Speech and language therapy with Deaf and hard of hearing Norwegian Sign Language users with aphasia

A case study

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Summary

The topic in my master's project is speech and language therapy with Deaf and hard of hearing Norwegian Sign Language users with aphasia. The purpose of my master's project was to explore the speech and language therapy being provided for Deaf and hard of hearing Norwegian Sign Language users who have been affected with aphasia. Aphasia is language disorders after acquired damage to the brain and can lead to different types of language and communication difficulties. Speech and language therapists have the competence to help people with aphasia, and in Norway, everyone affected with aphasia has the right to receive therapy from a speech and language therapist.

The four research questions this project was meant to answer was:

- What is the current status of speech and language therapy provided for Deaf and hard of hearing Norwegian Sign Language users who are affected by aphasia?
- How is the speech and language therapy experienced from the perspective of a client within the group of Deaf and hard of hearing?
- How is the speech and language therapy experienced from the perspective of a speech and language therapist who provide therapy for this group?
- How can speech and language therapists contribute to meaningful service for Deaf and hard of hearing Norwegian Sign Language users who are affected by aphasia?

I chose a qualitative approach to the project, and the project was conducted as a case study. The methods being used was semi-structured qualitative interviews and observation with a client and a speech and language therapist having experience with speech and language therapy with Deaf and hard of hearing Norwegian Sign Language users with aphasia.

The results of this study show that no available information as of today in regard to an overview of the SL therapy offer available for DHH NTS users with aphasia in Norway. Despite diligent efforts, I have through this project not succeeded in getting an overview of which SLTs or rehabilitation institutions that provides SL therapy for DHH NTS users with aphasia. Furthermore, my results show that the consequences of aphasia have been of large consequences for the client in this study. As a result of the stroke, the client had to move to a nursing home with only hearing people, which has had a negative impact on his opportunities for participation in linguistic and social communities. The client does not have access to NTS in his everyday life. He is offered SL therapy four times a year, for periods of two to three weeks at a time. The client describes the importance of being offered SL therapy as extremely valuable, as this gives him the opportunity to communicate on NTS. Regarding the SLT's perspective on the current state of SL therapy offered for DHH NTS users with aphasia, the results of the study show that the SLT is not sure what these clients are offered either. Among those who receive SL therapy from her, they are met with a holistic approach to aphasia with roots from what is known for aphasia rehabilitation in hearing persons.

Acknowledgement

In memory of my dear uncle Åge, who sadly passed away during this semester.

A tough semester is over, and it is now time to finish this work and my two years of master's studies in speech and language therapy at the University of Oslo.

I want to say a big thank you to the participants who have given so much of themselves in this project. Without you, this would never have been possible. Thank you so much.

Family and friends, thank you for your patience and kind words when I have found the work on the task to be insurmountable.

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Dear Luca and Arnfinn
Words become poor when I try to describe how important you have been that I have now mastered to submit my thesis. Thank you for showing such great faith and commitment to my project from beginning to end.

Maria Haldorsen

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1 Introduction

The topic for this master's project is speech and language (SL) therapy with Deaf and hard of hearing (hereafter DHH) Norwegian Sign Language [norsk tegnspråk] (hereafter NTS) users with aphasia. The purpose of this project is to explore and make visible some current experiences and reflections regarding SL therapy provided for DHH NTS users with aphasia.

1.1 Background and purpose

The idea for this project is arisen from my personal experiences of working with and towards DHH NTS users, as well as from my professional interest in the field. Already on my first year of my master's degree I started getting interested in the field of speech and language therapy regarding DHH NTS users. In addition to being a master's student I got the opportunity to work in a care home providing services for DHH persons. Through working with DHH residents and colleagues I became more aware of health care regarding DHH NTS users and got curious about SL therapy regarding this group. My ideas developed from vague thoughts and wishes about contributing to awareness about service provided for DHH NTS users that SLTs and other health care workers are likely to meet. From that my ideas grew to become this master's project.

Given the opportunity to choose a topic for my master's thesis, I wanted to conduct a master's project that might contribute to a meaningful and equivalent SL therapy suited for NTS users with aphasia. Furthermore, I seek to include DHH NTS users with aphasia in the project about them and to contribute to make their perspectives visible. By also including the experiences from the speech and language therapists (SLTs) who are serving this group, this project aims to get a greater depth in the current status of service provided for DHH NTS users with aphasia. (The reader should note that the English terms "speech and language therapy" and "speech and language therapist" are used in this thesis, and elsewhere, to denote a profession and do not specifically refer to spoken language, cf. the Norwegian equivalent terms "logopedisk oppfølging" and "logoped", which make no such apparent reference.)

1.2 Research questions

This project was meant to answer four research questions regarding DHH NTS users with aphasia. The research questions for this project are:

- What is the current status of speech and language therapy provided for Deaf and hard of hearing Norwegian Sign Language users who are affected by aphasia?
- How is the speech and language therapy experienced from the perspective of a client within the group of Deaf and hard of hearing?
- How is the speech and language therapy experienced from the perspective of a speech and language therapist who provide therapy for this group?
- How can speech and language therapists contribute to meaningful service for Deaf and hard of hearing Norwegian Sign Language users who are affected by aphasia?

