedicated to my loving sister, Gugge; without her, this dissertation couldn’t have been completed. There are no words to describe the way she touches my heart and continues to inspire me day after day.

To all my children – you are my heart and soul

“One of the deepest of all human longings is the longing to belong, to be a part of things, to be invited in. We want to be part of the fellowship. Where did that come from?”

— John Eldredge

“True belonging is a spiritual practice of believing in and belonging to yourself so deeply that you can share your most authentic self with the world and find sacredness in both being a part of something and standing alone in the wilderness.”

— Brene Brown
Abstract

How an individual feels about themself during childhood and adolescence, both in terms of mental and physical health, is important; studies have shown that hearing loss (HL) can lead to an unhealthy quality of life associated with isolation, decreased social activity, and symptoms of depression. This dissertation is based on four different sub-studies to gain insight into deaf and hard of hearing (DHH) individuals and how HL could impact their daily lives. The young adults with HL included in this dissertation can convey a very central perspective that can have an impactful change in the available interventions and treatments in school life, working life, and even in their leisure time. The overall aim of this dissertation is to study the living conditions and life experiences of young men and women who are DHH. Despite the increased proportion of people with HL, there still seems to be challenges for establishing inclusive environments for people with HL. This dissertation hopes to shed some light on the experiences of people with HL and also to explain the link between HL and social inclusion and exclusion.

In Studies I and IV, an online survey titled Life and Health of Young People (Swe: Liv och Hälsa Ung) was conducted. The survey’s participants were pupils attending grades seven and nine in compulsory schools and year two in upper-secondary schools throughout all municipalities within the county of Örebro, Sweden. This survey examined young people's living conditions, lifestyles, and health. The data for Study I was obtained in 2011, so additional research was performed to see if the DHH students experienced better well-being in mainstream schools in 2017 than 2011. Study IV also aimed to determine whether somatic problems and mental ill health correlated with physical disability and well-being.

In Studies II and III, interviews were conducted with 16 participants (10 male, six female), aged 24–31 years, and all had severe-to-profound HL. The interviews were built on how the participants’ see them self and
also their relationships with family, friends, and partner. A semi-structured interview guide comprised of open-ended questions that allowed for asking follow-up questions was used.

The results of Study I showed that people with DHH experienced lower levels of well-being than those who had no disability. The results also showed that those who went to special schools felt that they had more friends and were more socially included than those who went to mainstream schools. The results of that analysis in Study II showed that the participants longed to be included and accepted, to create an inclusive social environment, to find friends and partners, and to communicate effectively so that they could be understood. In other words, they desired to feel a sense of belonging. Study III identified that most hard of hearing (HHI) individuals experience communication barriers in higher education, at work, and during leisure time. These barriers lead to feelings of loneliness and make it difficult to achieve social inclusion. Another result in Study III revealed how important technology is for social interactions and relationships. The technology has helped reduce several barriers when it comes to communicating with others. Both Assistive Technology (AT) and Information and Communication Technology (ICT) are important tools for facilitating social interactions and maintaining social activities with friends and partners and creating inclusive arenas. The findings of Study IV revealed that adolescents without disabilities rate their well-being higher, have lower mental ill health, and have fewer somatic problems than adolescents with DHH. The results also showed that boys rate their well-being, mental ill-health, and somatic problems higher than girls. These patterns were the same, regardless of whether the adolescents had a disability or what year they were in school.

From the findings of this dissertation, it can be concluded that the largest obstacle to achieving social inclusion is communication barriers. The desire for belonging would be easier to satisfy if DHH individuals had more opportunities to communicate with hearing individuals, both in school, at work, and in leisure time. Whether this can be achieved by various methods of assistance or by providing education on Swedish Sign Language (SSL) to more people has yet to be determined, but a more inclusive social environment must be achieved.

**Keywords:** Deaf and hard of hearing, social inclusion, social exclusion, communication, identities
List of papers

This dissertation is based on the following papers, which are referred to in the text by their Roman numerals:


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<tbody>
<tr>
<td>DHH</td>
<td>Deaf and Hard of Hearing</td>
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<tr>
<td>HH</td>
<td>Hard of Hearing</td>
</tr>
<tr>
<td>HL</td>
<td>Hearing Loss</td>
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<tr>
<td>CI</td>
<td>Cochlear Implants</td>
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<td>SSL</td>
<td>Swedish Sign Language</td>
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<tr>
<td>HRF</td>
<td>Swedish Association of Hard of Hearing People</td>
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<tr>
<td>WHO</td>
<td>World Health Organization</td>
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<tr>
<td>LSS</td>
<td>Act concerning Support and Service for Persons with Certain Functional Impairments</td>
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<tr>
<td>SoL</td>
<td>Social Services Act</td>
</tr>
<tr>
<td>ICF</td>
<td>International Classification of Functioning, Disability and Health</td>
</tr>
<tr>
<td>ICD</td>
<td>International Classification of Impairment of Diseases</td>
</tr>
<tr>
<td>ICIDH</td>
<td>Classification of Impairment, Disability and Handicaps</td>
</tr>
<tr>
<td>IASSW</td>
<td>International Association of Schools of Social Work</td>
</tr>
<tr>
<td>IFSW</td>
<td>International Federation of Social Workers</td>
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<tr>
<td>SDR</td>
<td>Swedish Association of the Deaf</td>
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<tr>
<td>FSDB</td>
<td>The Swedish Association for the Deafblind</td>
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<tr>
<td>DHB</td>
<td>The national association DHB</td>
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<tr>
<td>SPSM</td>
<td>The Special Education School Authority</td>
</tr>
<tr>
<td>RGD/RGH</td>
<td>The national upper secondary school for deaf and hard of hearing</td>
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Classical composer Ludwig van Beethoven’s (1770–1827) experience with deafness is well-known. However, few comprehend how substantial his daily struggle with deafness was. In the 1700s and 1800s, very few people had knowledge about hearing loss (HL). As a musician, Beethoven’s deafness hindered him from hearing musical notes, which made communicating and socialising difficult. According to Beethoven:

For two years, I have avoided almost all social gatherings because it is impossible for me to say to people “I am deaf” ... If I belonged to any other profession it would be easier, but in my profession, it is a frightful state (as cited in Thayer & Krehbiel, 1992, p. 284)

Already suffering from increasing deafness and fear of social isolation in his thirties, Beethoven became known for his grumpy mood. By the time he was 45, his hearing was completely gone. However, despite his total deafness, Beethoven was still able to continue composing because he knew how the music sounded inside his head. Beethoven spent nearly 10 years composing while deaf, and one of his pieces during this time included the famous *Ninth Symphony*. Nevertheless, his deafness led to isolation, loneliness, and the loss of his social life. Beethoven gave up performing publicly, selected a few friends to interact with, and only communicated through written conversations (Cooper, 1991; Holmquist, 2011).

Beethoven’s life provides an excellent example of the difficulties that accompany HL. Individuals with HL struggle to feel included and are often limited when it comes to social activities and participation in society (Jonsson & Hedelin, 2018). However, Beethoven’s life also shows that it is possible to be successful despite HL.
Hard of hearing (HH) is an international term for several different diagnoses. HH can vary widely, ranging from a mild reduction in hearing to profound HL or deafness. “Deaf” is used to refer to an HL so severe that little to no functional hearing exists. However, most international research has not made this distinction, simply referring to “deaf people” or “deaf people and people who are hard of hearing”; internationally, the abbreviation (DHH) is used to refer to this group of people (Brice & Strauss, 2016; Ford & Kent, 2013). This dissertation will also adopt the abbreviation DHH to refer to individuals who are deaf or hard of hearing without distinguishing whether the persons are medically classified (according to an audiogram) as being deaf or HH. A medical distinction is not made because this dissertation aims to examine individuals’ experiences of living with HL; thus, each individual should decide which distinction he or she prefers.

Being DHH is an invisible disability that often goes unnoticed. For this reason, people who are DHH are often ignored or forgotten, and those with typical hearing do not understand the daily struggles of people who are DHH. However, DHH is the most frequent sensory deficit in human populations, affecting more than 5% of the world’s population; 466 million people (34 million of whom are children) are DHH (Swedish Association of Hard of Hearing People [HHR], 2018; World Health Organization [WHO], 2021). In Sweden, over 1.5 million individuals have some degree of HL, from mild HL to deafness. More than half of all people with HL in Sweden (nearly 712,000) are of working age (between 16 and 64 years old), and according to the WHO (2021), DHH is one of the most common functional reductions in working life.

Despite the large number of people with HL, inclusive settings for people who are DHH are still lacking. While a considerable amount of the research on DHH has concentrated on children, few studies have focused on young adults’ (aged 18–30 years) experiences of having HL, including their experiences in different social settings (e.g., school, work, and leisure time). Thus, this dissertation’s overall aim is to supplement the existing research by studying the living conditions and life experiences of young adults who are DHH. By understanding how these young adults experience their social relationships, the situations and structures that are problematic for DHH young adults can be elucidated.
Specific aims of the included papers

I. The aim of this quantitative study is to compare the well-being of adolescents who are deaf and hard-of-hearing (DHH), who are deaf or hard-of-hearing (DHH) and have additional disabilities, and those without disabilities; second to compare the adolescents from the two deaf and hard-of-hearing groups and their experiences of inclusion and exclusion in school; and third to ascertain whether any gender differences exist between the two mentioned groups of deaf and hard-of-hearing adolescents concerning experiences of inclusion and exclusion.

II. The aim of this qualitative study is to examine HH young adults’ experiences of social identity and group membership. The goal was to gain deeper insights into their experiences of social identity and group membership in order to provide better support and to improve health outcomes.

III. The aim of this qualitative study examines HH young adults’ experiences of social interactions and social relationships in higher education, working life and at their leisure time.

IV. The aim of this quantitative study is to examine deaf and hard-of-hearings adolescents’ experiences in mainstream school and their well-being, somatic problems, and mental health.
Background

To contextualize and clarify the rationale for this dissertation, this section provides a brief description and background of DHH. Thereafter, a historical background of disability in general is presented. Then, the context of the Swedish school system for people who are DHH will be introduced. Finally, a review is provided to obtain an understanding of how social work and health and welfare among the DHH population are related to this dissertation. This background section functions as the foundation for the rest of this dissertation.

Conceptualising Hearing Loss

Misperceptions around the terms ‘hard of hearing’ and ‘deaf’ are common regarding both their definitions and correctness of use. HL is the partial or total inability to hear sound in one or both ears. HH encompasses a wide range of HL, including tinnitus, Meniere’s disease, and audio hypersensitivity. People who are HH usually communicate through spoken language and can benefit from hearing aids, Swedish Sign Language (SSL) or/and cochlear implants (CIs) and other assistive devices, as well as captioning. Deaf people have profound HL (i.e., little-to-no functional hearing), and they often use sign language for communication (WHO, 2021). The difference between being deaf and HH is that people who are HH have enough residual hearing to receive passable assistance from an auditory device, such as a hearing aid or other system. Both individuals who are deaf and those who are HH may speak in a way that is difficult to understand due to the inability to hear their own voices (Senghas & Monaghan, 2002).

Different types of HL often occur concurrently. Some individuals can hear well when talking to one or two people, but have difficulty understanding what is said when many people are speaking. Some use hearing
aids or have received CI. Thus, several aspects are used to define hearing status: how much the individual is able to hear (labelled from mild to severe HL), when the hearing started to decrease (from birth or later in life), at what age the reduced hearing was identified, and how the individual communicates with hearing people (e.g., sign language, hearing aids, CIs). For example, the term “deafened” uses to describe an individual who developed deaf as an adult and subsequently faces different challenges than a person who became deaf at birth or as a child (Dobie & Van Hemel, & National Research Council, 2004).

HL is classified based on ear anatomy, the type of HL, the degree of disease, and the configuration of the audiogram (Szarkowski, 2017). From a medical perspective, different classifications are used for people with some form of HL (e.g., deaf, CI users, HH, etc.). These classifications are often based on the hearing status and decibel levels determined by an audiogram (Werngren-Elgström et al., 2003).

A CI is a hearing aid that grants the seriously hearing impaired or deaf the ability to perceive sound. While a standard hearing aid only works for those with certain types of HL, the CI can help most children who are born deaf because the implant conducts the impulses nearly all of the way to the auditory nerve. Acquiring a CI does not connote an equal ability to perceive sound as biological hearing; rather, these devices provide sufficient information to perceive the most important speech signals (Gustavsson, 2009). A person with severe HL or deafness may join in conversations and use their implant to perceive sounds to varying degrees, effectively developing their speech and language. The majority of those with CIs often identify themselves as persons with a hearing impairment of varying degrees and have thus spoken Swedish as their first language (Roos, 2008).

‘Deafness’ is an umbrella term for the partial or total inability to hear out of one or both ears, and it can affect any age group, from birth to late adulthood. There are different definitions of the term ‘deaf’, and d/Deaf people often have profound HL, with very little or no hearing at all. They regularly use sign language for communication (WHO, 2018). The distinction between ‘Deaf’ (D) and ‘deaf’ (d) is used to highlight the difference between cultural identity and audiological factors. Using the term “Deaf” means emphasizing the socio-cultural and identity of being deaf (Wrigley, 1996). The most appropriate term for describing this condition
is “deaf” or “Deaf.” The former (d) refers to the physical condition in solely medical terms of having HL (Burke et al., 2020). It differs whether deaf people use hearing aids or not. Some choose to operate on CIs, while others do not want to. The medical term deafness should not be confused with the word deaf; the person does not necessarily need to be classified as being medically deaf. The reason for this distinction is that this classification does not always directly relate with how much the person hears and uses speech—it also involves their identity. Being deaf is about the feeling of belonging in a cultural and linguistic minority, where sign language is an important part of the community (National Research Council, 2004). Thus, the medical or pathologic perspective views deafness as a disability that can be corrected with the help of hearing aids or CIs and as a disability that can be corrected via medical treatment, so the deaf person is ‘normalized’. Identity, language development, and a person's personal relationships are not taken into account (Blume 2010).

The latter (D) refers to a Deaf person who identifies with a larger community of Deaf people and the Deaf culture. The individuals who adopt this term do not consider deafness to be burdensome or a disability. Furthermore, the degree of hearing loss is not of importance. Instead, these individuals see themselves as part of a cultural and linguistic minority group (i.e., part of the Deaf community and culture). Thus, the term “Deaf” is used in a cultural sense (Holcomb, 2012; Kusters et al., 2017; Szarkowski, 2017). Deaf people connect and communicate with each other using sign language, and they share norms and cultural traditions (Barclay, 2017; Holcomb, 2012; Szarkowski, 2017).

There is always an obvious difference between people who are HH or those who are deaf (d/D). However, variations are based on an individual’s hearing status and degree of integration in the community (Holcomb, 2012). The differences which are highlighted above are that, for the most part, HH people benefit from the use of assistive systems. But the differences are highly dependent on how the individuals grew up—that is, their family’s attitudes and adaptability, their access to sign language and other aids, and additional factors that shaped their self-image and social-emotional outcomes (Harvey & Kentish, 2010).
Understanding Disability: Moving from a Medical Model towards a Social and Environmental Relative Model

This section examines how disability is explained and understood and how this understanding and the vocabulary used to refer to disability have varied over time.

The two most commonly applied perspectives used by disability scholars are the medical model and the social model (Barnes & Mercer, 2010). However, the oldest perspective historically is the moral/religious model. According to this model, disability is a punishment from God, and people with disabilities are possessed by evil powers or are objects of God’s punishment (Henderson & Bryan, 2011).

During the mid-1800s, the moral/religious model was replaced by the medical/individual model of disability (Retief & Letšosa, 2018). The medical model is based on what non-disabled people think is normal and thus includes their prejudices (Lindqvist, 2017). This model defines and categorises disability as a tragedy that should be avoided in every way. From this view, a person who experiences disability is a “burden” upon their family, friends, society, etc. (Llewellyn & Hogan, 2000). Consequently, people with disabilities, as well as their friends and/or family, experience stigmas because of their relationships with individuals who are stigmatized by others (Green, 2003; Lilley, 2013). The medical model takes an individualised perspective, characterised by theories that focus on the individual and his/her medical status (i.e. physical abnormality, disorder, or deficiency) and functional limitations in the environment. This perspective results in the use of terms like “handicapped”, “invalid”, “cripple”, and “retarded” (Creamer, 2009).

The view of DHH as a functional disability can also be understood from different perspectives, especially regarding the matter of accessibility. According to the medical model, the lack of accessibility is due to an individual’s disability (Davies, 1999). This model is also reflected in society’s view of DHH people, which perceives these individuals as having a medical flaw that should be ‘corrected’ through operation, treatment, training, or rehabilitation so that they can become ‘normal’. The focus has been placed on the individual’s diagnosis and functional ability, and
disability has been equated with impaired or lost bodily functions. This view of disability originates from the medical model (Lindqvist, 2020).

In response to criticism of the medical model, the social model of disability was established in the 1960s and 1970s (D’Alessio, 2013). Essential to this model is the belief that disability is a socially constructed phenomenon; according to the social model, society “disables people with disabilities, and therefore any meaningful solution must be directed at societal change rather than individual adjustment and rehabilitation” (Barnes et al., 2010, p. 163). Thus, disability research should not deal with the disability but instead focus on the environment.

The social model clearly differentiates between impairment and disability. Instead of theorising disability, disablism, or impairment as initiating with the individual, the social model attempts to understand which of these are reconstructed as a display of social relationships (Thomas, 2004). From a social perspective, the environment is an obstacle if an individual does not have access to a certain part of society, for example, through the lack of knowledge of sign language, access to an interpreter, or functioning hearing technology. Thus, the environment prevents accessibility to certain places, and the community is the primary reason the individual becomes disabled (Oliver, 1996).

In the early 1970s, critical voices, including those from the disability movement, argued that people with disabilities should be included in society like those without disabilities. Additionally, the absence of different social factors (e.g. gender, sexuality, ethnicity, and culture) in the social-relational model was critiqued (Thomas, 2010). The WHO recognized the shortcomings of the International Classification of Impairment of Diseases (ICD) and commissioned several researchers from around the world to revise the disability-oriented classification. In 1980, the International Classification of Impairment, Disability, and Handicaps (ICIDH) was published as a tool for the classification of the consequences of disease and of their implications for the lives of individuals. The ICIDH was revised from 1993–2001 after being criticized for being based on the medical model. In 2001, the new revision was approved, and the name was changed to the International Classification of Functioning, Disability, and Health (ICF). The ICF was translated into Swedish by the National Board of Health and Welfare in 2003.
The ICF moved from being a classification of ‘disease consequences’ to one of ‘health components’. It consists of four domains: body function, body structure, activity participation, and environmental factors. For people with hearing loss, the ICF acts as a tool to describe different possibilities for inclusive settings and changes the view of disability from considering the disability’s consequences (a medical point of view) to considering its components (a social-relational perspective). The ICF is based theoretically on the biopsychosocial model, which unites the medical model with the social model; from this, the relational model was developed (National Board of Health, 2016).

Around the same time the social model of disability emerged in the United Kingdom, the environmental relative disability model was developed in Sweden as a result of the welfare state (Berg, 2004). This model perceives ‘disability’ as a relationship between the individual and the environment. The individual has an impairment, but it is in the interaction between the individual and the environment that the disability occurs (Söder, 1982). The basis for this disability model was that the environment around the individual can change, in that way reducing the amount of disabling conditions, evading the stigmatisation of individuals with disabilities, and allowing their inclusion in society (Holme, 1999). According to the environmental relative disability model, disability can be reduced by adapting the social environment so that an individual’s disability does not produce unnecessarily substantial consequences (Lindqvist, 2020). This model views disability as the absence or limitation of opportunities to participate in normal social life on an equal level with the rest of the population due to physical and social barriers in a society, rather than a lack or limitation of a physical, mental, or sensory function. Thus, the problem of lacking accessibility arises from obstacles in the environment and society’s attitude regarding those who are different. This suggests that the problem is solved by changing society rather than the individual (Dittrich & Tutt, 2008).

The development of the environmental relative disability model led to a change in disability research during the 1980s and 1990s. In the 1990s, many studies showed that socially integrated people had primarily been of a physical type—that is, disabled and non-disabled individuals had not been socially integrated (Söder, 2013). These findings piqued an in-
terest in studying the social relationships and interactions between disabled and non-disabled individuals. For example, one study examined how blind children related to their seeing friends (Jansson, 1996), while another investigated how deaf people navigated their disability during social interactions with others and in the environment (Heiling, 1993). The environmental relative model adds the missing element: the struggle through the developmental process towards interaction with the external world. The environmental relative model encompasses three key assumptions: (1) disability arises from inequalities between the individual and the environment; (2) disability is situational or contextual; and (3) disability is relative (Goodley, 2011; Tossebro, 2004). Thus, the environmental relative model considers the difficulties that arise from the normative design of the environment, for example, at school or at work.

Disability researchers in Scandinavian countries have significantly contributed to the introduction of the environmental relative model to disability research (Nirje, 2003; Tossebro, 2004; Söder, 2013). At its core, this model declares that a gap exists between the functional ability of the individual and the surrounding environment. These barriers could be either physical or social barriers that hinder their access to facilities or employment and prevent them from appreciating their rights. Barriers that hinder participation for people with disabilities vary (Glendinning, 2003), and what is considered normal, or deviant is, according to social constructivism, a result of what individuals encounter in society due to cultures and languages (Burr, 2015). In other words, similar to the relational model of disability, culture and society influence how people speak about disabilities and the people who possess them.

Hearing loss can be interpreted from the medical, social, and environmental relative model. From a pathological perspective, being DHH is defined by the medical extent of hearing damage. From a cultural perspective, it is defined by how well an individual can communicate (Brunnberg, 2003). In previous studies, people with DHH have been contextualised in the medical model discourse, while DHH in early childhood has been examined using a social or environmental relative model. The environmental relative model attempts to account for the complexities and varieties in the lives of people who are DHH, as they, alongside family members and friends, negotiate their developing plurilingual identities.
in the face of challenging discourses surrounding language and social inclusion. In this case, ‘plurilingual’ indicates multilingualism at the individual level and distinguishes the different determinations, fields, and types of competence that the individual may have in his/her use of two or more languages (Coste et al., 2009).

This dissertation will utilise an interactive perspective of DHH. In other words, the discussion of DHH will take a social and environmental relative model, but the medical and biological aspects of the disability will not be excluded. The opportunities for participation given to people who are DHH rely on the availability of linguistic, cultural, auditory, and other knowledge (or lack of accessibility) of the environment, but the medical diagnosis can also impact an individual’s accessibility and identity.

The Context of the Swedish School System

According to Swedish law, all children have the right to education appropriate to their needs. In Sweden, the residential municipality is responsible for ensuring that the needs of students who require special support are met (The Education Act, 2010). Children and adolescents who have disabilities can apply to one of the country’s special primary or secondary schools. And the state in Sweden is responsible for these schools, which, according to Chapter 12, Section 2 of the School Act (SFS, 2010), should provide young people with education adapted to their needs.

The question of which type of school—mainstream or special school—is most beneficial for children who are DHH has been raised often in research and in the public debate among specialists, parents, and individuals who are DHH (Angelides & Aravi, 2007). Importantly, school placement affects the psychosocial health of DHH adolescents (Gilman et al., 2004). In these contexts, a common concern is how well each type of school achieves the inclusion of people with disabilities—that is, how well it makes them feel like involved participants in daily activities. In Sweden, as in many other industrialized countries, the official stance is that an inclusive school not only provides high-quality teaching to all children but is also a crucial platform for changing discriminatory attitudes, creating a supportive local community, and promoting an integrated society (UNESCO, 1994). These adolescents are at risk of being socially excluded and exposed to bullying in mainstream schools. In special schools
for DHH individuals, on the other hand, they could encounter a different culture and, potentially, a different language than what is spoken by their parents (Hindley, 2005).

In Sweden, about 90% of all DHH students’ study in municipal or independent schools; thus, these students have limited access to hearing technology and support from their teachers due to poor hearing conditions and large classes (Swedish Association of Hard of Hearing People, 2015). These students must handle the consequences of being DHH (e.g., managing communication) in order to take advantage of the teaching (Bååth, 2017). Existing research shows that the length of education is shorter among people with disabilities in Sweden than in the general population (SCB, Statistics Sweden, 2019). Furthermore, people with hearing loss are significantly underrepresented in higher education around the world (Bell, 2018). In Sweden, only 10–15% of DHH students continue studying after upper-secondary school (Swedish Association of Hard of Hearing People, 2007), which is low compared to the total proportion of persons in Sweden who continue to higher education (around 45%) (Swedish Association of Hard of Hearing People, 2007). In higher education, as many as four out of 10 DHH university students report having problems with a poor sound environment and difficulties concentrating on, remembering, and hearing what the lecturers and others say (Swedish Association of Hard of Hearing People, 2011).

At mainstream schools, the child has the right to use hearing aids, such as a telephone loop and microphones for teachers and classmates, and to receive support from hearing teachers. This support is provided within the regular teaching. However, the classes in mainstream schools are often large, the sound environment is inadequate, and the teaching is not adapted to the communication needs of students who are DHH. The adjustments that are made for a student who is DHH vary widely (Swedish Association of Hard of Hearing People, 2011). Hearing classes are often small, and the audio environment is customized with hearing aids (e.g. a loop and microphones) used throughout. In mainstream schools that educate DHH adolescents, teachers face different challenges when it comes to meeting the needs of all DHH adolescents. This is partly due to variations in DHH adolescents’ communication skills (Ntinda, 2019).
According to the Swedish National Agency for Education in Sweden (2011), children with HL can choose from three options for school in Sweden: (1) a mainstream school, (2) a hearing class integrated in mainstream school, or (3) a school specializing in students with HL (Swedish National Agency for Education, 2011). According to the HRF, just over two-thirds of all DHH individuals attend a mainstream class or smaller hearing classes. The other third goes to a special school (Swedish Association of Hard of Hearing People, HRF, 2007). In the special schools’ 10-year curriculum, the first part of the syllabus concerns the school’s mission and values and has great similarities to the compulsory school curriculum. The second part sets goals and overall guidelines, while the third establishes knowledge requirements (National Agency for Education, 2016). In the special schools, both the teaching practices and environment consider the needs of DHH students. The Special Education School Authority (SPSM) functions as the governing body for these special schools and has the responsibility of offering a bilingual environment. This means that students who are DHH are given the opportunity to develop bilingualism—SLL and traditional Swedish in both its written and spoken forms. Classes in both the special schools and in regional and municipal hearing classes are smaller, and the teaching is more pedagogically and technically adapted to the students’ hearing loss (Wennergren, 2008).

There are five public schools for students who are DHH. The locations include Stockholm, Lund, Vänersborg, Härnösand, and Örebro. Currently, there is only one upper-secondary school option for DHH students: the national upper-secondary school for the DHH (Swe: riksgymnasiet för döva [RGD] riksgymnasiet för hörselskadade [RGH]). At RGD, teaching is conducted in SSL, if necessary, teaching takes place with the help of a sign interpreter. At RGH, teaching takes place in spoken Swedish with the support of hearing aids, some teachers also use signs as support. It is possible to choose to study for three or four years for both RGD and RGH. RGD and RGH are locally integrated in four different upper secondary schools hearing students located in Örebro. The curriculum (Lpf 94) for RGD/RGH is the same as for other upper secondary schools and all educations in RGD/RGH follow the same provisions as for other upper secondary schools. The only differences that
Another option is the hearing class in the neighbouring hometown. Thus, the start of school for these students may mean moving to a new city, often without their family, and renting a home for which the municipality offers various options. There are seven municipal schools in Sweden, and they are located in Stockholm, Piteå, Hässleholm, Jönköping, Uppsala, Malmö, and Göteborg—each of these utilise standard hearing classes. The municipality gathers a few DHH children in a class in a school with hearing children. Another alternative is for the child to be integrated into a hearing class. In this case, the child has the right to SSL and aids for his learning situation (The national association DHB, 2021).

While basic education is compulsory from the age of seven until finishing grade nine, special schools have an extra compulsory school year (10th year) (Special Education School Authority, 2013). This is because their goal is for students to become bilingual and acquire all of the necessary knowledge in two languages (National Agency for Education in Sweden, 2017). The special schools also utilise the following adaptations: smaller teaching groups, optimal sound and light environments, staff with specialized training, advanced hearing technology equipment, and a hearing awareness plan. The spoken language of instruction is Swedish, but all students read sign language as a subject from year one (Swe: Riksförbundet DHB/The auditory line, 2021).

Special schools have been in Sweden for several years and were, at first, based on the medical model (Takala & Roos, 2016). According to this model, DHH children should learn to speak and read by reading lips. Some argued that sign language is too rudimentary and thus intellectually limiting (Lundström, 2005) and inhibitory to speech development (Jacobsson, 1997). Thus, only oral communication was used in education. However, in the 1960s, the Swedish Association for the Deaf argued for the right to use SSL in an educational setting (Svartholm, 1993), and SSL has played a significant role in communication and teaching in special schools since the 1970s (Dammeyer & Ohna, 2021). Sweden was the first country to acknowledge SSL as an intrinsic language (Svartholm, 2010) and to state that DHH children had the right to learn sign language.
In 1981, SSL was recognized as a language and given the status of a national minority language (Andersson & Hammar, 1996; Official Reports of the Swedish Government [SOU], 2008:26). This increased the need for teachers who had mastered SSL (Takala & Roos, 2016). Before the 1980s, SSL was taught in short courses in separate schools, the goal of which was mainly vocational education (Pärsson, 1997; Richardsson, 2018). In the 1980s, large investments were made both in compulsory and upper-secondary school so that DHH students could benefit from the same programme as hearing students (Pärsson, 1997).

There are different meanings of what the best school placement is—special school or mainstream school. Maybe there is a greater importance in how we observe disability, because this will affect how the children will define their identities and abilities. For example, Roos and Fischbein (2006) highlighted the “auditory perspective” and the “visual perspective” from an environmental relational perspective. They meant that, if we change our view and believe that it is the environment we must change, not the children, then the school will be a school for all children, disability or not. This will be an important view rather than choosing the “right” school.

Social Work Policies and Laws Among the Deaf and Hard of Hearing Population—Seeing Problems or Potential?

From a global perspective, social work has been defined as a profession that “endorses social change” within which the “principles of human rights and social justice are fundamental” (International Association of Schools of Social Work [IASSW]; International Federation of Social Workers [IFSW], 2001, para 5). Social work is a practice profession and academic discipline that promotes social change and development. Social work, including all public, voluntary, and private practices, as well as groups concerned with individual and community welfare, has a significant place in social work (Barry & Hallett, 1998). For many years, social work has held social justice as an essential part of its effective practice, definition, professional identity, and code of ethics (International Federation of Social Workers, 2021). Similarly, Davis (2007) suggested that rights, dissimilarities, and social
justice are central key aspects of social work. Moreover, the main discourses
of social work disturb normative expectations and practices (Carniol, 2010).

From this viewpoint, social exclusion is a concept that should be ad-
dressed by social work practice through processes that address marginalisation,
promote inclusion, and reduce the impact of dissimilarity. Professional
social workers must possess the knowledge and abilities to address the issues
of inclusion and admittance of individuals with disabilities (Carter et al.,
2012). Furthermore, professional social workers must be aware of employ-
ment, educational, and social challenges facing persons with disabilities.
One of the main characteristics of social work is to recognize needs and
determine the necessary assistance and interventions for people with disa-
bilities. Thus, social workers must have a strong knowledge of the Social
Services Act, (SoL), and the Act on Support and Service to Certain Disabled
People (LSS), as well as these laws’ relationships with each other. Further-
more, social work is rarely temporary; the need for support can be lifelong,
and the support must be adapted to the individual’s age, situation, etc. Thus,
social workers must be able to work with people of different ages (National

In Sweden, state, municipality, and county councils are equally responsi-
ble for providing assistance that guarantees good health and economic and
social welfare. The Act Concerning Support and Service for Persons with
Certain Functional Impairments regulates activities provided by different
services for adults, as well as activities for children and young adults, who
are inactive and/or have not yet completed their education (National Board
of Health and Welfare, 2019). Social workers often work with the whole
family as clients who have been excluded or marginalised in their own soci-
ety, both economically and socially. Thus, the Social Services Act
(2001:453) states that these workers must have appropriate training and ex-
perience for these consequences (Chapter 3, Section 3). In other words,
professional social workers should be able to assist different kinds of people
with different needs. Moreover, the Support and Service for Some Disabled
Persons Act (1993) states that enough staff members must be available to
provide quality support, service, and care (§§ 6).

On the personal level, social work is a practice with the ability to influence
and advance an alternative discourse. Social work can help people over-
come barriers, challenge negative stereotypes, and improve public under-
standing, thereby increasing awareness of the oppressive aspects of life faced
by people with disabilities (Fook, 2002). This can be achieved through social workers’ capabilities to form the appropriate discourse, their authority to make decisions regarding their service users, and their social positions (Burke & Harrison, 2009). On the societal level, social workers can establish a sense of community, increase awareness of domineering practices among communities, and alter public discourse regarding certain social groups (Dominelli, 2002; Strier, 2009).

Effective social work practice with DHH people entails an exclusive assortment of various knowledge, skills, morals, and ethical considerations. Fundamental to positive social work practice are good communication skills and awareness of and attention to the power of language (Rossiter, 2005; Fook, 2002). Good communication skills allow social workers to build optimistic working relationships with service users, employers, families, and colleagues (Egan, 2010; Baxter & Glendinning, 2011). Furthermore, social workers must be able to avoid language that creates distance between the social worker and their service (Rossiter, 2005; Fook, 2002). Through communication, the social worker must access information related to the client’s family, financial situation, social networks, etc. Additionally, the social worker must support the client. To achieve both tasks, a trusting relationship must be developed in which communication is an essential foundation (Lundin et al., 2009).

Furthermore, social workers must be able to switch between competence skills and personal relationships to bring about change. They must show that they are willing to understand the client’s situation, construct possible interpretations, and make the problem visible. Thus, a duality characterises the relationship between the social worker and client. One part is a competence relationship that provides support and is characterised by a difference between the individuals. The second part, the personal relationship, has an ethical aspect through which the social worker overrides his or her possible power. Despite their differences, the social worker communicates that the client has the same value as others (Madsen, 2001).

Hearing loss can be defined as conferring to either medical or social models. How these models notify practitioners’ attitudes about HL may have an influence on caregivers’ abilities to provide competent and accessible care. However, research on language use among experienced social workers has found that they use the medical model’s language in their discourse with and about disabled people (Hawkins et al., 2001). Language
based on the medical model indicates that the problems are found with the individual instead of society, and it also preserves concepts of deviance and undesirable difference. These concepts are fundamental to the construction of disabled individuals as an out-group (“them”) and professionals as an in-group (“us”)—a key aspect of “othering” (Martin, 2011). This approach has received increasing criticism from researchers in social work (e.g. Adams et al., 2002) who have critiqued the traditional forms of social work that have focused on creating individual solutions rather than addressing the social power structures that affect the individual.

People who are DHH may need different support from the community than hearing people, and the attitudes of service workers and different definitions of HL can affect the way that services are delivered to DHH populations (Kuenenberg et al., 2016). Social workers who assist DHH clients must acquire the right skills to communicate with clients and be able to differentiate normal from deviant behaviours in the context of HL. Before meeting the client, it is good to include as much information about the client as possible and also investigate if there has to be an interpreter at the meeting. This is essential for DHH clients to get the best help possible. Another practical implication would be that some of the social workers could learn sign language to fulfil the communication needs not only of DHH clients but also of other individuals with communication barriers, such as people with intellectual disabilities. Social workers who use sign language should be as common as those who can interpret other languages. Research (Glickman, 2003; Sheridan et al., 2010) has shown that social workers who are DHH themselves are often the best social workers for DHH people because they use sign language themselves and also have an intimate knowledge of the obstacles and opportunities one may face with HL. They also have the necessary communication skills to respond to clients in the best way.

In the social model, disability is not seen as a personal limitation or as the individual’s burden. Rather, it is a natural human phenomenon and a social and political issue of rights for the entire society (Oliver & Barnes, 2010). Thus, functional limitations arise in the relationship between the environment and the individual. In the social work context, strategies must be adapted to each individual. People with disabilities who require social services have the right to make demands on the professional’s knowledge, skills, and attitudes. Furthermore, the support and efforts proposed and implemented should be constructed on a solid knowledge base (National
Board of Health and Welfare, 2007). Without suitable solutions, DHH is often mistaken by professionals, when they, for example, do not respond to accusations or have poor writing or oral communication skills. The resultant misinterpretations can lead to the DHH individuals being pathologized as having a low intelligence, disorder, psychosis, or mental retardation (Pollard, 1994). This could be considered an essential issue of public health that can be addressed and advocated by social workers (Barnett et al., 2011).

Therefore, studying the social structures and their economic, health, and welfare ramifications (which are closely related) is crucial. According to the Council on Social Work Education ([CSWE], 2014), social workers are one of the largest groups of mental health and human service providers. Social workers provide a significant amount of health and well-being services. Though health and human services have proven to be a difficult area of service for DHH individuals, it is surprising that little research has been performed to explore how social workers provide services to DHH. For example, according to the National Association of the Deaf (2018), the greatest form of discrimination against DHH individuals is the deleterious insufficient care provided by health and welfare care practitioners, which will be discussed in the next section.

Health and Welfare Access Among the Deaf and Hard of Hearing Population - Could it be Without Barriers?

While physical barriers in the surrounding environment can create feelings of exclusion and hinder the rights of people with disabilities, the welfare system can act as an equally big barrier. The welfare system has its own rules, responsibilities, and decision-making. Those who make the decisions (e.g. social workers, employers, insurance funds, and health care workers) all have important responsibilities, as their decisions have an immediate impact on people’s lives (Lindqvist, 2020).

The political goal of the disability rights movement should be the removal of barriers imposed by social structures and attitudes. Access to health care and the welfare system without barriers is a clearly defined right for all individuals, disability or not disability (The National Board of Health and Welfare, 2020). Therefore, the goal should be to promote the environmental
relative model in society. This will help promote and ensure the social inclusion of people with disabilities, to generate a barrier-free society, and evolve an optimistic identity for those with disabilities (Oliver, 1996). The National Board of Health and Welfare (2020) works to ensure that the Swedish population has equal access to good health and social welfare through high-quality health and social care. For example, Chapter 3, Section 1 of the Health and Medical Care Act (SFS nr, 2017:30) describes the goal of health and medical care as offering quality care to the entire population with the same conditions, regardless of the location in Sweden. Due to the intrinsic value of all human beings, the whole population should also be treated with honour in a way that preserves individuals’ pride when engaging in social services, health, and medical care.

In Sweden, children and adolescents with disabilities are a prioritised group in public health policy. The Swedish National Institute of Public Health (2011) is answerable for viewing how the circumstances for health in children and adolescents have developed in Sweden. However, both children and adolescents with disabilities are less satisfied in school and are more exposed to bullying than children without disabilities. Among people with disabilities, the proportion of people who have self-rated good health is significantly lower than among people without disabilities (SCB, Statistics Sweden, 2020). Research (Nadeau & Tessier, 2006) has shown that adolescents with disabilities have significantly more anxiety, fear, depression, headaches, eating disorders, low self-esteem, body dissatisfaction, and a lower quality of life. Furthermore, children with mild, moderate, or severe disabilities experience more mental health problems and more stress-related symptoms in their daily lives compared to children without disabilities (The National Board of Health and Welfare, 2020). Though many DHH individuals have no physiological difficulties other than hearing loss, they run a higher risk of developing poor mental health and somatic problems than hearing people (Fellinger et al., 2009; Hindley, 2005; Hintermair, 2010; Van Eldik et al., 2005). This could be problematic because the ability to understand and interpret health care information is significantly lower among the DHH than it is among hearing populations (Komaric et al., 2012). This in turn can lead to them not receiving the health care that they need and instead obtaining unnecessary health problems, such as behavioural issues, not related to their HL (Novotney, 2011).
Despite these aims, however, the consequences of HL create a public health problem that affects all ages, parts of society, and occupations in Sweden. Over 496,000 people who are DHH have hearing aids, but another 250,000 people lack these hearing aids and/or other forms of assistance that would allow them to engage in effective communication (Swedish Association of Hard of Hearing People, HRF, 2018). Thus, there is still much work to be done to create the equality and accessibility for which disability policy should strive. For example, people who use sign language continue to experience inequalities in accessing health care, health information, health research, and health-related careers, which restrict their ability to attain optimal good health for themselves and their families. Indeed, people who are DHH have substantially more health problems, including being overweight, exhibiting suicidal behaviours, and also facing domestic violence, more than the hearing population (Barnett et al., 2011). While health care has focused on the causes of DHH, it has missed the emotional and interpersonal needs of this population (Sheppard, 2004, 2015). This has led people who are DHH to feel disadvantaged by health care and to be misdiagnosed by health care professionals due to misunderstandings and misinterpretations (Sheppard et al., 2018). There are also differences in girls’ and boy’s health. Unlike girls (and women), boys (and men) tend to report having better mental health, but, at the same time, have greater problems taking care of their physical health (Courtenay, 2003). Statistics show that DHH girls and women are twice as likely to experience poor health as DHH boys and men (Swedish Association of Hard of Hearing People, HRF, 2018).

In summary, as the text highlights above, both social workers and people in the health and welfare sectors want to do good work for people with disabilities as for the rest of the population, but still there are some barriers that hinder people with HL—for example, communication barriers and a lack of knowledge about DHH situation. This must be addressed to promote feelings of inclusion and well-being among people with disabilities. For example, there should be qualified interpreters who are competent in interpreting services effectively, precisely, and in an unbiased manner in the living area to guarantee that resources can be made available when the client needs it. The Public Administration Act (13 § 2017: 900) and the Health and Medical Services Act (HSL) both stipulate the right to a language interpreter when a person/patient who is not fluent in Swedish has contact with authorities.
The regions' interpreting centres have an obligation to provide so-called everyday interpretation to the DHH and to deaf-blindness as collective groups. This obligation is legally protected in the HSL. Thanks to a report (The right to an interpreter - no question of interpretation, 2020) from the Swedish Association of the Deaf (SDR), Swedish Deaf Youth Association (SDUF), Swedish Association for the Deafblind (FSDB), and The National association (DHB) (2020), research has been conducted on the available interpreting services in Sweden. In the report, each of the regions in Sweden maintained the freedom to decide how their local economies would be prioritized. As such, acquiring an interpreter when you need one was dependent on factors such as: (1) where in the country you live, (2) when in the year you requested interpretation assistance (it is easier at the beginning of the year than at the end), and (3) the type of event you are attending (it is easier to get an interpreter for a wedding than to engage politically in your spare time). Sweden should follow in Finland’s example, where DHH individuals have the right to a minimum number of hours per year with an interpreter and are guaranteed ample opportunities to apply for additional interpreting hours. But though Finland’s example is better than Sweden, what should transpire when the 180 hours are over? According to our laws, which have been presented in these two sections, this is not the correct way to make people feel included from a social work perspective or from a health and welfare perspective.
Research on the Deaf and Hard of Hearing Population

This section presents the research relevant to the present dissertation. Most of the studies presented in this chapter address DHH experiences during school, work, and leisure times. This section is organized into four main units. The first section focuses on what it means to be DHH. The second section highlights school experiences. The third section presents the research on the labour market pertaining to DHH, and the final section covers the social interactions and relationships of people who are DHH.

Being Deaf and Hard of Hearing

How an individual feels about themself during childhood and adolescence, both in terms of mental and physical health, is important; studies have shown that hearing loss can lead to an unhealthy quality of life associated with isolation, decreased social activity, and symptoms of depression (Iwagami et al., 2019; Kochkin & Rogen, 2000; Kral & O’Donoghue, 2010; Swedish National Institute of Public Health, 2011). Many DHH individuals become depressed, have a higher degree of illness, and often have poorer health and a more negative self-image than the hearing population (Punch & Hyde, 2011). They often receive inadequate—and sometimes completely inaccurate—care, violating the most fundamental principles of ethical medical practice (Brakstad, 2012). Although DHH is not a cause of mental health problems, some associated issues, such as fatigue, stress, and poor health, can arise and increase the risk of mental health symptoms. Some research has discussed the links between hearing loss and mental distress, which can include a wide range of symptoms, such as anxiety and depression (Fellinger et al., 2012; Saito et al., 2010). Additionally, anxiety and depression could lead to health inequities,
mainly through stigmas, discrimination, and social exclusion (Nakkeeran & Nakkeeran, 2018).

DHH citizens with an additional disability have a more difficult time both in school and at work than hearing students or those with just DHH alone. Describing DHH with other disabilities is a challenging task that has been attempted by numerous authors (Ewing & Jones, 2003; Guardino, 2008; Guardino & Cannon, 2015). The possible combinations of disabilities with DHH are almost limitless, so specific subgroups will not be addressed here. However, a few examples of the most common ones include tinnitus, specific learning disabilities, cognitive impairment, attention-deficit hyperactivity disorder/attention deficit disorder (ADHD/ADD), and emotional behavioural disorder (Guardino, 2008). It is common for children with HL to have another disability, such as tinnitus and a reading and/or writing disability (Musyoka et al., 2017). In fact, approximately 25–33% of children with HL have multiple potentially disabling conditions (Holden-Pitt et al., 1998; McCracken, 1994; Moeller et al., 1990).

**Being a Deaf and Hard of Hearing Student**

According to the School Act, schools in Sweden must consider the different needs of their students and make adjustments to provide the support that every child needs to develop as much as possible (SFS, 2010). As mentioned previously, parents can choose between special or mainstream schools regardless of their child's level of disability (Tvingstedt, 1998). Most DHH students in Sweden attend mainstream schools (80%), which is similar to the rate in other countries, such as Australia (85%; Power & Hyde, 2002; Punch et al., 2004), the UK (85%; Berry, 2017), and the US (85%; Data Accountability Centre, 2008). Despite the high number of DHH students who attend mainstream schools, few studies have focused on mainstream schools in Sweden within recent years (see Tvingstedt, 1993; Bagga-Gupta, 1999; Heiling, 1999; Brunnberg, 2003; Holmström, 2013).

Research has indicated that DHH students who have attended both special and mainstream schools have expressed that academic demands are higher in mainstream schools. These demands lead to increased commitment to school, which produces better academic outcomes and
social skills (Hao et al., 2018; Todorov et al., 2021). Research has also shown that DHH students in mainstream schools get better grades and increased opportunities for social interaction with hearing pupils and teachers, which can promote social inclusion in the future (Hendar, 2008; Lynas, 1999). Hintemair (2010) found that positive DHH participation in mainstream classrooms, including good communication and social experiences with peers, is important for promoting students’ quality of life, good mental health, and good social relationships. In adolescence, the ability to have conversations with peers and other important people is crucial for feelings of inclusion. In contrast, a lack of social skills can lead to rejection by others and place individuals at risk of developing mental health problems (Radovanović et al., 2020). Furthermore, a lack of interaction with the social environment can lead to situations like unemployment or marginalisation (Elksnin & Elksnin, 2006; Davidsson & Petersson, 2017).

Conversely, research has found that DHH students who feel isolated and lonely in mainstream schools do not reach educational goals to the same extent as hearing students. Coniavitis Gellerstedt (2008) showed that students with DHH in mainstream schools experience poorer school situations than those who go to special schools or hearing classes. One explanation could be the communication difficulties. DHH students in mainstream schools have to work hard to adapt to teachers and peers while absorbing the necessary information (Dalton, 2013). Doing so is energy intensive and provides little time for other activities. Furthermore, DHH students educated in mainstream schools need more eye contact from the teacher and more help to follow the teacher’s instructions (Tsach & Most, 2016), and complying with listening to the teacher or the other students requires more effort from these students (McGarrigle et al., 2019). Such intensive effort usually leads to fatigue (Hornsby et al., 2017). Moreover, a Swedish study by Hendar (2005) that examined children with HL who attended special schools found that 40% of the children had additional disabilities and needed special support to manage school. Generally, the combined difficulties caused by HL associated with some other disability have a negative impact on adjusting to education and work (Jarvelin et al., 1997).
Coniavitis Gellerstedt (2014) also stated that sound in mainstream classrooms rarely meets the requirements for optimal teaching conditions. The sound environment is of great importance for learning, problem solving, memory, concentration, and communicating. This means that it is especially important to have a good sound environment in rooms used for teaching, concentration, and communication (Iglehart, 2016). Obstacles in the environment affect the students’ learning, and background noise is one of the factors that leads to barriers for DHH students in school (Gremp & Easterbrooks, 2018).

Another obstacle in mainstream schools is developing close friends. Since school is a major part of all young people’s everyday lives, it plays an important role in their social relationships (Korp & Berhanu, 2014) and identity development. Those who experience a greater community in school have a more positive self-image and better self-esteem (Grover et al., 2015). Holmström’s (2013) study of interactions in mainstream schools shows that mainstream classrooms are often prepared with serval hearing technologies, instead of focusing on DHH students’ needs. The results showed that these DHH students sometimes felt marginalized. Studies have also shown that young people who are DHH experience fewer close social relationships and value their self-esteem more poorly than hearing young people do (Mejstad et al., 2008; Schick et al., 2012). Punsch and Hyde (2005) showed that most DHH students in mainstream schools had few close friends and often felt lonely.

Additionally, DHH adolescents felt that they were unlike other adolescents in school because of their assistive audiological equipment (Berry, 2017; Terleksí et al., 2020). Scherer (2002) addressed this duality of Assistive Technology (AT); AT is not only a tool for achieving independence, but it is also a visible sign of disability. Individuals with hearing aids are assessed more destructively by the hearing population regarding characteristics like intelligence, accomplishment, and behaviour. This phenomenon has been recognised as “the hearing aid effect” by several researchers (Blood et al., 1977; Blood et al., 1978; Brimacombe et al., 1983; Cameron et al., 2008; Cienkowski & Pimentel, 2001; Dengerink & Porter, 1984; Johnson et al., 2005; Ryan et al., 2006). Thus, having HL can lead to feelings of shame and guilt attached to the condition (Hétu, 1996).
Most studies on inclusion for people who are DHH have found that attending mainstream schools can result in feelings of isolation, rejection, and loneliness (Stinson & Antia, 1999). DHH students have difficulty forming social relationships with their hearing peers. Some have friendships with hearing peers but have little or no interaction with them outside of school, and DHH students feel excluded, isolated, and lonely more often than their hearing peers (Antia & Kreimeyer, 1996; Martin et al., 2011; Nunes et al., 2001; Wauters & Knoors, 2007; Xie et al., 2014). There were also different barriers that DHH had to overcome. Some of these included accepting their HL and linguistic difficulties as well as educational and cultural differences. These barriers could lead to different mental health issues for DHH students (Bratt, 2018).

Several of these issues that arise in compulsory and high school continue also at the university level. Studies have shown a continuation of these barriers, such as problems with communication, identity, fatigue, and inclusion (Antonson, 1998). DHH students who enter University may be used to attending smaller classes with well-developed technology. In University, there are often larger classes and a lot of group work. For these students, the transition to the University environment can be stressful to handle. The academic level of students has also been shown to influence whether the student is included socially. If they cannot participate in conversations in the same way as others due to their hearing loss, the students are automatically excluded, especially when work is to be done in a group context. Several DHH people have stated that they feel stupid because they do not understand what the people around them are saying (Aberdeen & Fereiro, 2014; Bennion & Forshaw, 2013). The DHH students also felt that hearing students had a deviant attitude, such as excluding them when they perceived that the DHH students differed from what they considered a normal behaviour (Antonson & Danemark, 1994).

A completed upper-secondary education is a basic necessity for achieving successful establishment in society. In Sweden, less than 40% of employed persons with disabilities have post-secondary education as their highest level of education. In comparison, 49% of the employed population has received post-secondary education (SCB, Statistics Sweden, 2019). Moreover, 38% of women with disabilities have received post-secondary education, compared to 25% of men with disabilities.
The level of education among people with disabilities has remained about the same since 2014 (SCB, Statistics Sweden, 2019). This lack of education could lead to exclusion from the community; research has shown that individuals who fail to complete their secondary education often end up in unemployment and/or early retirement (Olofsson & Öst, 2011; Olofsson, 2014). A large Swedish study of the DHH population examined the post-school outcomes. Rydberg, Gellerstedt, and Danermark (2009) have studied equality in education between the hearing and DHH. The results showed that school started 50 years later for DHH than for hearing. It also turned out that DHH people had received more vocational training, while hearing people had the greater opportunity to learn theoretical subjects. The results revealed that the educational levels were lower in the DHH group than the hearing group across all age levels, and only 5% of the DHH population had completed at least three years of post-secondary education (Rydberg et al., 2009). DHH students also have difficulties being included in the mainstream’s settings. Both DHH boys and DHH girls feel an increase in loneliness and anxiety and experience a lower level of social support, even if they are involved in their studies and do not experience more stress than hearing students (Movallali et al., 2018). Thus, despite normal intelligence and abilities, the DHH population continues to have lower completion rates for postsecondary education (Stinson & Walter, 1997) and higher rates of unemployment (Blanchfield et al., 2001; MacLeod-Gallinger, 1992; Schroedel & Geyer, 2000) than the hearing population.

People with disabilities have greater difficulty coping in school and being established in society. This can lead to alienation and social exclusion after school, both in their working lives and social interactions. Though the number of DHH students registered in post-secondary education has increased globally, the amount of DHH participation still does not match that of the hearing population (Punch et al., 2004). This highlights the importance of preparation for higher education when planning DHH students’ transitions to the labour market (Lang, 2002) and employment (Emmet & Francis, 2015).
Navigating the Labour Market as a Deaf and Hard of Hearing Person

People who are DHH experience difficulty gaining suitable employment and progressing in their careers, even when their knowledge and educational levels are sufficient or more than sufficient. Many studies have shown an important link between education and occupation. A person’s educational level is a key factor in understanding the employment status of adults who are DHH; Commonly, individuals that have finish higher education have better work opportunities (OECD, 2012). The level of educational accomplishment also affects the type of occupation a person can pursue. How DHH individuals are treated in elementary school and then by colleagues, employers, and supervisors has a big impact on how they perceive their HL (Swedish Association of Hard of Hearing People, HRF, 2009).

Thus, colleagues and supervisors should take adaptive measures to improve the working environment for people who are DHH. The DHH population has a more difficult working life than hearing people; they experience negative psychosocial consequences at work, such as emotional distress, fatigue, exclusion, and stress. One explanation of that is that their work environment is not typically adapted with the right sound environment or work aids (Danermark & Gellerstedt, 2004; Kramer et al., 2006; Morata et al., 2005). Thus, the work environment can cause stress for the DHH population, which can in turn lead to stress-related issues, such as tense muscles and headaches (Danermark & Coniavitis Gellerstedt, 2004). Another research in the labour force in Sweden showed that DHH individuals more frequently report less physical health and psychological well-being than hearing individuals at the same work (Coniavitis Gellerstedt & Danermark, 2004). Furthermore, research has shown the positive impact of meaningful work on different aspects of life. Several of these aspects include economic benefits, the need for organization on a daily basis, the need for social interactions outside the family, the need for approval and status, and the need for identity (Barnes et al., 1999; Szebehely et al., 2001).

While numerous people who are DHH have attained a wide-ranging variety of occupations and fulfilling careers, this population has historically experienced greater unemployment and underemployment rates
and lower levels of educational attainment compared to hearing people (Anon, 2006; Capella, 2003; Danermark, 2006; MacLeod-Gallinger, 1992; Punch et al., 2004). Emmet and Francis (2015) examined the employment, education, and income levels of DHH people using data from a nationally representative study of adults aged 20–69 years. They found that DHH individuals were nearly two times likelier to be unemployed or underemployed and to have lower levels of income than hearing people. One factor in this difference was that the DHH adults had lower levels of education than hearing individuals. Their challenges and communication barriers, development of reading skills, and educational accomplishment all resulted in partial work opportunities.

Those with DHH also face some attitude barriers from co-workers. Buchanan (1999) stated that, in addition to resistance to employing DHH individuals, the automation of many job functions reduces opportunities for uneducated DHH. In an older study, Hétu, et al. (1990) recounted that several colleagues confessed that they had a negative view of DHH individuals. On the opposite side, DHH employees were asked how they felt about discussing their HL. Several reported that they had experienced derogatory statements concerning their hearing from their colleagues. In another study (Hétu et al., 1994), DHH participants reported that they felt the need to hide their HL due to attitudes from colleagues. In the focus groups, it was found that HL was perceived as a very negative trait. Throughout that study, it became evident that DHH individuals felt that they had to hide their HL in order to be accepted and they were also worried about losing their jobs. The same pattern was shown in a Danish survey, which showed that just over 40% of the participants did not say anything about their HL at work because of their colleagues’ attitudes (Clausen, 2003). Supporting data from the Swedish Association of Hard of Hearing People (HRF, 2008) regarding Swedish conditions found that two-thirds of DHH people did not report their HL at work to avoid being treated differently from hearing co-workers.

Feelings of isolation and exclusion are also experienced by the DHH population at work. Negative emotions, such as social exclusion, withdrawal, shame, anxiety, fear, and a feeling of being misunderstood at the workplace, have psychosocial effects. Often, this is connected to the surrounding sounds, which are perceived as disturbing and tiring (Hua et al., 2015; Tye-Murray et al., 2009). According to Danermark and Coniavitis
Gellerstedts (2004), a larger proportion of people with HL experience physical and mental stress in the workplace than those with normal hearing. The most difficult workplace situations reported by many DHH individuals, however, involve group situations, such as departmental and staff meetings, in-service training sessions, and work-related social functions (Laroche et al., 2000; Scherich, 1996; Scherich & Mowry, 1997). All of these situations are affected by the fact that there are several people in a room sitting and discussing at the same time.

DHH workers have reported feeling socially isolated and lonely in the workplace, experiencing exclusion from social communications and interactions (such as those that occur during lunch breaks), and feeling like they have missed important information and informal conversations (Foster & Macleod, 2003; Steinberg et al., 1999). Significant factors in a positive working climate for DHH people are helpful colleagues and good employer support. Social support at work can come from co-workers and supervisors and from colleagues trying to understand how to communicate in the best way or help with certain tasks, such as answering the phone (Baldridge & Swift, 2016; Dong & Guerette, 2013; Haynes & Linden, 2012).

**Social Interactions and Relationships for Deaf and Hard of Hearing People**

Access to hearing is necessary for a variety of practical purposes in everyday life. For example, people need to locate where a sound comes from, be able to present their speech and express their needs, hold a dialogue and communicate, etc. Access to hearing is, therefore, of particular importance to relationships, self-image, and how individuals deal functionally with different situations—for example, in school, at work, and during leisure time (Andersson & Arlinger, 2007).

Being excluded from social contexts due to HL is more common than unusual, and social loneliness and isolation from others are common experiences for those with HL (Margaret Brown & Cornes, 2015). For this population, being excluded from hearing groups at school, at work, and in daily life is normal (National Research Council, 2004). These trends are supported by previous research that identified the importance of
speech intelligibility and auditory abilities for inclusion (Duncan et al., 2021; Eichengreen & Zaidman-Zait, 2020; Most et al., 2012).

Communication skills are essential to achieving feelings of inclusion and having relationships in different social settings. According to Glick and Rose (2011), social relationships can even encourage social communication skills. Punsch and Hyde (2005) also highlighted the importance of communication in achieving social relationships, showing that DHH people feel limited by their HL and believe that they would be more social and outgoing, have more friends, and be more popular if they did not have HL. These findings have been confirmed in other research on the importance of social relationships (Antia et al., 2011; Bat-Chava & Deignan, 2001; Bat-Chava et al., 2005; Batten et al., 2014; Leigh et al., 2009; Most et al., 2012).

Communication type (speech or sign) is also an important predictor for the friends and partners of people who are DHH. Even though they want to have hearing friends, people with DHH will choose friends from the same population depending on their communication skills (Antia et al., 2011; Nikolaraizi & Hadjikakou, 2006; Wauters & Knoors, 2008). Indeed, communication problems are one of the main barriers to establishing friendships with hearing people. Misunderstandings and intolerance can occur when DHH individuals have conversations with hearing people, and such complications have been shown to result in fewer social relationships for people who are DHH (Bat-Chava et al., 2005). One hindrance to social relationships with hearing people could be that this population is unable or unwilling to learn different ways of communication that work for DHH people and allow them to be part of social interactions (Olivia, 2004).

Information and communication technologies (ICT), such as smartphones, tablets, the internet (e.g., Facetime and Skype), and social networking sites (e.g., Facebook, Instagram, and Twitter), have become essential for people with DHH to interact in social forums with friends (Toofaninejad et al., 2017). Another essential tool for interaction is AT, such as hearing aids and other tools, devices, or systems that allow a person to perform a task in an easier and safer way. ICT and AT are vital for inclusion within different social contexts like school, work, and leisure time with friends, as they allow persons who are DHH to participate fully in society, education, and work (Maiorana-Basas & Pagliaro, 2014). Many
people with DHH have attained social interactions and relationships through ICT, such as participation in chat sites and social media, which has led to perceived good communication and closeness among friends and family members (Joo & Teng, 2017). Furthermore, ICT tools give people who are DHH the ability to express themselves and share these visual expressions widely. Useful tools, such as text/videophones, smartphones, and the internet, can be a key factor in enabling individuals who are DHH to participate in daily life and be included in society without communication barriers (Akamatsu et al., 2006; Pilling & Barrett, 2008).
Theoretical Framework

The previous sections have clarified the topic and context of this dissertation. This section discusses the theoretical approach and how some of the central concepts are interpreted. The aim of this section is to explain how identity, social inclusion, and social exclusion are understood. A framework was applied to explain the relationship between DHH and experiencing either social inclusion or social exclusion. Social interactions can be challenging for anyone to achieve, but it can be a bigger barrier for those who are DHH because effective interaction depends on communication, social awareness, and the appropriate timing of behaviours (Engels et al., 2002).

This framework also applies the concepts of *identity*, *stigmatisation*, *marginalisation*, and *group membership*. These concepts will be explained from a symbolic interactionism theory that addresses how society is shaped and maintained through frequent social interactions among individuals (Cooley, 1902; Goffman, 1967; Mead, 1967). Like other people, the identity of people who are DHH is created by individuals through self-perceptions, as well as others’ perceptions (Stier, 2003). Vital for symbolic interactionism is the idea that individuals use language and significant symbols in their communication with others (Mead, 1934), which will be linked to DHH individuals. Identity is based on roles, other people’s attributions, social constructions, and language. These are essential skills to participate in socialisation and communicate with others. However, someone who is DHH may use language differently from hearing people and may not be able to carry on conversations in the same way; this can result in feelings of being left out and unable to make friends (Luckner et al., 2012), which could in turn lead to feelings of stigmatisation, isolation, marginalization, or social exclusion. In this theoretical framework, these concepts will be problematised in the light of DHH individuals’ lives. Finally, at the end of this section, an overview of how these theories have been used in the four studies will be presented.
Identity, Group membership and Stigma

Identity
The concept of identity is complex and can be explained and described in different ways, and an unambiguous or simple definition of identity does not exist. "Who am I?", is a question that is not always easy to answer and has led researchers for centuries to try to find out what identity is (Bergen & Braithwaite, 2009). Erikson (1968) believed that identity develops throughout life. According to Erikson, identity is an individual’s experience of himself as a person in a social context through life, the person’s individual style, and how it is perceived by the individual himself and by people in the individual’s environment (Erikson, 1968). To understand the human self and what characterises the individual, an understanding of how different contexts affect a person’s various identities is required (Crisp & Turner, 2010). Still, identity and how it is and is not identified must be determined, as many complex views on identity exist.

At the daily level, identity represents the characteristics that collect people into different groups and allow them to choose where they belong. For example, in society, people are commonly categorised and labelled (e.g. woman, man, Swedish, Spanish, etc.). In most cases, individuals describe themselves in terms of occupation, income, age, housing, etc., which highlights their social position, taste, and style. In other words, identities are formed in comparison to someone or something (e.g., hard of hearing, hearing, or deaf) (Stier, 2019).

Identity also develops through the social constructs that exist in the society in which the individual lives through interactions with others (Burr, 2015; Giddens, 1997). Both Cooley (1902) and Mead (1934) claimed that identity develops through social interaction; thus, everything around the individual influences his/her behaviours, ways of thinking, and beliefs about what is right or wrong (Giddens, 1997). These behaviours, mindsets, and feelings change depending on whom the individual is interacting with, what the individual does, and their motivation (Burr, 2003). If an individual is not able to live up to others’ expectations, this can affect the individual’s self-perception, which is an important part of identity (Stier, 2019).

Many attempts have been made to explain what ‘identity’ is. In this dissertation, the understanding of identity is based mainly within the works of
Mead (1934), Cooley (1902), and Goffman (1963). Mead (1934) explained identity as “the self”, or an individual’s own entity. In Mead’s concept of the self, a person is able to see him or herself not only as a subject, but also as an object. Mead (1934) believed that only by the individual gaining experience of various social interactions could they then become self-aware and exist as an individual consciousness. We achieve identities based on what is predictable and how we want to be perceived. These identities are established through communication, both through language and our behaviours (Carbaugh, 1996). For Mead (1933, 1938), the ‘self’ arises as a result of reflexivity—the individual’s capability to reflect back on their own thoughts and achievements in social interactions and social relationships (Howard, 2000). Thus, Mead (1934/1976) believed that the self is expressed through two different phases—“I” and “Me”—which attempt to explain the different dimensions of the self. The human reflexivity may appear in the form of the internal dialogue between the “I” and the “Me”. These concepts cannot be distinguished, as the self cannot exist without one or the other. “Me” is based on the fact that, in relation to “us”, we use the words to take over the other’s attitude. The “I” stands for a spontaneous response to this attitude takeover, which by definition cannot be expressed in language (Mead, 1934/1976). Without “Me”, “I” would have nothing to relate to, no framework of experiences for social situations. Without “I”, no new experiences would be made. Thus, Mead viewed identity as a process in which the key elements for identity construction are social interaction and social surroundings (Mead, 1934/1976).

The “generalised others” and “significant others” are two more key concepts discussed by Mead (1976) that have a great impact on identity and personality. Generalised others can be seen as society and its prevailing collective norms and attitudes, while significant others stand for a person’s close contacts. In other words, they are the people who are of great importance to the individual and, therefore, have a great impact on him/her (Mead, 1934/1976).

Cooley continued Mead’s work by explaining that the self and society were part of the same phenomenon and that they were both interdependent (Carbaugh, 1996). Cooley believed that our identities, both consciously and unconsciously, were constantly affected by societal messages. The same applies to our own actions, which, in turn, are informed and influenced by society (Carbaugh, 1996). Both Mead and Cooley found that there were
variations within the self that were all based on the social interactions we have around us.

According to symbolic interactionism, individuals use language and significant symbols in their communication with others, which is also a significant feature of identity, because language is used to generalise others. In other words, communication works as an important aspect of learning about the self and the social world we are living in. According to Giddens (1997), in communication with others, individuals can experience participating in society. If communication does not occur, the individual risks feeling isolated and excluded, which can lead to a negative self-image and self-esteem. Therefore, communication with others is a fundamental part of building social relationships, which are essential for socialisation and experiences that allow individuals to grow as they interact with others. Giddens (1997) believed that all individuals need others—that comparisons and reflections with others allow individuals to find a place of belonging and stability, which is important to identity. While Giddens believed that identity is changeable and dynamic, like Mead, he also focused on the individual’s choice about who he or she wants to be and be seen as by others (Giddens, 1997; Mead, 1934/1976). According to Giddens (1997), this choice is based on a series of decisions that an individual makes according to his/her knowledge and experiences. Erving Goffman (1959) confirmed Mead’s (1938) argument that the identity of an individual is constructed through social interactions.

According to Goffman (1963), ‘identity’ can be defined in three ways: (a) “personal identity”, (b) “social identity”, and (c) “Ego-identity”. The “personal identity” is rooted in the individual’s personality and character traits that make him or her truly unique. This identity refers to the qualities that distinguish one individual from another, such as his/her social security number, fingerprints, appearance, and handwriting. This is the idea that two people could never be the same. It doesn’t matter if two individuals share the exact same socialization experiences or are in the identical group or have exactly the same ideas; every individual is unique. The “personal identity” must constantly relate to other subjects; thus, there is always a relationship between the self and the other, as well as an exclusion (Ricoeur, 1992). “Social identity” relates to social interactions with others. For example, when individuals meet a person for the first time, they usually attribute characteristics to the person based on a first impression of, for example, appearance, body language, and social interactions as well as stereotypical expectations.
Individuals, therefore, have expectations of how others should act according to these stereotypical assessments. When someone possesses a trait that is not compatible with stereotypical expectations and this trait cannot be avoided, the individual can be classified as stigmatised (Goffman, 1963). Social and personal identity thus to a large extent constitute others’ definition of and expectations of the individual, while the “Ego-identity” of identity can be described as the individual’s self-perception (Goffman, 1963). Goffman claimed that the “Ego-identity” is a subjective and reflexive phenomenon. It is the image of oneself that an individual acquires through their various social experiences. While others also build this image, the individual has extra freedom to modify it. By examining the “Ego-identity”, the feelings the individual has towards his or her stigma can be identified.

Identity and hearing are interconnected because of the negative impact of HL on the individual’s self-image. People who are DHH experience feelings of being abandoned and isolated from society because they are not able to communicate fully, which threatens their identity. Being seen as they see themselves is important. Thus, revealing a HL or hearing aid gives the environment a chance to change the overall picture of who the individual is (Espmark et al., 2003). The individual defines, analyses, and assesses him/herself based on which group he/she belongs to. This group provides the individual with several collective self-images—that is, a social identity that may vary in number depending on how many groups the individual belongs to (Hogg & van Knippenberg, 2003). As Goffman (2005) argued, belonging to a group of people with the same characteristics as oneself is essential. People can share common anomalies when they sense a community and moral support with others. For example, central to symbolic interactionist thought is the idea that individuals use language and significant symbols in their communication with others. According to Helkama (2004), our self-perception and identity have a close relationship to which group we belong to. Status and power differ between different groups, and minority groups belong to those who have a lower status in society. Low status causes negative effects of various kinds and assumes that the identity that is determined by group membership is maintained because of comparison with other groups; the self-esteem of individuals who are members of a minority group is also reduced.


**Identity and Group Membership**

Crisp and Turner (2010) described how identity can also be viewed from a social perspective. This is shown in how strongly people tend to categorise circumstances, events, other people, and themselves into meaningful and guiding categories that create ways to assess, organise, and clarify the world around them. By categorising themselves based on which groups they belong to, consider themselves to belong to, or wish to belong to, people create an important identity (Christensen, 2004). The identity is not only linked to an individual trait, but it also has several collective points of reference, such as lifestyle, gender, and class affiliation. It also has distinct points of reference to our individual histories, such as HL and SSL (Johansson, 2018).

Based on symbolic interactionism, identity theory (Cooley, 1902; Goffman, 1967) is founded on the relationship between society and individuals. The theory assumes that identity is derived from roles, other people’s attributions, social constructions, and performances (Banton, 1965; Goffman, 1967). Social constructions, which are rooted in language, create the image of a human. People’s character, thoughts, feelings, and experiences are also the result of language (Burr, 2015). An individual’s sense of self is part of his/her social behaviour; thus, the sense of self occurs and is defined and redefined through social interaction. Members in certain groups recognise or share a certain language, beliefs, norms, and culture; they also share common images of identity that exceed individual group members and are reflected in cultural factors (Burr, 2015). You do not have to be physically deaf to define yourself as deaf. Åkerström (2005) believes that it can be an identity that is embraced as well. A deaf identity can be understood as part of the individual’s identity in the same way as the gender identity (Fredäng 2003).

In a social relationship between people who are DHH and their hearing friends or partners, both groups may experience fatigue, stress, anxiety, depression, isolation, and a negative self-image resulting from communication difficulties (Hétu et al., 1993). Isolation and exclusion are strongly bound to the loss of social relationships. In fact, the inability to communicate with one’s surroundings can lead to deviant behaviours, as communication is essential to social relationships, shared decision-making, and autonomy (Worrall & Hickson, 2003). For people with HL, the disability is of a communicative nature (Danermark, 2006), and communication is a prerequisite for social community that affects the individual’s self-esteem and identity.
Tajfel (1978) argued that personal identity guides an individual’s behaviour when they are alone or have social interactions with friends or colleagues. The “right” way to behave is determined by the values and norms upon which the group has decided, either consciously or unconsciously. According to Danermark (2006), an unspoken norm of full hearing creates feelings of shame or stigma about HL.

Stereotypes allow individuals to create simplified categorisations or collections of characteristics to understand other people (Allport, 1954). Stereotypes, prejudices, and discriminations are terms used to describe stigma (Tye-Murray, 2009). They serve as a method for identifying individuals from other groups based on characteristics such as age, disability, gender, occupation, race, etc. Stereotypical perceptions are about occasions when unique individuals are lumped together into homogeneous groups that are assumed to think and act in a similar way (Haslam et al., 2002; Tajfel & Turner, 1986). Stereotypes are biased against another person according to which group he/she belongs, which can lead to preconceptions of other people (Fiske et al., 2002). While stereotype dimensions are stable across cultures (Fiske et al., 2007), different groups are positioned differently in different cultures (Fiske et al., 2002). Fredäng (2003) believes that the environment’s perspective on deafness makes its mark on how deaf people develop their identity. For DHH who use SSL, individuals have a tendency to have negative stereotypes of them. An example of where this might manifest would be society’s view of sign language, which is primarily used as a visual aid in communication and not as an independent language. This means that they are based on the general hearing criterion and that they categorise the deaf together with hard of hearing (The government’s official investigations, (SOU, 2006:29).

It is important to point out that stereotypes can be both positive and negative. Individuals are lumped together with a group that is attributed positive traits and high expectations, or that the person is given negative traits and low expectations. Both forms of stereotypes mean that individuals’ unique characteristics are ignored (Haslam et al., 2002; Tajfel, 1978). Stereotype threat arises when individuals become aware of negative stereotypes related to a group identity; this can cause individuals to experience a worry about confirming that stereotype (Steele & Aronson, 1995). Group identity is significant in the identity process. Identity creates a certain self-perception and affects self-esteem positively or negatively based on the status one’s group membership has. People tend to compare different groups to maintain a
positive identity (Helkama, 2004). Research has indicated that group stereotyping and preconception are more expected when identities are noticeable, while moderating the salience of intergroup variances can alleviate prejudice (Bigler & Liben, 2006; Hewstone et al., 2002).

According to Helkama (2004), self-perception and identity have a close relationship with the group to which an individual belongs. Status and power differ between groups, with minority groups possessing a lower status in society. Low status causes negative effects of various kinds. Because the identity that is determined by group membership is maintained through comparison with other groups, the self-esteem of individuals who are members of a minority group is also reduced. Identity theory states that individuals express an ingroup bias by emphasising their favour of the in-group over the out-groups (Abrams & Rutland, 2008; Tajfel & Turner, 1986). Thus, group membership is an essential part of an individual’s self-concept; individuals socially categorise themselves and others, and by preferring their in-group, individuals maintain a positive identity and increase their sense of self-worth (Tajfel & Turner, 1986). Identity and group membership are therefore important conditions for feeling socially included.

Group identity is shaped by a collective feeling of “we”, which infers a strong emotional kinship and belonging with others in the same situation (Fredäng, 2003). However, for people with HL, being part of the hearing culture can be a struggle due to communication barriers. Individuals’ lack of success in finding friends with whom to identify can lead to exclusion and isolation in school, at work, and during their leisure time. This causes individuals to distance themselves, expressively or unwittingly, from hearing people to evade problematic situations in which they might be misjudged. Such withdrawal can lead to a lack of social interactions and relationships with hearing people. According to Cooley’s (1902) theory of the looking-glass self, individuals see themselves in a mirror and then start to imagine how they seem to others. Based on this imagination, they anticipate what others think of them, which evokes a subtle reply. Positive definitions from others are reflected in favourable self-views, while negative definitions have the opposite effect.

A key aspect of every human being’s development is the ability to interact socially (Rahim, 2010). When casual social interaction turns into more regular contact, it evolves into a more emotional relationship, and the term social relationships is used instead. Communication creates social interactions.
and maintains social relationships (Rose & Montemayor, 1994). Our self is formed through communication with others and, according to Mead (1934/1976), it is impossible for anyone to grow a self in the absence of social interaction and social relationships. Communication is often based on verbal conversation, which could be a challenge for DHH individuals.

Collins and Repinski (1994) argued that close relationships are ones in which two people interact with each other frequently in different environments and exert significant influence on each other’s thoughts and behaviors. Social interactions and relationships are essential for an individual’s identity process and self-esteem, and they impact people’s physical and psychological well-being. These social interactions allow individuals’ self-perceptions to be grounded on how others view them (Rahim, 2010).

Context is also a significant aspect of group membership. Good self-esteem requires a balance between an individual’s personality and identity, and the construction of this identity depends on the context in which the individual lives (Read et al., 2015), as the social situation affects an individual’s understanding of him or herself. Part of the person’s identity is created by the individual’s perceptions of the self, while the other part is created by others and their perceptions of the individual. If the knowledge of the self does not match others’ knowledge of the person, it can arise.

DHH individuals often switch between deaf, hearing, and DHH identities depending on whom they meet or in which situation they are (Fellinger et al., 2007). According to McIlroy and Storbeck (2011), DHH individuals continually seek to experience a sense of belonging in the deaf and/or hearing world. Additionally, identifying as deaf or HH can be a way of adapting to society and avoiding being discredited and perceived as non-adaptive. DHH individuals must thus determine how strongly they identify with each culture. Individuals’ identity or group membership is not static, but rather dynamic, changing with the situation and context. For example, in some situations, people who are DHH are experienced as being deaf (e.g. when they are swimming and must take off their hearing aids). This different context can complicate DHH identity and, in turn, lead to stigma. In this area, DHH individuals face a number of threats in how they construe their identity and group membership, both in navigating stigma and maintaining access to needed support (Hétu, 1996).
Stigma

One of the things that has a big impact on how individuals view themselves and how individuals and groups are marginalised is the concept of stigma (Goffman, 1971). The concept of stigma comes from a Greek word that denotes bodily signs to indicate something unusual or an impairment of a person’s moral status (Goffman, 1971). The term ‘stigma’ is used to refer to a particular attribute (which can also be a moral attribute) for which a person carrying that attribute can be discredited and suspected. Through this act, the stigmatising party is able to consolidate their normality. However, stigmatising does not have to coincide with the normality of this party, nor does the stigmatised party have to possess any real suspected trait (Goffman, 1963). Thus, stigma is a social construct based on differences between people due to special characteristics that result in depreciation. Stigma also involves the process in which the environment defines a person as aberrant, and it is often found in the context of disability (Möller & Nyman, 2003). Stigmatisation arises because of people’s reactions to a group or individual due to negative stereotypes, prejudicial attitudes, and discriminatory behaviours (Major & O’Brien, 2005; Tye-Murray, 2009). A ‘stigmatisation process’ can thus consist of actions and values, as well as institutionalised phenomena, that are intended to give a certain person or group a stigma. This process is created through the use of symbolic mechanisms within a system of opposites; as a result, it consists of an unequal power relationship in which the classifying party has access to sufficient resources to achieve an interpretive preference for reality. Additionally, the stigmatised party can, through the integration of others’ expectations, exhibit uncertain behaviours that submit to maladministration, shame, and poor reputation (Goffman, 1963).

The stigma towards DHH people lies within the negative perceptions and attitudes of the normal-hearing population. This stigma leads to discrimination and exclusion, which can affect the well-being of those who are DHH (Dahlborg Lyckhage, 2015). Some DHH individuals have incorporated the negative perceptions and feelings associated with HL—that is, these feelings become that individual’s own internal oppressors. DHH people generally try to hide their HL in social settings, and they apply self-stigmatisations by reflecting their views on what a person with HL is believed to be.

Self-stigmatisation can be summarised as an individual’s cognitive, emotional, and behavioural responses to expectations and experiences of being
stigmatised. It can manifest itself as guilt, shame, hopelessness, self-accusation, self-contempt, and self-deprecation (Goffman, 1963). Self-stigmatisation arises when a person is aware of different kinds of stereotypes and prejudices, but nevertheless stigmatises himself. A person is expected to be stigmatised in parallel with society’s norms and expectations (Tye-Murray, 2009). For example, the stigmatisation towards hearing aid users lies with it the negative perceptions of the ‘normal-hearing’ population and attitudes. This kind of stigma leads to discrimination and exclusion, which can affect the well-being of hearing aid users. An environment’s negative reactions to hearing aid users can be described with the term “hearing aid effect” (Clark & English, 2013). DHH individuals generally hide their disabilities in social environments to a large extent. They apply self-stigmatisation by reflecting their views on how a person with a hearing impairment is believed to be perceived (Hétu, 1996).

A lack of confidence combined with feelings of shame and inferiority are attributes that are usually associated with the image of a person with HL (Hétu, 1996). Punsch and Hyde (2005) stated that adolescents with HL wanted other people to treat them like everyone else, which meant that they often hid their hearing aids with their hair or did not use the aids they really needed while in school. Hearing’s individuals’ perceptions of how DHH are perceived by DHH individuals as a declaration of how that person is, becoming an important aspect of their self-image (Roos, 2006). Living as a hearing-aid user means an automatic departure from the norm of full functionality. When a person holds attributes that deviate from such norms, stigmatisation occurs, and the individual is treated differently by people’s conscious and unconscious attitudes. This makes it difficult to create a society for all individuals (Dahlborg Lyckhage, 2015).

Studies have shown that those who are DHH experience stigmatisation in their workplaces (Southall et al., 2010; Southall et al., 2011). These DHH workers were exposed to negative attitudes, which led them to isolate themselves. Furthermore, use of hearing aids elicited negative feelings, even from the person wearing them, as they conveyed disability or incompetence to the people around the individual at work. The conceptions DHH workers held of themselves due to their hearing aids were based on comments from hearing people around them and how hearing people think about hearing aids (Wänström et al., 2014).
Social Inclusion, Marginalisation, and Social Exclusion

Social Inclusion

‘Social inclusion’ and ‘social exclusion’ have many implications, and they are used in many forms of reflections, reproductions, analyses, and discourses, as well as day-to-day social work practice. As Sheppard (2012) claimed, social work originated from the concepts of inclusion and exclusion, which are key to understanding social work. This section will describe how these two concepts are important for understanding people who are DHH. The concept of inclusion, like many others, has many definitions, but this dissertation views inclusion as a lifestyle in which everyone is a valuable and full member of the group. According to Falvey and Givner:

Even after inclusion is operationally defined, it remains an elusive term. Part of the confusion arises from assumptions associated with inclusion—that it is a program or that it is a research devised strategy. The underlying assumption, however, is that inclusion is a way of life—a way of living together—that is based on a belief that each individual is valued and belongs (2005, p. 10)

The concept of ‘social inclusion’ emerged at the end of the 1980s when the European Community (EC) first used the term ‘social exclusion’ (Wilson, 2006). The term ‘inclusion’ replaced the earlier concept of integration through an international process that originated with the Salamanca Declaration (UNESCO, 1994). In Sweden, inclusion was initially translated as ‘integration’, but the concept of inclusion has recently been used (Linikko, 2009). Social inclusion is multidimensional; in other words, two or more aspects of inclusion are required for a person to be considered socially included (Edgren-Schori, 2000; Furäker & Berglund, 2001; McMahon et al., 2016). Social inclusion has been defined as having the opportunity to participate, to contribute to social activities, to have social relationships with others, and to be accepted by individuals with and without disabilities (McMahon et al., 2016).

Nilholm (2006) noted different views on the importance of inclusion. According to Stichweh (2021), individuals can be included and excluded...
from certain groups and not from others at specific times or in certain situations; social inclusion is not something that is permanent or static. Stensaaesen and Sletta (2000) described social inclusion as being accepted into a group and having the opportunity to participate actively in positive interactions with the other members. In this description, social function is the focus. Thus, understanding the concepts of inclusion/exclusion enable observations and descriptions of the different conditions relating to a sense of belonging or a lack of affiliation (Jönhill, 2012).

All people have the right to be recognised as a full member in school, at work, and in society, to sense a feeling of belonging within these groups. As mentioned above, the concepts of social inclusion and social exclusion are not solid states; instead, they are social processes that can be related to different events and actors (Janson, 2001). Not having social interactions with people with different socially relevant attributes or impersonal institutional attitudes seems to be the most common mode of life for people who are DHH. The sense of identity and belonging in the group membership of people who are DHH depends on feelings of social inclusion and recognition in the group. Wanting to be part of a socially inclusive area, including one for a developmentally different feature, is a normal human desire that can probably be traced to its survival benefit. Therefore, it is essential that people seek social inclusion and everyday belonging while avoiding social exclusion (Ainsworth, 1989; Barash, 1977; Baumeister & Leary, 1995; Baumeister & Tice, 1990; Bowlby, 1969; Hogan, 1982; Hogan et al., 1985). Baumeister and Leary (1995) suggested that a sense of belonging is a fundamental human incentive, along with base needs like food, water, and shelter. Furthermore, ‘belonging’ results in a universal pattern whereby social inclusion is used to reward and social exclusion is used to punish.

According to Madsen (2006), inclusion is a form of action used to counteract the exclusionary processes in the social arenas in which children live their daily lives, such as school. It is important for individuals to understand that they are included in their social context, and for children, this begins in their school environment. Asp-Onsjö (2006) identified the three areas of inclusion: physical, social, and didactic inclusion. Thus, a child at school may be physically and socially included in the social community at a regular school but may lack education tailored to that student’s specific needs, such as a disability. In contrast, Gustavsson (2004) claimed that there are four
types of inclusion: ‘physical, functional’, ‘social’, and ‘societal’. ‘Physical inclusion’ gives everyone access to the same arenas, while ‘functional inclusion’ allows individuals to perform tasks together and share resources. Social inclusion means participation in social interactions and networks. Finally, ‘societal inclusion’ is a social perspective by which everyone has access to the same resources in the society. According to Gustavsson, ‘physical inclusion’ has been the most dominant way of including different groups in majority society, and most resources have been developed for this type of inclusion. However, significantly fewer efforts have been made to provide resources for other types of inclusion. Gustavsson (1998) argued that people with disabilities have a harder time experiencing social inclusion in certain groups outside the family when establishing contact is made by unilateral choices. Furthermore, society rejects people who are not like themselves and do not have the same social status in the group. These attitudes create a barrier for people with disabilities and reflect how they see themselves and their identities. This is something which could lead to marginalisation or even to exclusion. Marginalisation could take many forms (Messiou, 2012) and may be situated within different time and place (Razer et al., 2013). In the next part a discussion of marginalisation will take part and be conceptualised in relation to DHH.

**Marginalisation**

The concept of marginalisation is either seldomly defined or has differing definitions (Messiou, 2012). When it is deliberated, it is regularly in relation to the concepts discussed above: ‘social inclusion’ and ‘social exclusion’ (Hansen, 2012). Svedberg (1995) believed that marginalisation takes place both against “knocked out/outsiders” and “anchored/insiders”. Thus, marginalisation is a position in a social structure that, like exclusion, is relative—a sense not belonging, feeling that one is neither a valued member of a group nor could one be able contribute within that group as they believe they must. Marginalisation can also be context related (Frisén et al., 2012; Razer et al., 2013). In some situations, the individual could be included, and in others situation they are marginalised. These experiences could form part of their identity (Hjörne & Säljö, 2013; MacLeod, 2012; Orsati & Causton-Theoharis, 2013; Skovlund, 2014).
Marginalisation is a form of socio-economic oppression that primarily aims to exclude certain people from the labour market in various ways. Individuals who are marginalised are denied access to the dominant society because they are not seen as sufficiently “worthy” or “capable” of inclusion (Young, 2000). Therefore, marginalised people become dependent on various social support measures to live decent lives and thus end up in a position of dependence on society. This deprives the individuals of their independence, makes them a victim of the often-dehumanizing treatment of public agencies, and reduces their opportunities (Grönvik & Söder, 2008; Young, 2000).

Regarding marginalisation, the evidence suggests that people with disabilities have both lower education and income levels than the rest of the population and are underdeveloped in their employment, despite their merits (Grönvik & Söder, 2008). According to the push and pull theory, different motivational factors lead to inclusion or exclusion (Gonäs, 1991). The push concept claims that individuals are pushed into things that they do not want, such as prestige, socialisation, or the need for a change at work, for example, due to negative external factors. Push factors are internal and are based on some apparent needs (Crompton, 1979). The pull concept suggests that individuals are attracted to activities that use their skills and experience in an optimal way, as well as those that provide better job opportunities. The connection between push and pull factors has been found to be linear, where demographic traits have been initiated to affect the strength of the connections between them (Kim et al., 2003; Uysal & Jurowski, 1994). Thus, an individual’s personalised traits will have an impact on how he/she sees his/her abilities. For people who are DHH, this depends on whether they define their hearing loss as a hindrance or as ‘one thing among a lot of other things’ about them. A pull factor could be an experience of sign language that benefits the individual when he or she works with others with a hearing loss, while it could also be a push factor, as such an ability could exclude the individual from other work.

Many definitions of social marginalisation exist, most of which are linked to the labour market. Möller (1996) defined ‘social marginalisation’ as social interactions and relationships in workplaces; he limited his discussion to this context, since this is where people work and integrate the most. Furthermore, he argued that all individuals who have the desire to be in-
cluded in a social life but who are not given the opportunity should be con-
sidered, by definition, to be socially marginalised. For example, developing 
a social identity that was not marginal was crucial to the social success of 
participants in Study II. A positive identity affects mental well-being, self-
confidence, and self-esteem, which in turn are important for succeeding in 
school and at work. For a person with HL to develop a positive social iden-
tity, environments in which it is possible to identify with others with the same 
conditions are necessary (Carter, 2014; Chapman & Dammeyer, 2017). 
Feeling socially stigmatized is grounded in an individual being deprived of 
something (Rydgren & Ruth, 2011). It can either be a comparison with the 
individual’s previous standard of living, such formally being employed, or it 
can be about comparing oneself with an external social reference group one 
wants to belong to. In both cases, it is about the individual comparing their 
perceived worse circumstances with a reference group that the individual 
believes has better conditions them themselves. Social marginalization can 
also be about the individual having a feeling that with the future comes 
poorer living conditions; they have a hard time seeing a bright future ahead 
of them (Rydgren & Ruth, 2011). Furthermore, according to Möller (1996), 
long-term unemployment is a directly decisive factor in social marginalisa-
tion, specifically social marginalisation in workplaces. This unemployment 
significantly distinguishes individuals from the non-marginalised and can 
create a kind of chronic social marginalisation that is difficult for them to 
escape. Möller highlighted this marginalisation as one of Europe’s biggest 
social problems.

In a Swedish study (Antonson, 1998) on identity, individuals who were 
HH felt they were in a “no-man’s land” between the hearing culture and 
deaf culture. This phenomenon of the “the marginal man” was discussed by 
Park (1928) and also in Golovensky, (1951) as relating to race and culture. 
Park’s student, Stonequist, further developed this concept in 1935 and 1937 
to include other reasons for marginality, such as marriage and education. 
According to Stonequist, the marginal man was a person descended from 
two “opposing” ethnic or racial groups, an individual who was released from 
Sources of social control through his alertness but was also exposed to stig-
matisation. In addition to biological and cultural factors, social changes can 
also bring about marginality (Stonequist, 1935). Stonequist believed that the 
marginal man represents, for example, individuals who contribute partly to 
either of the two social groups and live between the two social groups. DHH
people often exist in two or three different social settings—the hearing world, the deaf world, and the HH world. Each setting has different expectations. Many times, these individuals feel that they do not belong to any of these settings. For examples, many DHH individuals are born into hearing families (Bullis et al., 1997) and most of the families are introduce about the HL from a medical perspective, as a problem. Therefore, most of the hearing parents, siblings, and other relatives, do not learn SSL and if someone in the family learn SSL it is mostly the mother or the siblings (Bullis et al., 1994). So, in the beginnings of the DHH child’s life they will start to the feelings of being marginalised and living between two worlds.

According to Jönsson (2003), the identity of a person who is DHH is that of a marginal person. This means that DHH individuals strive to be as similar to everyone else as possible to attain social inclusion, even though they feel marginalised. To be integrated and included in the hearing world can be accomplished via appropriate communication (Goldblat & Most, 2018). However, the lack of communication in the workplace creates confusion that, in many situations, leads to DHH individuals’ social exclusion from colleagues as well as deviation from what is considered a normal situation. Lack of communication with colleagues and employers adversely affects social interactions due to three reasons: (1) difficulty hearing, (2) colleagues’ and employers’ negative attitudes toward HL, and (3) shortcomings of employees in their approach to HL (Punch et al., 2007; Tye-Murray et al., 2009). These aspects affect the social interactions between those who are DHH and their work colleagues.

Close relationships must be nurtured through caring acts and conversation. Otherwise, the relationships suffer and could even end (Danermark, 2006). Trost and Levin (2010) argued that successful group participation requires mastery of the group’s language of communication. If DHH individuals could be able to communicate with the hearing population through sign language, the latter would allow many DHH individuals to experience greater inclusion in society (Danermark, 2006). However, whether the use of sign language leads to full participation in conversations has yet to be determined. To reduce feelings of exclusion, many people who are DHH choose to avoid communicative situations, which in turn can lead to social exclusion.
Social Exclusion

Problematising and analysing social exclusion are common in the field of social work. However, not much theoretical consensus exists on the definition of the term ‘exclusion’. And the term is complex. This is apparent within both academic and policy-oriented definitions, such as the one from Levitas et al. (2007):

Social exclusion ... involves the lack or denial of resources, rights, goods and services, and the inability to participate in the normal relationships and activities available to the majority of people in society, whether in economic, social, cultural or political arenas. It affects both the quality of life of individuals and the equity and cohesion of society as a whole. (p. 9)

Though a universally agreed-upon definition for ‘social exclusion’ does not exist, absence of contribution to society is a core aspect of nearly all definitions of the term. Social exclusion involves multiple interlocking dimensions, including social resources, contribution, and quality of life (Levitas et al., 2007). Conversely, ‘social inclusion’ is generally defined as the opposite of social exclusion (Rimmerman, 2013), but this is not totally true. This will be problematised and discussed below.

Typically, exclusion pertains to the labour market, and exclusion from the labour market typically is used to discuss long-term unemployment with no prospect of new work. However, exclusion can also be economic when standards of living diverge from normality. Cultural exclusion indicates that the main patterns of standards and behaviours have an exclusionary outcome for those who follow and express diverse patterns. Goffman (1963) noted that people who are stigmatised are “reduced in our minds from whole and usual persons to tainted and discounted ones” (p. 12). For this reason, stigmatised people are excluded from—or exclude themselves from—environments that are stigmatising. Concepts of self-exclusion have also been used to modify and problematise social exclusion by insinuating that the person is responsible for his/her exclusion.

Social exclusion, which is the focus of this dissertation, is demonstrated by the limitation and circumscription of social contacts, social relationships,
and group identity (Kronauer, 1997). However, this is not only a consequence or a value of other societal changes but is also a process. According to Madsen (2006), the term ‘exclusion’ holds two meanings, the first of which means keeping someone out who is already outside. The second is to eject anyone who, to that point, has remained inside. Thus, exclusion can be performed either through an active ‘know out’ or a ‘passive’ ‘prevent anyone from coming in’. This refers to the theory of push and pull (Gonäs, 1991), which was discussed in the marginalisation section.

Much research in social work has used the concept of exclusion as a synonym for marginalisation—that is, exclusion from the labour market, economic exclusion in the form of poverty, and social exclusion from friends and family equal marginalisation (Axford, 2010; Buchanan, 2006; Dominelli, 1999; Pierson, 2010; Sheppard, 2012; Taket et al., 2009). Moreover, a common normative misinterpretation is that the presence of social exclusion is in itself a problem and that inclusion is the only solution to this problem (Schirmer & Michailakis, 2015). However, if inclusion means that individuals are measured as applicable in society by different social systems (i.e. family, work, etc.), exclusion means the opposite. Thus, exclusion indicates a condition in which individuals are not measured as applicable in communication, such as DHH people who can only communicate with sign language; in this case, they are not part of the social system (Luhmann, 2005).

The concept of ‘social exclusion’ was originally designated to describe workers who ended up outside the labour market in French society in the 1970s. Today, it is used to denote how some people are exposed to exclusion in various respects in different social contexts (Björkman, 2005). Thus, social exclusion also has a social dimension in that individuals are totally or partially excluded from the system that allows integration into society. Exclusion then infers an individual’s feeling of not being accepted, not being worthy, and not being a full member of the group (Falvey & Givner, 2005).

Social exclusion is also a summary concept of the processes that lead to certain categories of people becoming marginalised. According to the relational model, exclusion is based on a mismatch of expectations, biological needs, and environmental opportunities (Goodley, 2011). This was the reasoning Fischer (2008) used when claiming that social exclusion is a vertical process that occurs at all levels of society. Thus, it does not matter if individuals are ‘high up’ in the community, having stable finances and a well-
paid job; they can still be socially excluded from friendships or companionship in certain groups. Therefore, individuals can, to a large extent, be included in society while still being denied inclusion in conversations or membership in different groups.

A summarised reflection on social exclusion adopted by this dissertation is that it is all about the processes through which individuals or groups are wholly or partly excluded from participation in society. This can include not being able to participate in different contexts as well as being prevented from participating effectively in economic, social, political, and/or cultural life. People can also be excluded from groups, conversations and work. Furthermore, some people choose to be socially excluded from certain groups. The sequential feature of exclusion permits people to experience shifting situations, unwarranted circumstances, and being periodically excluded and included. Nevertheless, being included in society is a question of being anchored through possessing a given place in society with work and housing (Edgren-Schori, 2000).

Auditory skills are substantial for perceiving and identifying sounds to distinguish and understand spoken language. Hearing loss often reduces an individual’s ability to communicate. This produces a delay in language acquisition which causes economic, educational, and work disadvantages and can lead to marginalisation, social exclusion, and stigmatisation (Swedish Association of Hard of Hearing People, HRF, 2018). The effect of HL on social interactions and relationships, mainly through its influence on verbal communication, has been discussed frequently (Morgan-Jones, 2001). For example, communication is often based on audition, which is especially difficult in social environments for DHH individuals because of the background noise emitted by nature or other people (Dobie & Van Hemel, 2004; Haynes, 2014). Thus, HL poses a complex problem, as today’s information society places a high demand on communication with others (Gullacksen, 2002; Swedish Association of Hard of Hearing People, HRF, 2018). Integration and inclusion in the hearing world are accomplished via appropriate communication (Goldblat & Most, 2018), and language is crucial to an individual’s self-image (Brunnberg, 2003).

This theoretical section has tried to highlight the different situations for DHH individuals with the help of these theories and concepts. The concepts of social inclusion and social exclusion both show a certain social order
that indicates how DHH individuals can simultaneously be included in certain environments but excluded in others. Through life, we are not referred to by a single system; we enter into and out of several different subsystems all the time, where we will also in some cases be marginalized. Being included, marginalized, or excluded affects our identity, how we look at ourselves, and how others perceive us. This, in turn, can sometimes lead to stigmas. We can also be in different systems at the same time as we move in different groups and contexts. DHH individuals could feel included in groups they feel they belong to—for example, with friends—and excluded in other groups such as school or at work. Sometimes inclusion in one system can, under certain circumstances, facilitate inclusion in another system (Madsen, 2006).

An Overview of the Theories in the Four Studies

Table 1

*Overview of the theories in the four studies*

<table>
<thead>
<tr>
<th>Study</th>
<th>Overview of the theories in the four studies</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Academic Inclusion and Social Inclusion and Social exclusion</td>
</tr>
<tr>
<td>II</td>
<td>Identity/Social Identity, Theory of the Looking-Glass, Group Membership, Stigmatization, Social Inclusion, and Social Exclusion</td>
</tr>
<tr>
<td>III</td>
<td>Identity/Social Identity, Stigmatization, Theory of the Looking-Glass Self, Social inclusion, and Social exclusion</td>
</tr>
<tr>
<td>IV</td>
<td>Social Inclusion and Social Exclusion</td>
</tr>
</tbody>
</table>
Research Methodology in the Four Studies

This dissertation includes four studies that are reported in four articles (see Table 2) and contains a mixed design with both quantitative and qualitative data. The quantitative data is used to increase the generalizability of the results and make it possible to obtain information about opinions and attitudes in a wider scale (Polit & Beck, 2010). The qualitative data is used to uncover a deeper understanding on an individual level. Kvale and Brinkmann (2009) demonstrated that qualitative research interviews are a valuable tool when the focuses are to create room for vulnerable individuals’ story-telling. In table 2, an overview of the four studies is presented. In the next section, ‘Methods’, a description and background of the research methodology for the four studies will give a deeper understanding.

Table 2

Overview of the studies

<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Data collection</th>
<th>Data analysis</th>
<th>Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Quantitative</td>
<td>6,652 adolescents</td>
<td>Descriptive and correlation analyses</td>
<td>Published</td>
</tr>
<tr>
<td>II</td>
<td>Qualitative</td>
<td>Individual interviews (n=16)</td>
<td>Content analysis</td>
<td>Accepted</td>
</tr>
<tr>
<td>III</td>
<td>Qualitative</td>
<td>Individual interviews (n=16)</td>
<td>Thematic analysis</td>
<td>Published</td>
</tr>
<tr>
<td>IV</td>
<td>Quantitative</td>
<td>5,924 adolescents</td>
<td>Descriptive and correlation analyses, ANOVA</td>
<td>Under review</td>
</tr>
</tbody>
</table>
Methods

In this section, the method is described in a way that shows how the work was carried out in the four articles. This section describes the research methodology for the studies, both quantitative and qualitative, and explains the rationale for selecting this particular methodology. It also describes why this methodology was selected as opposed to alternative methodologies.

Participants and Procedures

Study I

The study was carried out as a total survey study and used a cross-sectional, quantitative approach to reach as many students in special schools and mainstream schools as possible. The population and sample consisted of students attending compulsory and upper-secondary schools in the county of Örebro, Sweden (approximately 300,000 inhabitants). The data was derived from the survey Liv och Hälsa Ung (Eng: Life and Health of Young People) that was carried out in 2011 (region of Örebro, 2011). The questionnaire was aimed at students in mainstream schools in all municipalities and special schools with pupils in the county of Örebro. Altogether, 6,652 adolescents, 13–18 years of age, attending grades seven and nine in compulsory schools and year two in upper-secondary schools participated. The participants in this study belonged to one of the following three groups: (1) no disability, (2) DHH, and (3) DHH with additional disabilities.

The teachers distributed the survey in the classroom, and the pupils answered the questionnaire individually and anonymously. The included letters contained login details for the survey. Each student received a unique code. The next step was to provide students with information about the study. The questionnaires were adapted to be answered on computer and tablet. All of the students answered the questionnaire individually. The majority (see Table 2) (94%) of the participants in the study had no reported disability and attended mainstream school. In total, 6% (392) of the participants had some kind of hearing disability (4% DHH and 2% DHH with additional disability). There were 224 DHH participants in the mainstream
school and 115 DHH with additional disabilities. In the special school, there were 31 students with DHH and 14 with DHH and additional disabilities.

### Table 3

**Frequencies for participants divided in 2011 and 2017**

<table>
<thead>
<tr>
<th>Frequencies for participants</th>
<th>2011</th>
<th>2017</th>
</tr>
</thead>
<tbody>
<tr>
<td>No disability</td>
<td>6268</td>
<td>5350</td>
</tr>
<tr>
<td>DHH&lt;sup&gt;a&lt;/sup&gt;</td>
<td>255</td>
<td>235</td>
</tr>
<tr>
<td>DHH with additional&lt;sup&gt;b&lt;/sup&gt;</td>
<td>129</td>
<td>222</td>
</tr>
<tr>
<td>Missing</td>
<td>0</td>
<td>116</td>
</tr>
<tr>
<td>Total</td>
<td>6652</td>
<td>5923</td>
</tr>
</tbody>
</table>

<sup>Note. </sup><sup>a</sup>deaf and hard of hearing, <sup>b</sup>DHH with additional disability,

### Studies II and III

In order to gain a better and deeper insight into how individuals experience living with HL, a qualitative design was used. The sample for Studies II and III consisted of 16 (10 males, six females) participants aged 24–31 years with severe-to-profound HL who were prescribed hearing aids. The study and the fieldwork took place in the middle of Sweden over an 8-month period from June 2011 to January 2012. The interviews took place in 2011–2012, and the participants were selected based on previously expressed interest in participating in further studies after having been involved in an earlier study. All participants used hearing aids on a regular basis, although they also relied on their lip-reading skills to be able to follow conversations. Being able to see the interviewer was therefore vital to understand the conversation. All of the participants identified themselves as “hard of hearing” and in some situations as “deaf”, so they switched identities depending on the context. They described themselves as physically and biologically “deaf”. The majority of the HH participants could not determine the cause and onset of their HL. All of them had suffered from HL since early childhood. Some believed it had been caused by ear infections when they were a child. Other participants stated that HL problems ran in their families, since their
parents or siblings were also HH. For others, their HL remained a mystery. All of the participants in this study had their HL for as long as they could remember, and they were trying to cope with it without being verbally explicit about how they dealt with it in their everyday life. However, initiating a conversation about HL seemed to be a positive experience for the participants. It was something they did not often talk about or reflective on. They expressed positive emotions about talking about themselves and their HL. Hearing something but not understanding it was a common experience among the participants. They were able to communicate in face-to-face situations and quiet environments, both with people around them and with me.

All of the participants had a school background at secondary and high schools in hearing and DHH classes, and all could use sign language daily. However, they also relied on their lip-reading skills to be able to follow a conversation. During the interviews, the participants were able to communicate in face-to-face situations and in sound interference-free environments. All of the participants worked except for two who were students; seven participants lived with a partner, and six of them were also deaf or HH (see Table 4). Of the 16 participants, two had gone or went to university. The remaining 14 had taken high school and/or a vocational course to prepare for the employment they currently had.

A total of 29 participants were contacted through Short Message Services (SMS), of which 16 agreed to participate. The 16 interviews were conducted in places chosen by the participants themselves. We wrote SMS to each other to set dates and times suitable for the participants. The participants lived as far as the middle of Sweden to the very south of Sweden, spanning anywhere from 10–40 miles in range from one another. Most of the interviews were conducted in a secluded room at the University in their hometown, but some of the interviews were done in their home environment, at a restaurant or at their workplace, all depending on the choice of the participants. The participants were informed verbally and in writing about the study. Later on, at my first meeting with the participants, I also informed them about the study and gave them an opportunity to comment on it and ask questions. Every participant signed an informed consent form and a release form, and they have all been anonymized. With the informant’s permission, all interviews were audiotaped. All participants gave their
consent to participate in the study after they were informed about the anonymity and confidentiality of their data. The interviews lasted between 1.5–2.5 hours. All interviews were prepared, conducted, tape-recorded, and transcribed in full for analysis.

Table 4

Background of the participants in study II and III

<table>
<thead>
<tr>
<th>Informant</th>
<th>Age</th>
<th>Gender</th>
<th>Impairment</th>
<th>Occupation</th>
<th>Marital status</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>27</td>
<td>Male</td>
<td>HH/profound</td>
<td>Installation electrician</td>
<td>Common-law spouse</td>
</tr>
<tr>
<td>2</td>
<td>28</td>
<td>Male</td>
<td>HH/severe</td>
<td>Confectioner</td>
<td>Single</td>
</tr>
<tr>
<td>3</td>
<td>30</td>
<td>Female</td>
<td>HH/profound</td>
<td>Enrolled nurse</td>
<td>Married</td>
</tr>
<tr>
<td>4</td>
<td>26</td>
<td>Female</td>
<td>HH/profound</td>
<td>Carpenter</td>
<td>Girlfriend</td>
</tr>
<tr>
<td>5</td>
<td>27</td>
<td>Male</td>
<td>HH/severe</td>
<td>Teacher</td>
<td>Common-law spouse</td>
</tr>
<tr>
<td>6</td>
<td>30</td>
<td>Male</td>
<td>HH/profound</td>
<td>Car salesman</td>
<td>Single</td>
</tr>
<tr>
<td>7</td>
<td>31</td>
<td>Male</td>
<td>HH/severe</td>
<td>Car salesman</td>
<td>Girlfriend</td>
</tr>
<tr>
<td>8</td>
<td>26</td>
<td>Female</td>
<td>HH/severe</td>
<td>Business assistant</td>
<td>Single</td>
</tr>
<tr>
<td>9</td>
<td>26</td>
<td>Male</td>
<td>HH/profound</td>
<td>University student</td>
<td>Common-law spouse</td>
</tr>
<tr>
<td>10</td>
<td>24</td>
<td>Male</td>
<td>HH/profound</td>
<td>Online salesman</td>
<td>Single</td>
</tr>
<tr>
<td>11</td>
<td>30</td>
<td>Female</td>
<td>HH/profound</td>
<td>Office assistant</td>
<td>Single</td>
</tr>
<tr>
<td>12</td>
<td>26</td>
<td>Female</td>
<td>HH/severe</td>
<td>Enrolled nurse</td>
<td>Boyfriend</td>
</tr>
<tr>
<td>13</td>
<td>30</td>
<td>Female</td>
<td>HH/severe</td>
<td>Business assistant</td>
<td>Common-law spouse</td>
</tr>
<tr>
<td>14</td>
<td>31</td>
<td>Male</td>
<td>HH/severe</td>
<td>Business assistant</td>
<td>Common-law spouse</td>
</tr>
<tr>
<td>15</td>
<td>26</td>
<td>Male</td>
<td>HH/profound</td>
<td>Enrolled nurse</td>
<td>Common-law spouse</td>
</tr>
<tr>
<td>16</td>
<td>27</td>
<td>Male</td>
<td>HH/profound</td>
<td>Student in municipal</td>
<td>Single</td>
</tr>
</tbody>
</table>

Note. *HH – hard of hearing
**Study IV**

The sample for Study IV consisted of 5,923 students attending compulsory and upper-secondary schools in the county of Örebro. The presented data in Studies I and IV have been derived from the survey *Liv och Hälsa Ung* 2017. The questionnaire was aimed at students in mainstream schools in all municipalities and special schools with pupils in the county of Örebro. The sample for this study consisted of adolescents aged 13–18 years of age, attending grades seven and nine in compulsory schools and year two in upper-secondary schools participated. The participants in this study belonged to one of the following three groups: (1) no disability, (2) DHH, and (3) DHH with additional disabilities. Based on a stratified simple randomized sampling procedure the sample for this study consisted of in total 5,923 adolescents. Nine of the adolescents did not answer the question about gender, 5,914 answered that they identified themselves as either a girl or a boy (86 adolescents that neither identified themselves as girls or boys did not participate in the study due to the small size of this group), 5,807 answered the question about disability and all adolescents answered the question about year in school. The majority (90%) had no reported disability. In total, 4 percent of the participants had a hearing disability, and 4 percent reported that they had a hearing disability and at least one additional disability.

As in study I, the purpose of the questionnaire, which students in compulsory and upper-secondary school have the opportunity to answer every third year, is to describe young people’s living situation, habits, and health. The questionnaire: “Life and Health Young” are a web-based population survey conducted in collaboration with the county’s schools. Teachers distributed the survey in the classroom, and the pupils answered the questionnaire individually and anonymously.

In Study IV (see Table 3), the majority (5,350; 90%) of the participants in the study had no reported disability and attended in the mainstream school. In total 4% (235) of the participants had some kind of hearing disability, and 4% (222) reported that they had DHH with at least one more disability (visual impairment, mobility impairment, reading difficulties, writing difficulties, dyslexia, ADHD or ADD, etc.). In this study, we called that variable for ‘DHH adolescents with additional disabilities.’
Data Collection

The data for the articles in this dissertation was collected through questionnaires (Studies I and IV) and interviews (Studies II and III).

Study I—Questionnaire

The questionnaire from which the study was derived is comprised of 90 questions. In the current study, 10 questions concerning disability, well-being, and social and academic inclusion. The concept of ‘well-being’ was operationalised using the following questions: How do you feel in general? How satisfied are you with your life? The concept of ‘social inclusion’ was operationalised using the following questions/statements: How happy are you in school? Do you often skip class? I have friends in school who want to spend time with me. The concept of ‘academic inclusion’ was operationalised using the following statements: I enjoy taking part in discussions during class; I feel comfortable asking the teacher questions during class; The teachers are good at creating a calm learning environment during class; The teachers are good at explaining things that we (students) should learn.

The participants were categorised based on their answers to the following question about their disability: Do you have any of the following disabilities? The following options were given: Hearing loss; Vision impairment that cannot be corrected with glasses or contact lenses; Mobility impairment; Reading difficulties; Writing difficulties; Dyslexia; ADHD or ADD; Other disability. In the questionnaire, a Likert-like scale ranging from 1 to 5 was used, with the value 1 corresponding to very bad/unsatisfied/never/etc. and value 5 corresponding to very good/satisfied/always/etc.

In the presentation of the results, those who self-reported only being hard-of-hearing were included in the DHH group, and those who reported having any other disabilities besides being DHH were included in the DHH group with additional disabilities.
**Studies II and III—Individual Interviews**

The interviews were conducted to assess the participants’ insights of themselves and also their relationships with family, friends and partner. A semi-structured interview guide comprised of open-ended questions that allowed for asking follow-up questions was used. The interview guide consisted of a modified version of “Cornell interview of children’s perceptions of friendships and peer relations” (CIPF), which was translated and adapted to Swedish conditions (Kernberg et al., 1992; Engström, Kallenberg, & Smedler, 1994). The questions from the CIPF instrument were about the informant’s social relationships with friends and if they had a partner.

The interview started with questions about their HL: (a) *How long have you had your hearing loss?* (b) *How old were you when someone discovered your hearing loss?* (c) *Describe your hearing loss and its effect on your life as a whole*. The interviewer then focused on how the HL affected their everyday lives and their relationships with their spouses and other family members. The interviews were then focus on their relationships with family, friends, and partners: (d) *Is someone among your family members hard of hearing?* (e) *Are any of your friends? Partner?*

The interview guide included background questions related to HL or communication modes in the family: (f) *How do you speak with family members?* (g) *Do you use sign language in your family?*

There were also questions about their identity: (h) *How do you identify yourself: hearing, hard of hearing, or deaf?* and their technology (e.g., the internet) use: (i) *How has the internet affected your opportunities for contact?* (j) *Is it easier to communicate with others via Facebook, MSN, Skype, or something similar today?*

Questions about employment and relationships (friends, social contacts, and partners) such as: (k) *Describe how you navigate your hearing loss in your day-to-day life, such as during school/work/social time, with friends through the internet?* (l) *Does communication work in the workplace?* (m) *In what way?*

There were also questions relating to relationships, such as perceptions of friendships, self-esteem, and social abilities: (n) *Are your best friends/partner, deaf or hard of hearing?* (o) *Does it matter?* (p) *How does your hearing loss affect your social life?*
Study IV—Questionnaire

The data for this study derives from the web-based survey Liv och Hälsa Ung 2017, where the questions were intended to gather knowledge about young people’s health, living conditions, and living habits. The questions are either accepted and validated questions that have previously been used in similar surveys or the constructions developed by the working group within the cooperating county councils/regions.

In the current study, the demographic characteristics of gender, year in school, and disability were used as independent measures. The following outcomes (dependent measures) were analysed: (a) WHO-5 well-being index (hereafter, simply referred to as WHO-5), (b) general well-being, (c) somatic problems, (d) mild mental illness, (e) support from teachers, and (f) four additional well-being indicators: belief in future, school and life satisfaction, and having friends.

Demographic characteristics. The demographic characteristics were measured as follows: gender, 1 = girl, 2 = boy; year in school, 1 = 7th grade in compulsory schools, 2 = 9th grade in compulsory schools, 3 = year 2 in upper-secondary schools; and disability, 0 = hearing adolescents, 1 = DHH adolescents, and 2 = DHH adolescents with additional disability. The following options were provided for additional disability: vision impairment that cannot be corrected with glasses or contact lenses, mobility impairment, reading difficulties, writing difficulties, dyslexia, ADHD or ADD, and other disability.

Well-being (WHO-5). For adolescents in the 9th grade and year 2 in upper secondary schools, well-being was measured with the WHO-5, which is among the most widely used questionnaires for assessing subjective psychological well-being; it has been translated into more than 30 languages. It consists of five items and has been found to have an adequate validity level, both as a screening tool for depression and as an outcome measure in clinical trials, and it has been successfully applied across a wide range of fields (Winther et al., 2014). A sample item is, “I have felt cheerful and in good spirits.” The items were rated based on the respondents’ experiences during the last two weeks, and a 6-point response scale ranging from 0 (at no time) to 5 (all of the time) was used. Cronbach’s alpha was .86.

General well-being. In order to keep the number of questions down for the younger adolescents in 7th grade, a single item was used to measure
general well-being: “How do you feel in general?” A 5-point response scale ranging from 1 (very bad) to 5 (very good) was used.

Somatic problems. Ten items were used to measure the following somatic problems during the last three months: headache, migraine, stomach ache, pain in shoulders/neck, pain in the back/hips, pain in hands/knees/legs/feet, tinnitus, difficulty falling asleep, and restless sleep. The items were rated on a 5-point scale ranging from 1 (never) to 5 (always). Cronbach’s alpha was .85.

Mild mental ill-health. Mild mental ill-health was measured with the question “During the last three months, how often have you felt...?” using the following five indicators: stressed, anxious/worried, sad/depressed, in control and irritated. The 5-point response scale ranged from 1 (never) to 5 (always). Cronbach’s alpha was .72.

Support from teachers. Support from teachers was measured with four items. A sample item is, “My teachers make me believe in myself and my schoolwork.” The 5-point response scale ranged from 1 (strongly disagree) to 5 (strongly agree). Cronbach’s alpha was .87.

Additional well-being indicators. Belief in the future was measured with the question “How do you see your future?” on a scale from 1 (I see my future as very dark) to 5 (I see my future as very bright). School satisfaction was measured with the question “How do you like it in school?” on a scale from 1 (very poorly) to 5 (very good). Satisfaction with life was measured with the question “How satisfied are you with your life?” on a scale from 1 (very dissatisfied) to 5 (very satisfied). Having friends was measured with the question “I have friends in school who want to spend time with me” on a scale from 1 (strongly disagree) to 5 (strongly agree).
Data Analysis

Study I and IV were analysed quantitatively while study II and III were analysed with a qualitative approach.

Study I

Before analysis, the gathered data was prepared. The dataset was checked for missing data and outliers. For this the “outlier labelling rule” was used. All values outside the calculated range were considered outliers (Hoaglin & Iglewicz, 1987). The data was then analysed using statistical software Statistical Package for the Social Sciences (SPSS) version 22.0.

Descriptive statistics were used to obtain the characteristics of the study population and its subgroups. Cross-tabulation and computation of Chi-square ($\chi^2$) was used for categorical variables, which is a non-parametric test recommended when analysing ordered categorical data (Svensson, 2001). The results presented correspond to the answer options 4 = good or 5 = very good, etc., on the Likert scale applied. Result are presented in percentages. A significance level of $p < 0.05$ was accepted as statistically significant. All percentages presented in the study are valid, with missing values left uncounted.

Study II

In Studies II and III, a qualitative design was used. In Study II, a qualitative data analysis was carried out using a qualitative content analysis approach (Elo & Kyngäs, 2007; Graneheim & Lundman, 2004; Graneheim, Lindgren, & Lundman, 2017), and in Study III a thematic data analysis was performed (Braun & Clarke, 2006; Nowell et al., 2017). Both content analysis and thematic analysis share similar purpose of analytically explore narrative resources from participants by breaking the larger text into small units (Sparker, 2005). The most important difference between content and thematic analysis is that the researcher in content analysis can focus more on the frequency of occurrence of different categories, but in thematic analysis, it is more about identifying themes and building the analysis in the most coherent way (Vaismoradi et al., 2013). In study II the content analysis was chosen because it is a good method to use if you have a large amount of text
to analyse, systematic coding and categorizing (Grbich, 2012).) In Study II, 
the codes and categories come directly from data. The manifest manifestation 
of the text has been studied, which means that the focus was on the obvious and visible content within the text.

This process includes open coding, creating categories and abstraction. All interviews were transcribed, and the participants were asked to read the transcripts and check for accuracy; all transcriptions were approved. After the printouts were complete, the recorded material was relistened for the purpose of validating the printed material. The advantage of printing the interviews was that the author had the opportunity to remember details that could be relevant to the analysis. Before the analysis, the interviews were read several times in order to get a sense of what the interviews were about, and as many headings as necessary were written down in the margins to describe all aspects of the content. The texts contained the participants’ stories about how they perceived their own identity and group membership. Variation was sought by describing the differences and similarities in the text. These were condensed, the text was shortened, and redundant words were removed, making the text more manageable. Subsequently, meaningful units were abstracted text that corresponded to the aim of the study. The headings were collected from the margins on to coding sheets. The material was carefully processed to ensure that no substantial part of the meaning-bearing units would be lost. Furthermore, the condensed meaning units were coded, and they were provided with so-called labels that reflected the central message of the condensed meaning unit.

To ensure the validity of the codes, they were checked against condensations and meaning units. Next, the condensed sentences were abstracted into codes (Lundman & Graneheim, 2004). The codes (e.g. unclear identity/certain identity, wanted or not wanted to be with others with hearing loss, friends with or without hearing loss, the context of importance of identity) formed the sub-categories: ‘Social identity within in-group or out-group’ and ‘Group affiliation based on the context’. These sub-categories became the category ‘Belonging to a social environment’. The category ‘Engaging in important communication’ was constructed by the sub-categories: ‘Communication difficulties in social environments’, ‘Sign language’ and ‘Body language as nonverbal communication’ (see Table 5).
Table 5

Categories and sub-categories in the results

<table>
<thead>
<tr>
<th>Category</th>
<th>Sub-category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Belonging to a social environment</td>
<td>Social identity within in-group or out-group</td>
</tr>
<tr>
<td></td>
<td>Group affiliation based on the context</td>
</tr>
<tr>
<td>Engaging in important communication</td>
<td>Communication difficulties in social environments</td>
</tr>
<tr>
<td></td>
<td>Sign language</td>
</tr>
<tr>
<td></td>
<td>Body language as nonverbal communication</td>
</tr>
</tbody>
</table>

**Study III**

Since the purpose of the study was to examine HH adults’ experiences of social interactions and social relationships in higher education, working life, and leisure time, the thematic analysis was selected (Braun & Clarke, 2006). The method makes it possible to recognise, analyse, shape, describe, and report themes created within a data set and is suitable when you have rich data material, based on loosely structured interviews and a more narrative approach, where you want participants as individuals and their stories to be highlighted (Braun & Clarke, 2006; Nowell et al., 2017). The identification of themes for the thematic analysis had a theoretical approach from a looking-glass concept borrowed from Cooley (1902), how the participants experience how the social interaction influence their thoughts about themselves. This method of analysis is open and flexible and is suitable for a data-driven analysis focusing on the data as a whole, which gives the reader a rich and general picture of the experiences, meanings, and reality of participants.

The approach was performed by reading through the interviews repeatedly to gain a general understanding and an overview of the data. In parallel with reading, parts of the texts were underscored, and repeated codes were noted down in the text as patterns. These patterns were then categorized based on what they were represented, for example higher education, work and friendships. This process was conducted individually for each interview. Then all the data were read through once again, and interesting characteristics were coded methodically, and all the codes and quotes were collected.
in a word document to develop an appropriate set of data linked to the specific aim. The codes were underlined with various colours to highlight interesting things compared to the aim of the study. The codes that had comparable senses were then gathered and established into possible themes, supported by quotes taken from the interviews. This phase involves sorting and collecting all the potentially relevant coded data extracts into themes (Braun & Clarke, 2006). These codes were then gathered together and grounded on resemblances and variances. The codes (e.g. loneliness, group discussion, and friends) that had comparable senses were then gathered and established as possible themes, supported by quotes taken from the interviews.

In the next step (searching for themes), codes covering the same themes focusing on social interactions and social relationships based on school, work, and friendship were gathered into inclusive themes. The codes were underlined with comments to highlight aspects that were interesting in relation to the aim of the study. This was performed through an ongoing process of verifying the reliability between the codes and the themes under which they were gathered, and between themes and the entire data set, to make sure that there was a comprehensible relation between codes and themes. Then the thematic analysis involved sorting and collecting all the potentially relevant coded data extracts into potential themes. These chosen potential themes were then refined into themes that were more precise yet wide enough to capture the essence of the data.

The last step in the thematic analysis resulted in two themes: (1) obstacles that hinder social relationships in education and at work and (2) the importance of having social relationships in leisure time. The two themes are based on four categories that emerged from the question about how HH people experience their social interactions and social relationships (see Table 6). The first theme, Obstacles that hinder social relationships in education and at work, was based on how the participants experienced the social interaction when they went to higher education and at work and also consisted of how difficult communication could be for people with HH when they interacted with hearing. The first category in that theme was group discussion as a barrier for social interaction in higher education, highlighting the obstacles to having communication in larger groups and the obstacles to being included with hearing people in school. The participants may be able to communicate and understand if they talk with one person in a quiet room, but the same person may have great difficulty understanding during a group
meeting when several people are talking, where there is background noise. The second category, *communication barriers, leads to exclusive feelings at work*, describes the participants’ experiences of feeling excluded from social activities at work. Success in social interaction at work depends largely on the willingness and ability to identify and resolve communication barriers encountered in the workplace.

The second theme, *the importance of having social relationships during leisure time*, consisted of social contacts in the form of friends and partners at school, work, and in leisure time. One of the categories in this theme, *the need of friends and partners*, focused on the difficulties in getting new friends and how the participants felt lonely. The last category, *initiating, and maintaining social relationships with AT and ICT*, points out the importance of both AT and ICT to start and preserve social relationships. People with HH felt they had better social interaction with all of their friends through online modes of communication.

**Table 6**

*Themes and categories that emerged from the analyses*

<table>
<thead>
<tr>
<th>Themes</th>
<th>Categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>Obstacles that hinder social relationships in education and at work</td>
<td>Group discussion as a barrier to social interaction in higher education</td>
</tr>
<tr>
<td></td>
<td>Communication barriers lead to exclusive feelings at work</td>
</tr>
<tr>
<td>The importance of having social relationships during leisure time</td>
<td>The need of friends and partners</td>
</tr>
<tr>
<td></td>
<td>Initiating and maintaining social relationships with AT and ICT</td>
</tr>
</tbody>
</table>
**Study IV**

Analyses were performed using the SPSS, version 26.0. Descriptive statistics were used to determine the characteristics of the study population and its subgroups. All percentages presented in the study are valid, with missing values left uncounted. Pearson correlation analyses were performed to test hypothesis 1. For hypotheses 2, 3, 4, 5, and 6, multiple ANOVAs with additional post hoc tests (Tukey) were applied. A significance level of p < .05 was accepted as being statistically significant.
Summary of the Studies Included in the Dissertation

Study I: Deaf and Hard-of-Hearing Adolescents’ Experiences of Inclusion and Exclusion in Mainstream and Special Schools in Sweden

Aim
The aim is to compare the well-being of adolescents who are DHH, who are DHH and have additional disabilities, and those without disabilities; second, to compare the adolescents from the two DHH groups and their experiences of inclusion and exclusion in school; and third, to ascertain whether any gender differences exist between the two mentioned groups of DHH adolescents concerning experiences of inclusion and exclusion.

Research questions: (a) How do hearing students, DHH students, and DHH with additional disabilities perceive their well-being? (b) What experiences do DHH students and DHH students with additional disabilities have of inclusion and exclusion in school? (c) Are there any gender differences in the two latter groups regarding experiences of inclusion and exclusion?

Major Findings
The overall results for Study I revealed that DHH and DHH with additional disabilities are satisfied to a greater extent in special schools than mainstream school. The result also shown that the well-being was depending on if you have a disability or not. A larger proportion of students without disabilities report feeling very good than DHH students and students who are DHH and have an additional disability.
One important factor to feel general well-being was which school you went to: mainstream school or special school. The results also show a correlation between disability, type of school, and students’ well-being, with a greater proportion of DHH students in special schools reporting feeling very good than of DHH students in mainstream school. The results further indicate that DHH students with additional disabilities in special schools report that they feel well to a greater degree than DHH students with additional disabilities who go to mainstream schools.

As the result, this revealed that the participants’ well-being are higher in special schools compared to mainstream schools. This result also indicates that this applies to feeling socially included in school, such as having friends. In this case, the difference in whether you were socially included or not depends on your disability. The more disabled one is perceived as being, the fewer friends they may acquire. The special school results show that DHH students report having friends they can spend time with to a greater extent than DHH students with additional disability. The mainstream school results show that DHH students reported having friends they can spend time with to a greater extent than DHH students with additional disabilities.

In this study, we also let the participants measure their academic inclusion. DHH and DHH students with additional disabilities in special schools seem to be willing to participate in discussions in the classroom to a greater extent than those in mainstream schools. There were also some gender differences in the results when it came to academic inclusion. For example, do the boys consider their teachers skilful at creating a good learning environment at a higher level than the girls.
Study II: Longing to Belong: Hard of Hearing Young Adults’ Experiences of Social Identity and Group Membership

Aim
The aim of this study is to examine young HH adults’ experiences of social identity and group membership. The goal was to gain deeper insights into their experiences of social identity and group membership in order to provide better support and improve health outcomes.

Research questions: (a) How do young HH adults experience their social identity? (b) How do HH adults experience group membership, and what influences their feelings of belonging to a group?

Major Findings
The results for the first research question, i.e., how do young HH adults experience their social identity, indicate that the participants specified their complications to positioning their self. They reported a sense of absence of their social identity since they felt they could not fit in completely with either the ‘Hearing world’ and the ‘Deaf’. They say they are ‘between two worlds’, the ‘. The problem that occurs to divide the world in that way is the experience of not being a part of none of them. The participants experience that the deaf people often exclude those who communicate orally, and those with cochlear implants. Such individuals are not measured to be ‘really’ deaf. In the hearing world D/HH individuals also encounter stigmatization because hearing loss is perceived to be a disability.

The second research question focused on how HH adults experience group membership and what influence their feelings of belonging to a group, indicate that group identity is not static. Loneliness and social isolation were also common experiences. Exclusion from groups composed of the hearing or deaf at school, at work, and in daily life was also frequently mentioned. The participants reported having lower social acceptance and fewer close friendships than their hearing peers because of the communication barrier.

The participants’ definitions of group membership were based on several criteria, such as how much they could hear, how safe they felt in the group, whether they could use sign language and how well their efforts and limitations were understood. In addition, identifying as deaf or HH can be a way
of adapting to society and avoiding being discredited and perceived as non-adaptive. HH individuals must thus determine how strongly they identify with each culture. These results in the present study revealed that some HH individuals “choose” to belong to the “deaf” group. They perceive their social identity as deaf because of the strong group feelings among deaf people. Both research questions highlight the importance of communication for the social identity and to feel a sense of belonging to a group. The results indicate that the participants longed to be included, to be accepted, to create an inclusive social environment, to find friends and partners, and to communicate effectively by being understood. In other words, they desired to feel a sense of belonging. The results of this study highlight the central role of communication, which can be considered a prerequisite to group membership. It is a key element in maintaining relationships with friends and partners because a shared communication system is necessary to prevent isolation.
Study III: Hard of Hearing People’s Interpersonal Interactions and Social Relationships in Their Daily Life

Aim
The aim of the study is to examine HH young adults’ experiences of social interactions and social relationships in higher education, working life, and at their leisure time.

Research questions: (a) How do young adults with HH experience social interactions in higher education and at work? (b) How do young adults with HH experience social relationships in their leisure time? (c) What are the opportunities and challenges with ICT and AT for people with HH in their daily life.

Major Findings
The findings showed that HH people expressed that they had no problem executing assignments in school and job tasks at work, but the complications were social interactions with hearing people because of the communication barrier involving large groups of people. There were also participants who expressed feelings of social exclusion because of the co-worker’s attitudes on disabilities. These experiences led to experiencing these feelings outside the working group and ultimately led to loneliness.

These results also showed that people with HL could feel ashamed of their communication abilities and of their hearing aids. In a similar way, the results show that both AT and ICT had a remarkable positive impact on their lives, both at school, at work, and during their leisure time. The experience of belonging to a group and the possibility of communicating with the rest of the population have a big impact on the informant’s life.

Most HH people experience communication barriers both in higher education, at work, and at leisure time. These communication barriers lead to feelings of loneliness and difficulties in achieving social inclusion in different groups such as group work in school, in group meetings at work both physically and over the internet, but also in social settings such as for a coffee break or lunch. At an integrated school, being included in a social context is something that many take for granted. For individuals with HL, the most obvious source of communication problems in school is the presence of
background noise. People in the study reported getting very tired of all the background noise, and that being around people talking all day was exhausting. They said that above all they are disturbed by the sounds of other people, for example voices, footsteps, scraping chairs, and other noisy activities. Especially if they are working in a group on a school assignment, HH people experience relatively high levels of stress and fatigue, which also affect their daily lives. The results revealed that all students experienced some degree of social awkwardness when entering the new learning environment. However, the experiences of HH students go beyond this to include perceptions of exclusion. These findings show that students with hearing loss are motivated to interact with others who can hear; however, large groups of people and the noises around them force the HH students into exclusion from others.

The desire to be socially included would be easier to achieve if there were more opportunities to communicate with hearing. Whether this can be attained by numerous approaches of support or by more people learning sign language has yet to be determined, but a more inclusive social environment should be accomplished someway. Society has an essential part in making DHH individuals feel social included. There should be the same opportunities for DHH individuals, like for hearing people, to educate and work, however they wish to. With appropriate and appropriate targeted support, such as with AT and ICT, people with DHH could move from social exclusion towards social inclusion and experience richer lives.
Study IV: The Psychosocial Status of Deaf and Hard-of-Hearing Adolescents in Mainstream Schools With and Without Additional Disabilities Compared with Hearing Adolescents

Aim
This study aims to examine the relationship of well-being to mental ill-health and somatic problems and to compare these three psychosocial health experiences among hearing adolescents, DHH adolescents, and DHH adolescents with additional disabilities. The following hypotheses were defined:

Hypotheses:

- **Hypothesis 1:** There is a negative relationship between adolescents’ general well-being and mental ill-health and between well-being and somatic problems; the lower the well-being, the more somatic problems and the higher the mental ill-health.

- **Hypothesis 2:** Hearing adolescents experience higher well-being, fewer somatic problems, and lower mental ill-health than DHH adolescents, who in turn experience higher well-being, fewer somatic problems, and lower mental ill-health than DHH adolescents with additional disabilities.

- **Hypothesis 3:** Boy’s experience higher well-being, fewer somatic problems, and lower mental ill-health than girls.

- **Hypothesis 4:** Adolescents in 7th grade experience better psychosocial status (fewer somatic problems and lower mental ill-health) than adolescents in 9th grade, who in turn experience higher well-being, fewer somatic problems, and lower mental ill-health than adolescents in year two in upper compulsory school.

- **Hypothesis** girls with additional disabilities in year two upper compulsory school experience the poorest psychosocial status, and hearing boys in 7th grade experience the best psychosocial status.
• **Hypothesis 6:** Hearing adolescents have more support from teachers, belief in the future, school satisfaction, life satisfaction, and friends than DHH adolescents, who in turn have more support from teachers, belief in the future, school satisfaction, life satisfaction, and friends than DHH adolescents with additional disabilities.

**Major Findings**

The results showed statistically significant associations between well-being, mental health, and somatic problems. The first hypothesis was supported, as the results revealed negative relationships between well-being and mental illness and between well-being and somatic problems. More specifically, DHH adolescents with lower well-being had more somatic problems and higher rates of mental illness.

The second hypothesis was also supported, as hearing adolescents had higher well-being, fewer somatic problems, and a lower degree of mental illness than DHH adolescents, and DHH adolescents had higher well-being, fewer somatic problems, and a lower degree of mental illness than DHH adolescents with additional disabilities. The third hypothesis was also supported. The analyses addressed gender differences in well-being, somatic problems, and mental illness. The result showed that girls had lower well-being, more somatic problems and higher mental ill-health than boys. Furthermore, hypotheses 4 were partially supported. There was a significant difference when comparing 7th- and 9th-grade students in compulsory schools and year 2 adolescents in upper secondary schools regarding somatic problems and mental ill-health. Adolescents in 7th grade had the least somatic problems and reported the lowest mental ill-health followed by adolescents in 9th grade. Adolescents in year 2 secondary schools reporting the most somatic problems and the highest mental ill-health. Regarding well-being there were no significant differences. Concerning hypothesis 5, there were like hypothesis 4, partially supported, DHH girls with additional disabilities in year 2 upper compulsory school do not experience most somatic problems as we had thought, instead it was in year 7 they had most somatic problems. Hearing boys in 7th grade experience the least somatic problems and lowest of mental ill-health. And for the sixth hypothesis, hearing adolescents reported more support from teachers, better beliefs about the future, school satisfaction and life satisfaction, and more friends than DHH adolescents and DHH adolescents with additional disabilities.
Ethical Considerations

The doctoral projects received funding from the General Heritage Fund and SFR. The project was ethically reviewed and approved by SFR 95-0138: 1C. This dissertation included both quantitative and qualitative studies; therefore, both methods will be considered in this section. In all four studies, the participants were not expected to be exposed to any risk by participating. All participants were informed about the ethical rules of the studies, both verbally and in writing.

In Studies I and IV, all information about the questionnaire and ethical considerations were handled by the schoolteacher in the classroom. Teachers of grades 7 and 9 at compulsory schools and year 2 at upper-secondary schools in all municipalities of the county of Örebro in Sweden distributed a letter to each adolescent containing information about a web-based survey and login details with a unique code. The adolescents answered the questionnaire individually and confidentially in the classroom.

For Studies II and III, the researcher informed all the participants. The goal was to ensure that the participants had a complete understanding of the purpose and methods used in the study, the risks involved, and the demands placed upon them as participants. Participants are also informed that they leave the interview whenever they want or withdraw their contribution until the day the article is submitted to the journal. All the interviews were held in places with a hearing loop so that even those with severe to profound HL could be able to participate. All the participants chose the location for the interviews and most of the interviews were conducted in a secluded room at the University in their hometown, but some of the interviews were done in their home environment, at a restaurant or at their workplace, all depending on the choice of the participants. The participants were informed verbally and in writing about the study. Later on, at my first meeting with the participants, I also informed them about the study and gave them an opportunity to comment on it and ask questions. Every participant signed an informed consent form and a release form, and they have all been anonymized. All participants gave their consent to participate in the study after they were informed about the anonymity and confidentiality of their data. All interviews were organized, conducted, tape-recorded, and transcribed in full for analysis by the first author. To protect the participant’s identities, the recordings
and transcriptions did not have any identifiable information in them. Furthermore, enough time was given to the participants to read all the information and answer the questions. It was essential that the participants completely understood all of their rights when participating in the studies. To achieve trustworthiness and confirmability, not only did both authors perform the analysis, but in situations of disagreement, they engaged in discussion until a consensus was reached.

All the participants in Studies I and IV were informed that Örebro University and Mälardalen University were responsible for the investigation and that, according to the Personal Data Act (PuL), they were entitled to receive their information once a year and, if necessary, get any errors corrected. In Studies II and III, the participants were informed that Mälardalen University was responsible for all data.
Discussion

This dissertation provides insight into the impact of hearing loss on young adults in their daily lives. The young adults with hearing loss included in the dissertation conveyed a central perspective that their disability impacted interventions and treatment at school, work, and even leisure time. The overall aim of this dissertation was to study the living conditions and life experiences of young men and women who are DHH.

Throughout the four studies in this dissertation, a pattern became evident, communication. Communication emerged as a recurring theme across both of the two qualitative Studies (II & III), but also in the two quantitative studies (I & IV), though in different ways. The results in the two qualitative studies indicated that the participants longed to be socially included, accepted by others, included in a social context, in close relationships with friends and partners, and be understood by others in communication with them. Indeed, an important aspect to feel included was the ability to communicate, as these abilities were vital to achieving social inclusion in school, at work, and in leisure time. In the two quantitative studies, the communication barriers in mainstream schools seem to be an obstacle to achieving social inclusion. But these results are findings base of questionnaire with questions about their well-being, friends in school, enjoy talking in class, and with the teacher, and so on.

The findings in Study I show that DHH adolescents have higher well-being, more social included, more friends, happier in school, and have better support by teachers in special school than in mainstream schools. In Study IV, there were similar results: hearing adolescents reported higher well-being, fewer somatic problems and mental illness, more support from teachers, better beliefs about the future, higher school satisfaction and life satisfaction, and more friends than DHH adolescents in mainstream schools. Of course, there could be serval explanations for these results. But
over the years, working with this dissertation, the importance of communicating has emerged as an essential aspect to becoming socially included in different settings such as school, at work, and in leisure.

**Communication: The Key to Social Inclusion in Different Settings**

For many people with hearing loss, existing in social settings, such as in school, at work, and leisure time, is like travelling to a foreign country where everyone is talking in a language they do not understand. This can prevent social inclusion, which means participation as a full member of society and the capacity to realise the conditions of social citizenship. The environmental relative model states that disability is the absence or limitation of opportunities to participate in normal social life on an equal level to the rest of the population due to physical and social barriers in society (Reiser, 2012). Thus, obstacles to social inclusion arise from the environment and society’s attitude towards those who are different, suggesting that problems of social exclusion are solved by changing society rather than the individual (Dittrich & Tutt, 2008; Ladd, 2003). This view of disability avoids expelling or preventing individuals from entering a system because they do not have the capability to participate in the same condition as people without a disability (Madsen, 2006).

Social inclusion can be promoted in various ways. A key factor that emerged through the four studies in this dissertation was the importance of communication to social inclusion; communication was the vital element to maintaining relationships and feeling socially included. In contrast, the relative lack of opportunities for those who are DHH to contribute to their surrounding societies highlights how their HL is established through social exclusion (Engels et al., 2002; Nowicki, 2006), which limits the possibility of an extensive range of social relationships. In Studies II and III, the participants highlighted the communication barrier and how their ability to hear was misconstrued with their capability to produce in school or at work. Thus, communication was a relational variable established within social relationships, which frequently impacted and was influenced by different relationships and social outcomes (Antia et al., 2011; Bat-Chava & Deignan, 2001; Bat-Chava et al., 2005; Most et al., 2012; Wolters et al., 2011). The
communication barriers sometimes led the participants to avoid social interactions in school or at work. Furthermore, they stigmatised the individual, causing them to be isolated during their leisure time as well.

The concept of social exclusion is not a definitive state in which social inclusion is the opposite. Instead, many factors cause individuals to be more or less excluded, depending on the degree of the individual’s vulnerability (Kieselbach, 2003). In other words, communication barriers themselves do not socially exclude the individual. Other factors, such as the absence of a social network, marginal economic status, and social isolation, all contribute to social exclusion. In Studies I and IV, the participants expressed feelings of loneliness both from their hearing classmate and from the teachers. Good relationships between adolescents and teachers have been considered a significant factor in resiliency and social inclusion (Baker, 2006), and therefore this has to be highlighted. This process of exclusion is not always obvious, as some norms of society that could lead to exclusion do not provoke reflection. Therefore, it is essential to understand social exclusion as a relational process (Sibley, 1995), and there has to be more to be done in educational settings.

It is also important to state that the individual does not go from being included to being excluded. The participants in Studies II and III felt like they “lived between worlds”. Stonequist, (1935) stated this by problematising Park’s “The marginal man”. DHH live and share cultures and traditions between two social worlds. Even if they sometimes socialized with hearing, they felt that they were never really accepted by hearing individuals. Their experience of not belonging was individual but had arisen through social processes in interactions with others. Therefore, the participants felt marginalised both in the hearing world and sometimes also in the d/Deaf world, and they experienced this marginality as a mental conflict. Instead of what Cooley (1902) meant with his looking-glass theory of personality, the marginal individual is looking in two glasses, and they both differ in how the individual sees his image of himself. This can create dissonance between who the individual is and who they want to be. In this way, individuals may feel that they do not really belong to any of the social groups of which they are part. Sometimes physical limitations may make them feel that they are marginalised and, in some cases, excluded, while at other times the limitations will be mental (Stonequist, 1935).
If a group of individuals who feel marginalized joins together, a minority group is formed, and a new social network, a subculture, can be established in this group, symbols can be important to test the affiliation, such as hearing aids. They may experience themselves as stigmatised or that society stigmatises them (Stonequist, 1935). Individuals who experience stigmas and share the same stigma categorisations with others that society applied to them tend to unite in small social groups of their own (Goffman, 1963). For DHH individuals, because of their problems to communicate in the same condition as hearing people, they can collectively create a safe haven for themselves. Participants in Studies II and III said that they chose to be with DHH individuals who could really understand and communicate in a way they enjoyed, but several of the participants expressed a longing for hearing friends.

**Addressing the Challenges and Barriers to Social Inclusion in School, at Work, and during Leisure Time**

Both in school, at work, and during leisure time, DHH individuals have no problem fulfilling assignments, work tasks, and other obligations. Thus, the greatest obstacles that could lead to a feeling of social exclusion (e.g. social isolation) are barriers to establishing and maintaining social interactions and relationships. Social interactions can be especially challenging for people who are DHH because effective interactions depend on communication, social awareness, and suitable timing of behaviours (Engels et al., 2002). For both men and women of all ages, HL complicates interpersonal communication and creates significant social problems for the individual. Consequences of HL include a reduced ability to communicate, delay in language acquisition, and economic, educational, and work disadvantages. These can lead to marginalisation, social exclusion and stigmatisation. To counteract this stigmatisation and marginalisation, disability policy and rights aim to increase inclusion, improve societal conditions for good health and create equal standings for the entire population (Government Bill, 2007/08: 110).

In Study I, school placement was found to affect the psychosocial health of DHH adolescents (Glickman & Gulati, 2003; Gulati, 2003), who were at risk of being socially excluded and exposed to bullying in mainstream schools. Some studies have shown that inclusion of DHH students in mainstream schools contributes to loneliness and social isolation (Newcomb &
Bagwell, 1995). Research has also highlighted that, while a school environment (special or mainstream school) may support social inclusion, it may not be the most supportive concerning academic inclusion, or vice versa. Inclusion could also have a negative impact on DHH students’ communication and interaction skills, as well as on their academic achievements (Stinson & Antia, 1999). Questions that need to be addressed are what perspective the educators in school have on their work and how they work to realise the DHH individual’s full participation (Roos, 2006). Results from Study I showed that DHH students have difficulties in mainstream schools communicating in the classroom in front of the other students. They also felt complications asking the teacher questions if they did not understand. This could lead to marginalisation, stigmatisation, or exclusion. If DHH students have difficulties having conversations in front of the others, they get silent, maybe isolate themselves from the others, do not form friendships, and even not finish their school goals and then find it hard to find a work. This is an example of when individual marginalisation becomes a system marginalisation.

In both Studies I and IV, DHH adolescents revealed that they did not believe in the future and have few friends to the same extent as hearing adolescents. Results from Studies I and IV also revealed that DHH adolescents with additional disabilities comprised the most vulnerable group. They were the least satisfied with school and life, had the least friends compared to both hearing and DHH adolescents, and reported the least support from teachers. Way et al. (2007) found that reduced teacher support was associated with depressive symptoms in adolescents. Teachers play an important role, not only because they provide knowledge, but also because they can support adolescents in reducing mental illness and the development of depressive symptoms (Hawkrigg & Payne, 2014). Poor relationships with teachers increase the risk of health problems and social exclusion (Lemma et al., 2014). Therefore, it is essential in schools to identify the individual’s potential and needs to achieve the best circumstances (Wilder, 2008).

In special schools, however, the DHH students encountered a different culture and possibly a different language than that of their parents (Roberts & Hindley, 1999). The results showed that students faced more communication difficulties that hindered them from developing social relationships in mainstream schools and simultaneously lowered both their interest in
school and school achievements (Prince & Hadwin, 2013). Such communication barriers and social-emotional difficulties have been linked to lower social skills and academic achievement (Beitchman et al., 1989; Beitchman et al., 1996). Antonson (1998) argued that DHH students feel isolated from their classmates because of their HL, even when they accept their HLs and find coping strategies. Long and Beil (2005) drew similar conclusions about the importance of SSL; SSL makes people who are DHH feel relaxed and able to participate fully. In Study IV, the results show that these factors are associated with consequences such as mental ill-health, depression, and anxiety, all of which potentially could lead to marginalisation and exclusion within the broader community (Prince & Hadwin, 2013). Furthermore, research has indicated that a sense of belongingness to school is linked with academic inclusion, and positive psychological, behavioural, and social outcomes (Prince & Hadwin, 2013).

Moreover, the in Studies I and IV, DHH students who felt isolated and lonely in mainstream school (despite the school environment being adapted to their needs) were not socially included. Students who attended special schools perceived themselves as more socially included (Angelides & Aravi, 2007). In Study I, the participants expressed that in special school, DHH students have more possibilities to communicate with others, report feeling less alienated and, to a greater extent, feel socially included when they are in an environment in which their peers have similar circumstances/disabilities (Angelides & Aravi, 2007). In Study I, the teacher’s important role were highlighted. In special schools, the teachers have the abilities, knowledge, skills, and experiences necessary for supporting DHH students, thereby allowing them to have the most effective education possible; in mainstream schools, they do not feel the same level of support (Adebayo & Ngwenya, 2015; Foster & Cue, 2008; Luckner & Howell, 2002; Hyde & Power, 2004; Werts et al., 2014). Structures around school, work, communication, and social interaction are generally not modified to the requirements that people with HL need. DHH individuals’ need infrastructures other than the basic ones society uses to communicate, and if society does not adjust, it limits DHH people and their opportunities for development and social relationships (Burr, 2003).

An important, shared result in Studies I and IV was the gender differences. In Study I, the result shows that regardless of the type of school and disability, boys reported good general well-being to a greater extent than
girls. The results also show that DHH boys and DHH boys with an additional disability in special schools reported a higher degree of satisfaction with their lives than DHH girls. In Study IV, girls reported poorer mental health and somatic problems more often than boys, especially if combined with another disability. More specifically, girls reported higher levels of mental illness, which manifested as stress, headaches, stomach pain, worry, and depressed mood. The results in Study IV showed that the mainstream schools do not fulfill their special needs and that there were social exclusions in both elementary schools, such as in upper-secondary schools. Furthermore, women with disabilities more commonly report reduced mental well-being and pain in the neck, shoulders, and back compared to men with disabilities (The Public Health Agency of Sweden, 2016). Compared to boys with disabilities, a lower proportion of girls with disabilities rate their health as “good.” Girls and boys without disabilities rate their health equally (The Public Health Agency of Sweden, 2020).

A potential explanation for the fact that DHH girls tended to report lower levels of well-being and higher levels of mental illness and somatic problems is that a good relationship with teachers was more important for girls than for boys. Poor relationships with teachers increase the risk of health problems, particularly for girls, who also have low support from classmates (Lemma et al., 2014). Especially, for girls who felt lonely, their teacher was the only one who could decrease this feeling; neither classmates nor parents could (Lothre et al., 2014). The relationships with teachers are more important for girls than boys, but research shows that teachers interact with boys more often than with girls, depending on the grade level of the students and the personality of the teacher (Measor & Sykes, 1992). Perhaps this is one reason why girls feel worse than boys. What experiences engender these differences? There are some social differences in gender roles.

Theories like symbolic interactionists have explained that boys and girls learn ways of behaving through interaction with parents at an early age, and then teachers and friends have a significant impact on the way to behave. Girls, like boys, have learned from their parents and other important relationships that the way they present themselves to others is the way that they believe that others want and expect to see them (Goffman, 1955). Cooley’s (1902) looking glass ‘self’ could explain some of the differences. In school, like in other places, social interaction performs as a mirror that helps individuals to measure their worth, values, and behaviour in interactions with
others. Individuals imagines thoughts of others’ that influence the development of their own self-image. Social interaction is more essential for girls than for boys. In social media, for example, research has shown that girls tend to connect friends on the internet with popularity. They think that they are less attractive and popular if they do not have a lot of friends or followers, and these patterns are the same in real life (Lenhart, 2015).

Why do the girls feel worse in upper-secondary school? One possible explanation could be that, in upper-secondary school, the grades get more significant because successful graduation from upper-secondary school has a high impact of choosing work in the future. There are also in upper-secondary school that girls and boys becoming young adults, starting to think about the future and their disabilities, may get more visible and exclude them from both social activities and physical activities, but also from partnerships to a greater extend that hearing adolescents? Another explanation that DHH girls feel more excluded than DHH boys could be that girls’ and boys’ social interactions differ. Girls’ communication modes are largely related to having a common language (Musselman et al., 1996). There could also be a link between stress and the feeling of liability to form their future and verify their true worth through their educational career.

Research (Maccoby, 2002) has shown differences between boys and girls and how they respond to school stress. Boys appear to be able to turn their anger externally, while girls tend more often to attribute the stress internally. There are also some indications that girls are more adapted to social relationships during development than boys (Brown & Gilligan, 1992), which may give them a perceptual benefit in terms of relational closeness. DHH girls with at least one additional disability rated themselves worse in most of the studied areas than all the other adolescents.

To experiences of being socially excluded in school was something all participants in Studies II and III talked about and considered their HL as the biggest obstacle for not having the ability to further higher education. Their explanation was that they do not have the opportunity to have discussions or group work with more than two people at the same time. They also assumed that their opportunities to succeed in school were hindered by their HL. For example, they meant that society’s view of their disability is associated with a low level of knowledge. Such attitudes can evoke feelings of stigmatisation and meaninglessness and make many people not even try to seek higher education levels. Feelings of embarrassment about one’s identity
have also been related to mental ill health among DHH stigmatized identities (Mak et al., 2007). Though, it is essential to note that the DHH identity is only one of many that a person may have. Our identities are complex and ever-changing depending on the context (Carbaugh, 1996).

Drawing conclusions about the employment of people who are DHH is problematic because they are a highly heterogeneous population, but studies have indicated that people with hearing loss have been under-represented in professional and supervisory occupations and over-represented in working class occupations, especially in the industrial sector (Hyde & Power, 1992; Schildroth et al., 1991). Other research by Emmet and Francis (2015) has shown that DHH people are less educated, which leads to unemployment and underemployment, and have lower incomes compared to the hearing population. After completing their education, individuals with DHH were nearly twice as likely to be unemployed or underemployed as those without HL. One essential finding both in study II and study III, as well as in research (Kennedy, 2001; Hauser et al., 2000; Punch et al., 2004), is the co-walker’s attitudes about HL, thereby potentially creating exclusion in school and at work. Many DHH in Studies II and III have revealed how they have convinced both colleagues and their manager that they were able to perform the tasks involved in the work and that colleagues were making fun of them when they did not hear. They felt that they were excluded from social settings at work, such as coffee breaks, lunch breaks, and so on. Cooper et al. (2003) found that social interactions with DHH individuals positively affected attitudes only when the DHH individual was of identical or higher status than the DHH individual.

In Studies II and III, participants talked about how they had been ridiculed by their co-workers. They could shout a few centimetres from the face, say that they would turn up the volume on the hearing aid and more. The participants said that they did not dare to ask again after not hearing two or three times. Then, they used to nod and smile. There was always a feeling of failure. And the ridicule of people for not being able to hear intensified the failing image they already had of themselves. It became like a stigma when the person experienced himself as weak and inferior. The identity of the DHH person was reduced to only being negative, and all the other good qualities were forgotten. This self-image also increased the fear of being excluded from group membership at work, which often led to people trying to hide as much as they could that they could not hear.
In Study III, the participants express the feeling of both marginalisation and exclusion. Serval of the participants talked about how they never felt totally included at the same terms as their hearing colleagues. Their experiences were both individual marginalisation but also an organisational/system marginalisation. At the individual level, they revealed that they did not provide equal access to resources because of their disability. They thought that their colleagues get more benefits and more opportunities for better job challenges. They also heard derogatory language about their HL, and there were both colleagues and managers that made fun of their HL, and sometimes they felt that they were bullying. During coffee breaks, lunch breaks, or meetings, they experienced other hearing colleagues finding different ways to isolate them, like purposefully leaving them outside. Some of these results could be explained in light of disability stigmatisation. DHH individuals are frequently marginalised because of their communication barriers and have to read lips, using hearing aids or use SSL to have a conversation. Their accessibility needs are often highlighted by hearing people (Mousley & Chaudoir, 2018). The same experience of co-worker’s attitudes about HL at the working place has highlighted before. In the studies by Southall et al., (2011) results showed how stigma towards hearing aid users in the workplace, among others, occurred frequently and what effects it had. In Southall et al., (2010) study clarified the results of the public's discriminatory attitude in a workplace and the essential part in the form of stigma that it constituted. In another study of Southall et al., (2011) show similar results how negative attitudes of co-workers towards their colleagues' hearing loss resulted in the participants choosing to withdraw which led to exclusion.

At the organisational/system level of marginalisation, they express that they never could feel the other hearing colleagues because they do not have to get the work in the same way as the others. They have a wage subsidy, so that the workplace is getting money to have the individual for some time. The participants revealed that often when these months were over, their employment would end. They felt used by the system. They also felt that their colleagues knew that and never saw them as full members at work. Therefore, the uniqueness of these communication strategies is likely experienced by most hearing individuals as disruptive to everyday social interactions (Goffman, 1963). This is a marginalisation in that they are either included at work but neither excluded because they have a work, and they have work colleagues. For some they will be included and for others, they
will be excluded. This could be, for some time and for others, many years with long-term unemployment. Long-term unemployment is, according to Möller (1996), a directly decisive factor in social marginalization and can create a kind of chronic social marginalization that is difficult for the individual himself to get out of.

But what will make a long-term unemployed individual become excluded instead of just risking becoming excluded? Maybe one answered could be that social exclusion is a combination of serval of factors. Even if you have not had the language you need or the education you want, as long as this is not preventing you from trying to understand or getting the education you want, you are not socially excluded, although you may run the risk being it (Stigendal, 2006).

It is essential to address the organisational marginalisation, because this will become an important aspect that also affects the social interaction and social relationships, both at the workplace and during people’s leisure times. According to Möller (1996), individuals that freely want to be outside the social group, like work, should not be included in the category of socially marginalized. But could you say that DHH individuals freely want to be outside? Maybe when the consequences are that colleagues are laughing about you and calling your name because you do not hear as everybody else, maybe then you decide to be outside that group of people. But before that, when you come as a new co-worker, the intention would be comfortable at work and to make new friends.

There were of course participants in Study III that had work they enjoyed along with co-worker friends. Participants in Study III who were satisfied with their occupation and had serval co-worker friends were usually working on their communication skills such as SSL, they recalled this as being a great advantage. Some of them were working with DHH children or adolescents, and they were very popular and felt valuable in their workplace. These participants seemed to be more comfortable with their HL and did not see the disability as a barrier.

In study I the DHH students and DHH with additional disabilities show that to feel the most social included in special school. In study IV all the results point out that hearing individuals in mainstream school were the ones who have the highest well-being, lowest of mental ill-ness and somatic problems. In study II and III all the participants express how they thought that their HL were a big obstacle to feel social included with hearing individuals.
both in higher education, at work and in leisure time. In the next sector a
discussion will take part how participants knowledge about communication
barriers could affect their identity and group membership.

**Communication as a Cornerstone for Identity and
Group Membership**

The ability to communicate with others is one of the most important hu-
man social functions and is essential for our own identity and group mem-
bership. Language is not only a communication tool, but it is also a tool used
to shape one's identity. Through language individuals are also able to estab-
lish and maintain their group membership. Likewise, communication has
the capability to either create distance or generate belongingness between so-
cial groups (Tajfel, 1978).

In Study II, all of the participants were influenced by social marginalisa-
tion or social exclusion in some way, and the reason for this exclusion was
that they could not communicate or had limited communications with oth-
ers. This influenced their self-esteem and identity. Some DHH individuals
also “chose” to belong to the deaf group. They perceived their *identity* as
deaf because of the strong group feelings among deaf people. This strong
community is something that many DHH persons seek (Brunnberg, 2003; Jönsson, 2003), as most individuals who are HH experience no obvious
identity as HH. This is because the group is heterogeneous, in that hearing
status is variable.

However, most of the participants in Study II recounted experiences of
changing their identity on some occasion by generating a disability identity
as an extension of their identity in Study II. The participants expressed that
if they felt the need to change their identity, they could switch group mem-
berships between hard of hearing, deaf, and, on some occasions, hearing,
depending on the people they were interacting with. They express that they
were using symbols (like hearing ais or SSL) and language to help them show
which group they belong to at that present time. Symbolic language refers to
the form, structure, and meaning of content for the words, images, and
tones that are created and interpreted (Fornäs, 1992). For example, if there
were hearing individuals, sometimes HH individuals said that they were deaf
and use SSL because then they do not have to improve themselves for the
hearing individuals. Their actual identity can, on several occasions, collide in comparison with the ascribed identity.

Hammarén and Johansson (2009) theorized about how the respondents’ identities can change during interaction or different roles according to Goffman (1959). Goffman explained that, when we enter a role, our identity is defined, and the role has certain structures that we must follow in order to adhere to the norm. In this way, our pattern of action is limited by the role we have been assigned or assumed. This is something that Goffman (1959) believes is something that individuals do consciously or unconsciously. Individuals actively emphasise certain aspects of themselves and hide others, depending on what the individuals will show of their identity at that time. Goffman exemplifies this through the individual’s ability to control the impressions given to the environment. When two or more individuals have contact, it becomes possible to check information. The individual’s ability to highlight certain aspects such as symbols and hide others is about being able to control the contact that is created and thereby show a non-real personality that becomes legitimate. The value charge of a symbol is learned in a society through what is called the socialization process. Through this process, one learns the cultural codes of a specific group (Jacobson, 1994). Symbolic forms only gain meaning when they are used in people’s communicative encounters and interactions (Fornäs, 1992). By limiting and regulating what is displayed between an individual and his/her surroundings, regulations and limitations of the contact can be performed (Goffman, 1959). These symbolic forms are also an indicator of what we could expect of others, such as stereotypes and norms.

The stereotype and norm of an individual is one who has the ability to see, hear, walk and talk. This means that a person with HL does not fit into the stereotype, which can lead to social exclusion (Mousley & Chaudoir, 2018). Furthermore, in Studies II and III, the results showed that if the participants experience problematic communication, they might withdraw to avoid difficult communication barriers between DHH and hearing individuals. This could lead to loneliness and social difficulties for people with DHH (Duncan et al., 2021; Eichengreen & Zaidman-Zait, 2020). The individual thus assumes a stereotypical role of “disabled” as an identity, a label that places him/her in a stigmatised compartment. Both these stereotypes and the development of the self are affected by interactions with others. The influence of stereotypes and how these could label marginalised individuals
will affect how they see themselves and imagine how to behave in front of others; this will be the part of the identity. For some individuals, their disability is the most prominent constituent of their self-concept (Cooley, 1992). The individual can also be classified as stupid or unpleasant if he or she does not respond to accusations or answers correctly, although his or her incorrect answers may be due to not hearing properly. This may also lead to stigma. Cooley (1992) stated that society’s stigmatisation of a characteristic of an individual is predictable to result in a negative self-image about the individual. The stigmatisation will then live on as a stigma, both in the individual but also in the society. This is evident in DHH individuals’ reluctance to acknowledge their disability, which according to Hétu (1996), is based on the negative consequences that might come from revealing the condition. In Studies II and III, the participants expressed that they may hold back and be quiet because they do not want to say the wrong things and embarrass themselves. They were afraid to call names and making fun of. Research (Punsch & Hyde, 2005) has shown that people with DHH lose a considerable number of social interactions that typically occur between friends because they cannot keep up with communication. Additionally, misunderstandings may emerge that isolate DHH individuals. Furthermore, the participants may also be self-critical when they have difficulty understanding others or when they make perceptual mistakes (Israelite et al., 2002). These negative reactions are also associated with hearing co-workers’ negative attitudes, as well as the uncooperative behaviours of others (Demorest & Erdman, 1989). This behaviour from hearing was an essential aspect for the participants to choose friends and partners with HL.

Almost all the participants in Studies II and III had most friends and partners from the same group (i.e. DHH individuals) outside of school and work. the participants think that it was much easier to relate to each other easier, as each knows what to expect from the other in such a case. This was similar to the findings of Goldblat and Most (2018), whose study showed that the majority of participants socialised with DHH peers outside their regular schools. Linguistic communication is important to individuals’ identity, and communication thus has a major role in identity development (Andersson & Lawenius, 1997). Functional social and communicative interaction is crucial for people with hearing loss to shape and develop positive self-esteem and identification. Both Goffman (1971) and Blumer (1969) argued
that the basis of social life is communication; thus, when HL limits communication, the consequences are significant. However, the attitudes about HL lie not only with the individual but also with the values and attitudes that exist in society, which can produce limitations and create social stigma.

Individuals who share the same symbols and stigma can seek each other out as a community to feel connected and morally supported, which several of the participants in Studies II and III explained was part of feeling a sense of belonging and not risking exclusion. Most individuals in this world want to fit into society’s definition of what is “normal” at all costs. They do not want to stand out or expose their weaknesses and thus be excluded from the social community (Goffman, 1971). Participants in Studies II and III use strategies, such as pretending to hear in certain situations in which they actually do not hear, smiling, and nodding and laughing when others laugh instead of asking what was funny, to try to hide their disability. However, the consequence of such coping mechanisms is that the individual is attributed to negative traits, such as being stupid or strange, which makes the disability even more extensive and could lead to stigma (Goffman, 1971). Both in Studies II and III the participant revealed that they sometime chose to be lonely and to live in isolation instead of appearing deviant. This could lead to a false identity image where the individual forgets his individual identity and instead strives for acceptance from society by being as similar to the majority as possible (Danermark, 2015). The sense of belonging to the majority of the society or group means power and security, which gives a high identification value and a sense of belonging that individuals long for (Jöns-son, 2003). The participants sometimes hide their hearing aids because it stands for a symbol of HL and the hearing aids become as a negative trait, a stigma, which they believed excluded them from the rest of the society. Individuals who are exposed to stigma may have good reasons to hide their hearing aids and HL, especially in environments where their social status is exposed. Previous research in the field shows that strategies such as denial, avoidance and social isolation emerge among stigmatized hearing aid users (Gagné et al., 2009), which is also reflected in Wänström et al., (2014) study which shown that the participants' embarrassment over their hearing aids arose from commentators from the hearing individuals around them. Hétu et al., (1994) show similar results where the work colleagues stigmatized view of their DHH colleagues was central to the DHH individuals' self-image and well-being in the workplace. Colleagues in the study saw their colleagues as
less capable of specific tasks and frequently joked about their HL. One thing that could reduce the feelings of stigma, and social isolation could be the ability to use AT and ICT. AT and ICT could be a key factor in enabling DHH individuals to participate in daily life and to be social included (Lersilp & Lersilp, 2019).

**Digital Inclusion with AT and ICT: Leading to Social Inclusion and Possibilities to Combatting Stigmas?**

As reading before in this dissertation: having good social relationships with friends leads to great health benefits for the most individuals, as these relationships provide opportunities for social, emotional, and psychological well-being (Ciarrochi et al., 2017). By socialising with other people, especially those with HL, DHH individuals develop their language and communication skills and learn their own opportunities and boundaries, which can lead to lifelong prosperity (Swedish Association of Hard of Hearing People, HRF, 2020). To have the ability to maintain relationships but also encounter new people on the same terms as others ICT has been identified as a significant feature for the social inclusion of DHH individuals. Research has shown the benefits of ICT, such as information seeking; education or work; health support; social interaction/social relationships; job seeking; self-determination; and identity expression for reduction of stigma (Dobransky & Hargittai, 2016; Chadwick et al., 2013; Darcy et al., 2017).

In Studies II and III, the participants expressed that hearing and speaking are barriers that interrupt communication with others and increase the disability, but both AT and ICT were important tools to communicate as everybody else. The results found that most of them used the internet daily to their advantage, for example, using social media/chat apps and face-to-face conversation apps and communicating through social media, such as the use through mobile devices (i.e. Facebook and Messenger). ICT might be a possible facilitator for improving young DHH individuals’ opportunities to belong and develop friendships. In Study III, all the participants expressed how both AT and ICT, such as hearing loops, lights, air-conditioning or ventilation systems that were not noisy, text/videophones, smartphones and the internet, were greatly beneficial in their lives. These findings were comparable to those of previous research on the importance of communication via the internet and smartphones (Akamatsu et al., 2006;
Pilling & Barrett, 2008). Thus, these can be useful communication tools for DHH people, as communication is not hindered, and they can function and feel like everybody else and living independently. Online communication allows confidentiality identity and can benefit DHH individuals by generating online social relationships, expressing their identities, and decreasing stigmas (Chadwick et al., 2013; Mcclimens & Gordon, 2009). Such a view strengthens Goffman’s (1963) thoughts of identity and information management and Cooley’s (1902) theory of looking glass. When individuals use social media, they easily produce a mediated form of their own self, by viewing their self as reflected in others’ comments and replies, likes, and shares; one first see him/herself in a mirror and begins to imagine how he/she appears to others, anticipates their judgment, and acts accordingly to these judgments.

As stated above, there are a lot of benefits with both AT and ICT to achieve social inclusion. But the social inclusion area is conditional on technology and that everything is working. Another form of social exclusion is developing “digital exclusion” (Seale, 2010). Digital exclusion is agonized by the inability to use ICT for some reason. It could be their own capability of using technology, or it could be that they do not have access to the internet because of poverty, technical errors such as reliable power supply and quality of technology, etc. (Wyche & Murphy, 2013). This digital exclusion can lead to the individual being disadvantaged and marginalized by society (Njoki & Wabwoba, 2013). This could also lead to a disability stigma and double vulnerability, as both the disability itself and the digital exclusion could lead to marginalization and/or social exclusion in society. Society has frequently brought attention to the importance of policy issues concerning people with disabilities’ communication rights via technology.

However, disability stigmas continue to emerge in connection to people with disabilities’ access to and use of digital technologies (Ellis, 2014; Theodorou & Mavrou, 2017). Therefore, digital inclusion requires a greater level of training and support for individuals to have the right opportunities to be able to use ICT (Darcy, Green, & Maxwell, 2017.) The goal has to be to use technology’s abilities to increase DHH individuals’ feelings of belonging, competence, autonomy, and self-esteem. Research shows that technology promotes these factors and also helps individuals state their own definitions of capability and “normality” (O'Bannon et al. 2015; Chadwick & Fullwood 2018; Chib & Jiang 2014; Dobransky and Hargittai 2016). There is
also research into disability stigma that shows that online interactions help people with disabilities to highlight their own potentials as individuals (Dobransky & Hargittai, 2006). This will benefit individuals to remove disability, as the leading character in the identity, and instead they could reconstruct their identity in a more optimistic way, until they choose to expose their disability (Bowker & Tuffin, 2002). Results have also shown that the use of ICT will reduce loneliness and give greater sense of belonging to a group of people or community (Damásio et al., 2012). This will be a strong predictor of fighting stigma and of finding facilities for social inclusion for DHH individuals as well as for people with other disabilities. Maybe AT and ICT will be the new cornerstone for social inclusion and reducing the needs of longing to belong?

**Limitations and Methodological Considerations**

A few methodological considerations should be made before proceeding any further. First, Studies I and IV were built on self-reported questionnaires of well-being and mental ill-health. These were subjective measures and therefore were susceptible to various types of measurement errors (e.g. bias) that may have led to distortion of the results or their interpretation. Furthermore, individuals can be biased when reporting their thoughts and experiences, as they are either consciously or unconsciously influenced by what is socially adequate or preferred (Devaux & Sassi, 2016). To validate the data, the questionnaires (Liv och hälsa ung) in this study were used for several years, and there was consistency in the results over time.

Second, in Studies I and IV, all the adolescents should have answered the questionnaire individually in the classroom. In a classroom situation with other adolescents, though, the possibility was higher that some respondents answered the survey questions inaccurately because they did not want their peers to see them as more vulnerable or less valid. Furthermore, some uncertainty exists about whether students with disabilities answered the questionnaire correctly. A relatively large internal non-response rate was identified for the disability and gender variables, as some of the students attending special schools never answered if they had a disability or not.

Studies II and III also require some important methodological considerations. First, for many of the participants, the interviews were their first opportunity to express their experiences of having a hearing loss. This led to a
significant amount of data and provided deeper insight into the participants’ life situations. However, the studies would have benefited from more data about different areas, such as the students’ experiences and thoughts regarding higher education (only a few of the participants had completed higher education). The interview would also have gained more knowledge about the students’ experiences if questions had been included about how the students had managed different social settings, expressed their loneliness and feelings of not belonging to a group of people and about living ‘between two worlds’, and how they coped with those feelings.

As another methodological consideration, the interviews were conducted in 2011 and 2012. Therefore, the data might be somewhat dated, and the participants’ lives may have changed. However, determining this would require substantial follow-up research. Furthermore, recent research (Duncan et al., 2021; Eichengreen & Zaidman-Zait, 2020) has revealed similar findings about experiences of social inclusion and the importance of communication ability. Thus, even though the data are dated, the findings are applicable to young adults who are DHH today. Nonetheless, it would be of value to supplement further studies with both a quantitative and qualitative design that includes more people who are DHH to determine whether additional individuals have had similar experiences.

Transferability in Studies II and III was achieved through detailed descriptions of the research process. To achieve interrater reliability (IRR) in the dataset, the research team developed a codebook with keywords generated from the data, as opposed to using a predefined set of categories or codes. Using this codebook for each of the 16 interviews was a time-intensive but essential initial step in safeguarding the trustworthiness and quality of coding during the data analysis. Credibility was achieved by letting the participants read the interviews and having the co-authors perform the data analysis. To enhance credibility, content, and context were both considered. To achieve trustworthiness and confirmability, not only did both authors perform the analysis, but in situations of disagreement, they also engaged in discussion until a consensus was reached. Credibility was achieved because the results could be transferred to comparable situations (Graneheim & Lundman, 2004; Lincoln & Guba, 1985).

Reflexivity, in which the researcher becomes aware of his or her personal role in the research process (Davies, 2008), was an important aspect of the
present project, especially in Studies II and III (i.e. interviewing the 16 participants). Each interaction presents an opportunity to influence both parties involved. According to Bourdieu (1996), researchers should expose themselves to the same objectification instruments that are used to examine other people. In other words, researchers should study themselves in the same way they are studying others. As knowledge is created somewhere between the researcher and the participants, it is important, both theoretically and ethically, for the researcher to consider how his or her presence may have affected the process (Ehn & Klein, 1994).

To produce valid data, the interviewees must provide honest, personal answers. The interviewer can contribute to this by clarifying questions in both surveys and interviews. However, interviewers can also influence the interviewees’ answers, both the interviewers’ presence in the room and unintentionally influencing the interviewees to give responses they think are desired (Repstad, 1999). While possibilities exist that the interviewees may have been influenced, the fact that these circumstances affected their answers is not definite.

Concluding Remarks and Practical Implications

From the findings of this dissertation, it can be concluded that the largest obstacle to achieving social inclusion is communication barriers. This means that DHH individuals can be social excluded from assurance and support within the family, friends and colleagues and also from professional support workers (such as social worker, medical worker such as: nurses and doctors). Because of their communication barriers they also have to struggle to reach their educational potential and also sometimes to have a good working career. The desire for belonging would be easier to satisfy if DHH individuals had more opportunities to communicate with hearings, both in school, at work, and in leisure time. Whether this can be achieved by various methods of assistance or by providing education on SSL to more people has yet to be determined, but a more inclusive social environment must be achieved. School plays an essential role in making DHH adolescents feel socially included. Adolescents in school experiences, which affect their well-being, mental health, and somatic problems, play a vital role in determining their future. The more positive experiences adolescents have in school, the more likely they are to achieve and sustain mental health and well-being later in
life. No sense of belonging or social exclusion in school can be interpreted as risk factors for mental illness, somatic problems and feelings of stigmatisation and marginalisation. It is, therefore, important to focus on providing support and following up as soon as indications (headache, depression, isolation, etc.).

In the dissertation’s findings section, there were also results that clearly demonstrated that teachers have a significant impact on adolescents’ well-being, mental health, and somatic problems, particularly for girls. Therefore, this dissertation provides valuable knowledge for school professionals (e.g. educators and other professionals within the school system) and for professionals in the field of social work who play a supportive role. For example, knowledge of the well-being, mental health, and somatic concerns that are prevalent in educational settings could help teachers recognize early indicators and give them insight into how to help adolescents. DHH adolescents have more social difficulties because of communication barriers; this may be a specific area that teachers should monitor, as in inclusive classrooms, which helps to promote positive interaction between DHH and hearing adolescents. Professionals (such as teachers) may gain a better understanding of the school situation for DHH adolescents. The teachers need to find the time to build good relationships and the capabilities to give DHH adolescents a suitable educational environment. Maybe one example could be having a traditional education teacher and a special education teacher in the same class. This could be useful for the knowledge development of the entire class, not just those with disabilities. Such a setting could provide support with appropriate resources and opportunities for students to achieve educational goals in school. Another example would be to provide knowledge about HL to hearing adolescents and teachers to improve their awareness and encourage them to talk and interact with their DHH peers and students. If we want everybody to be included, we maybe have to start with the school’s policies, the Education Act and curricula, to see how the school’s governing documents address adolescents with disabilities. The new curriculum is very clear that in order to achieve the goals in school, you must be able to reflect, evaluate, analyse, critically examine, and put things in a larger context. This is exactly what some adolescents with disabilities have difficulties with and could exclude.
Despite DHH individuals having ordinary intelligence and abilities, they continue to have less of a University education and a higher amount of unemployment and underemployment than hearing individuals. The findings in this dissertation showed what contributing to this situation are factors such as the DHH individual’s educational achievement levels, as well as environmental and attitudinal barriers found at school and at work. For example, the most difficult school and workplace situations reported by DHH individuals involved group situations such as group meetings, and work-related social functions such as lunch breaks and other social. Thus, the largest barrier to inclusion was communication shortcomings, and the desire for belonging would be easier to fulfil if more opportunities were given to communicate.

Finally, it is important to highlight what emerged as an extremely important part of the work on this dissertation. How included are DHH individuals? Through the whole work with this dissertation, the participants express that they were excluded in different ways from the society. We in Sweden have policies rights and regulation of law to ensure that all citizens should feel included, and we work hard actively against marginalization and exclusion in most forms. We say that we are citizens on the same terms and that everyone should have full citizenship. But in practice, this citizenship is conditional. It is limited to some citizens, especially those with a disability, and in this case, those with DHH. To clarify the reasoning, I will give an example about an individual who is dependent on having an interpreting service. Having an interpreting service looks different depending on where you live in our country and which municipality you live in. Each municipality decides for itself how much financial resources it should spend on this service each year. Therefore, the opportunity to have an interpreter will look different. You have a greater opportunity to get an interpreter at the beginning of the year than at the end, which limits your citizenship time limited. It is also the municipality that decides which commitments they give interpreters to, which makes your citizenship conditional on the professionals. It is therefore important to have a need in the right municipality, at the right time of year, and for the right engagement. What does a person who needs an interpreter do in November if he or she needs to be in a trial or has to be at the hospital? This is something that needs to be reviewed so that individuals with DHH can feel like citizens on the same terms as everyone else,
to be included in society as everybody else. We have come a long way, but still, we have a lot to do to achieve that none must... *Longing to Belong.*

**Suggestions for Further Research**

Examining DHH individuals is complex because of several impactful variables. The aspects of hearing loss differ not only from individual to individual but from situation to situation and over time in the same person (Szarkowski, 2017; Whitaker & Thomas-Presswood, 2017). These variables have to be taken into account in future research. There are numerous variables that have an impact on the results in research (Shaver et al., 2014); for example, the degree of hearing loss, age, amplification usage, age upon identification of hearing loss, age at receiving early intervention services, communication, and language abilities (Marschark et al., 2015). Other variables impact how people with HL perceive their abilities, knowledge, and self-image, such as the home language, parents’ education, number of family members and the family’s hearing status (Knoors & Marschark, 2012). Additional factors include the school the DHH individuals attended (special or mainstream schools), the number of students in the classroom, the awareness/attitudes of the hearing students and the availability of supports and services (Knoors & Marschark, 2014). Other features, such as geographic location, age, race, and socioeconomic status, should also be considered (Davis-Kean, 2005). Though it is difficult to control all of these variables statistically, researchers must at least understand and discuss these factors as possibility bias or outcomes. This will enable the researchers to understand the complexity of being DHH. More significantly, reflection on these features should influence the progress of effective research designs that will hopefully provide better and more useful or generalisable findings.

There needs to be more research on capabilities to identify predictors of academic achievement for DHH individuals in school. Previous studies have focused almost exclusively on reading and mathematics (Spencer & Marschark, 2010). There would be an interest in highlighting other academic subjects, such as science and social studies. There are also important to examine achievement across a broader array of academic domains for postsecondary education and employment. Much research is available on various types of accessibility, such as technical accessibility in schools and workplaces, as well as how many people choose higher education and gain
employment. However, more knowledge about the life situations of students is needed, as well as what could be done in the workplace so that individuals with disabilities can participate on their own terms (Larsdotter Frid & Krantz, 2013).

A significant gap in research on DHH students is evidence of effective practices for improving their outcomes. Well-designed impact studies in education, especially DHH students, are hard to find (Shaver & Blackorby, 2014). Future research is needed to study the social interaction between children who are DHH and hearing in diverse phases of school life, as well as to improve social interaction and establish an social inclusive school environment for children who are DHH.

There is not much research about interpretation use and how this is perceived for the user (Roos, 2006). There would be interesting to investigate how DHH experiences the different conditions which are depending on the geographer, the economic condition, and which time in the year you want to have an interpretation. How inclusive or excluded do users think this is? It would also be interesting to see how the feelings of social inclusion for DHH if there were possibilities to implement sign language throughout the school from pre-school to 9th and then make an evaluation if there are differences in experiences around social inclusion.

There is still a lack of knowledge about middle-aged DHH individualise as they are continuing their education, a new career, or starting a family. I really want to do is to meet all these participants and interviewed them all again.
Svensk sammanfattning


Personer med hörselnedsättning kan prestera såväl som sina motsvarigheter utan hörselnedsättning när det finns rättvisa utbildningsmöjligheter och anställningsmöjligheter (Schroedel och Geyer, 2000). Dessa rättvisa möjligheter är beroende av att den enskilda studenten eller arbetaren har tillgång till den information som krävs för att lära sig eller för att få jobbet gjort. Arten av denna kommunikationsåtkomst beror på individuella behov och de hjälpmedel som finns tillgängliga för att tillgodose dessa behov.


Resultaten av studie I visade att personer med DHH upplevde lägre grad av välbefinnande än de som inte hade någon funktionsnedsättning. Resultaten visade även på att de som gick i specialskola upplevde att de hade fler vänner och var mer socialt inkluderade än de som gick i integrerad skola. De studenter med DHH och DHH och fler funktionsnedsättningar upp-
levde också att de hade större möjlighet till akademisk inklusion i specialskola då de vågade ställa fler frågor framför de andra i klassrummet. I studie I framkom det också vissa könsskillnader. Pojkarna i alla grupper (utan funktionsnedsättningar, DHH och DHH och minst en till funktionsnedsättning) mådde bättre än flickorna.


I studie III gjordes en tematisk analys (Braun & Clarke, 2006; Nowell et al., 2017) för att identifiera, analysera, organiser, beskriva och presentera teman inom data. Resultaten i studie III visade på att sociala interaktioner och sociala relationer i högre utbildning (högskola, universitet), på arbetet och på fritiden var mycket beroende av hur kommunikationen fungerade mellan de med en hörselnedsättning och de som var hörsande. T.ex. så framkom det att nästan vid alla grupparbeten i skolan exkluderade de med en hörselnedsättning eftersom de har svårt att höra när det är fler som samtalar på samma gång, inte är vänt mot en, om det finns andra ljud runt omkring en etc. Det framkom också att de många gånger kände sig social exkluderade på sitt arbete eftersom de hade svårt vid fikapausar, luncher eller tillfälliga stopp i korridoren med flera personer, hålla en diskussion vid liv eftersom det var svårt att höra konversationen med flera personer. Mycket av
det sociala gick förlorat och flera informanter berättade att de hellre drog sig undan istället för att göra bort sig genom att man kanske hade hört fel, eller för att man inte ville fråga om och om igen vad som hade sagts. Det framkom också i studie III hur viktigt teknologin är för sociala interaktioner och sociala relationer. Teknologin har hjälpt till att reducera flera barrier när det gäller att kommunicera med andra. Både vad som gäller Assistant Technology (AT) och Information and Communication Technology (ICT) är viktiga redskap för att kunna upprätthålla sociala aktiviteter med vänner och partner.

I studie IV fanns ett intresse att se om ungdomarnas välbefinnande blivit bättre, sämre eller likartad sen Liv och hälsa ung 2011, nu när vi hade tillgång till Liv och hälsa ung 2017. I studie IV fanns också ett intresse att se över den mentala hälsan och somatiska besvär för de eleverna med en hörnedsättning i skolår 7 och 9 vid alla grundskolor och i år 2 på alla gymnasieskolor. I denna studie är alltså fokus på alla studenter oavsett skolform, specialskola eller integrerad skola.

Resultaten visade på att eleverna med en hörnedsättning mådde sämre gällande välbefinande, somatiska besvär och mental hälsa än de höraned eleverna. Resultaten gällande välbefinande visade att barnen mådde lika dåligt 2011 som 2017. Allra sämst mådde de som hade en hörnedsättning och ytterligare någon funktionsnedsättning (Rörelsehinder; lässvårigheter; skrivsvårigheter, ADHD, ADD eller andra funktionsnedsättningar). De som mådde bäst var de utan någon funktionsnedsättning och i alla grupper (utan funktionsnedsättningar, DHH och DHH och minst en till funktionsnedsättning) var det pojkarna som skattade sig högst inom alla kategorier, där högt resultat indikerar på gott välmående, inga somatiska besvär och god mental hälsa.

Ett annat resultat visade på att det fanns en skillnad i hur eleverna mådde beroende på vilken årskurs de gick. Eleverna mådde bäst i årskurs 7 och för varje årskurs mådde de sämre och sämre i både välbefinnandet, somatiska besvär och den mentala hälsan. Men för gruppen DHH och ytterligare en funktionsnedsättning visade det sig att de mådde allra bäst när de gick år 2 på gymnasiet och detta resultat gällde både pojkar och flickor.


De två andra som jag vill tacka som funnits vid min sida och stöttat och hjälpt mig men säkert också dragit i sitt hår av ren frustration är mina handledare. Min huvudhandlare Christian Kullberg och min bi-handlare Munir Dag. Jag har haft turen att dela samma korridor med dem i flera år under min handledningstid så dörrarna till deras rum har alltid stått öppen för mig när jag behövt fråga något. De har också läst och läst och kommit uttröttnligt med mängder av råd och tips. Vi har också skrattat mycket ihop och åtit många ’örfilar’. När det gäller handledarskapet vill jag också passa på att tacka postumt Elinor Brunberg. Det här var hennes projekt från början. Hon ville söka upp de med hörselnedsättning som hon själv hade studerat i sin egen avhandling, för att se hur livet var idag med dem. Hon frågade om...

Under min doktorandtids så har jag också hunnit att avverka tre avdelningschefer. Min första chef under doktorandtiden var Mats Ekermo. Han fanns där mina första år som nybliven doktorand och försökte pussla ihop min undervisning med mina doktorandkurser, vilket ibland var ”mission impossible”. Under tiden med Mats Ekermo vid rodret fick jag två underbara flickor, Lorina och Nelia, på ett kanske normbrytande sätt, vilket stundtals inte var så lätt i detta byråkratiska land. Men Mats såg till att det aldrig på något sätt blev problematisk för min del, utan han underlättade livet på många sätt.


fått ”ner mig på jorden” på 10 minuter. Jag vill också tacka Lenas man Rai-
er som är Gugges och min ”Google man” och som ställt upp så mycket på
oss båda och för att han aldrig sagt ett ljud att jag ringt i tid och otid.

En annan människa som har betytt mer än jag med ord här kan beskriva
är Christine Gustafsson. Christine och jag började jobba tillsammans redan
2015 med ett projekt i samarbete med Västerås stad. Sedan ingick vi tillsam-
mans i ett EU-projekt (NURED) under tre år. MDH, HVV var partner till-
sammans med Finland (Arcada), Riga Stradina universitet och Tallinn He-
alth Care college. Detta projekt hade många utmaningar på olika sätt och jag
lärde mig otroligt mycket som forskare och människa under dessa år. Det
resulterade även i två vetenskapliga artiklar och två svenska artiklar under
doktorandtiden. Men framförallt fick jag en möjlighet att lära känna en av
de mest underbara människor jag någonsin mött, Christine Gustafsson. Hon
har lärt mig så otroligt otroligt mycket. Hon har varit min mentor och nära
vän under alla dessa år och idag vill jag inte leva en vecka utan att träff-
ha henne. Det är få människor som jag tycker innehar en sådan professionalitet
och ödmjukhet som hon har. Och ett jättetortala talamod med mig. Hon har
lyssnat och lyssnat på mitt kappaprat i flera år och vi har även skrivit en
artikel i denna avhandling tillsammans (artikel 2). Jag vill också passa på att
rika ett stort tack till Per Gustafsson som tillsammans med Christine lånat
ut sitt hem till mig för att jag skulle kunna sitta och skriva ifred. Ett otroligt
stort tack också till Agnes Gustafsson för all språkgranskning på Christines
och mina artiklar. Tackatt du tog dig tid med våra texter som jag förstår var
en utmaning ibland. Ett extra stort tack för att du ville vara illustratör på
denna avhandling och skapade en perfekt bild av hur jag såg på ”Longing to
belong”. Du är så begåvad!

Carina Loeb, min vän, kollega och gudmor till min äldsta dotter och jag
till din, tack för att du är du och som alltid funnits vid min sida. Under dessa
år har vi gått igenom så mycket tillsammans och du har många gånger varit
min ventil när luften tagit slut. Vi började i psykologin, du ett år före mig,
och sen har vår resa fortsatt i snart 20 år på MDH. Alla som lär att känna
dig vet vilken underbar person du är som ger så mycket av din intelligens,
kreativa förmåga och din värme. Du sätter alla framför dig själv och blir ge-
nuist glad av att lyfta andra. Jag fick också förmånen att skriva den sista arti-
keln i den här avhandlingen tillsammans med dig (artikel 4) och jag vet att
det snart blir flera (vi har ju några tycken på gång redan). Det är fantastiskt
att ha en vän som du i mitt liv och ser fram emot att bli gammal med dig.


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att betyda så mycket för mig. Vi har verkligen både skrattat och gråtit tillsammans. Ni blev verkligen mina vänner för livet och det är jag så tacksam för.


Man kan ju inte rangordna tacken på något sätt men ett av de viktigaste tacken måste ändå bli till Maria Müllersdorf och MDH, HVV. Utan att Maria Müllersdorf som då var vår akademichef, hade arbetat för att det skulle bli en forskarutbildning (tillsammans förstås med flera andra) så hade jag förstås inte kunnat skriva denna avhandling. Att MDH gav oss adjunkter den fantastiska möjligheten att kunna doktorera på halvtid gjorde att flera av oss kunde både fortsätta som adjunkter och samtidigt doktorera. Tack min fantastiska arbetsplats Mälardalens högskola (MDH och främst HVV) för denna möjlighet!


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Our Australians sisters, Sue, and Halle. Both of you are always in our hearts. For the whole life we have been longing for you and I hope that all of us four sisters could live in in the same country one day! We will always love you both! Halles husband Martin, I will also thank you for your proof-reading and for that you are a wonderful man!


Hoppas jag inte “glömt” någon! I så fall är det bara i all välmening. Det handlar bara om en lätt förvirring så här några timmar innan denna skapelse skall tryckas! Tack allihopa! Nu ska jag sluta...


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