1.3 The structure of the thesis

The introductory chapter is followed by a theory chapter (chapter two) that is meant to lay the theoretical foundation that the project is built upon. Through the theory chapter, the reader will be given a brief introduction to what is meant by being Deaf and having hard of hearing, and a summation of key elements in the history of Deaf people. Further there will be given an overview in important structures in sign languages, followed by a brief introduction to phonetics in sign languages and phonology in NTS. I will then give the reader an introduction to different approaches to language impairment and aphasia. Further there will be given an account of aphasia in bilinguals and difficulties that often co-occurs with aphasia.

Chapter three is the methodology chapter. Here I will give an account of methodology and research design used in the study. Methodological choices made by the researcher during the process will be explained and I will give an account of how validity, reliability and ethics have been accounted for throughout the project. In chapter four, the results of the project will be presented and discussed. One research question at a time will be answered and discussed in the light of the theory on which the thesis is based. In chapter five I will give a brief summary of the main elements that emerged in the project, and I will present the limitations of the study. At last, I will outline some thoughts regarding future directions for SL therapy among DHH NTS users with aphasia.

2 Theory

2.1 Deaf and hard of hearing

The population of DHH consists of a varying accumulation of people, and is highly heterogeneous (Young & Hunt, 2011, p. 9). DHH can be identified by various characteristics, such as severity and age at onset of hearing loss, aetiology, or linguistic and cultural identity (Israelite et al., 2002; Austen & Coleman, 2004). Distinctions are often made between *deaf* and *hard of hearing* (Hindley, 1997), whereas the hearing status defines whether a person is being identified as *deaf* or as *hard of hearing*.

According to World Health Organization (WHO, 2021) having *hard of hearing* refers to having a hearing loss ranging from mild to severe. When having *hard of hearing* one usually benefits from using hearing aids, cochlear implants and other assistive devices, and usually communicates by spoken language (WHO, 2021). According to WHO (2021) *deaf* people have a profound hearing loss, which implies very little or no hearing. *Deaf* people most often use sign language for communication (WHO, 2021). In real life, this distinction is not always that clear. What is more common is that persons with a hearing loss are matching their communication methods and complexity of communication to whom they are communicating (Young & Hunt, 2011, p. 6). They may use different means of communication in different contexts, e.g., NTS with their signing friends and family, spoken Norwegian with their hearing neighbours, and also some kind of hybrid forms, such as speech with signs [tegn til tale] with their colleagues. The perspective on deafness that WHO is representing is in line with a disability understanding of deafness, whereas deafness is synonymous to a profound loss of hearing. This coincides with audiological deafness, which is being used in a medical context, and refers to low results in hearing tests (Vonen, 2006).

In an educational context, the implication of deafness is regarding the consequences of hearing impairment for the perception and acquisition of spoken language (Vonen, 2006). The term pedagogically deaf (or educational deaf) refers to those who through hearing cannot perceive or acquire spoken language spontaneously in regular communication with spoken language users (Vonen, 2006).

People who consider themselves Deaf often have a perspective on deafness, where being Deaf is seen as being part of a sign language cultural community, which represents a cultural understanding of deafness (Vonen, 2006). Being culturally Deaf means being part of a Deaf community, and persons who are considering themselves as Deaf in the cultural sense do not necessarily have problems with being able to hear (Young & Hunt, 2011, p. 1). For instance, it is possible to be culturally Deaf if one has grown up in a culturally Deaf family, having sign language as first language, and one identifies oneself with being Deaf (Young & Hunt, 2011, p. 1). Though this is a way many Deaf people identify with being Deaf, the cultural model of deafness is still struggling to be accepted, and the cultural identities of those being Deaf have been denied, diminished and oppressed (Ladd, 2003; Lane, 1992). In research there is a tendency that many researchers follow a medical model of deafness, with an aim to "cure" or "fix" hearing loss (Anderson et al., 2018, p. 1814). However, most Deaf people view themselves as members of a rich culture with a shared experience, history, art and literature, as opposed to being disabled or in need of being fixed (Ladd, 2003; Lane, 1992).

According to Young and Hunt (2011, p. 1) lower case 'd' is generally used when referring to the audiological condition of not hearing and is mostly applied to those who use spoken language. Upper case 'D', on the other hand refers to those who are members of a Deaf community and who uses sign languages, such as NTS (Young & Hunt, 2011, p. 1). In this understanding, the word 'Deaf' is akin to other markers of cultural-linguistic identity such as Norwegian or Swedish. This means that it is possible for a hearing person to be 'Deaf' e.g., if they grew up in a culturally Deaf family with NTS as preferred language. Likewise, it is also possible for a culturally Deaf person to be referred to as 'hearing' if they are behaving out of cultural character (Young & Hunt, 2011, p. 1).

This thesis will emphasise a cultural understanding of Deafness according to which being Deaf is seen as an identity, and not a condition (Young & Hunt, 2011, p. 12). What makes a person interesting in regard to this project is not their hearing status, but their identity as Deaf and as being a NTS user with aphasia having experiences with SL therapy. Although the client in this project would have fitted in both the term deaf and Deaf, it is not relevant in this project to distinguish between the different terms. Hereafter the term Deaf will be used throughout the thesis, emphasising a cultural understanding of Deafness.

2.2 Discrimination of Deaf people

To give the reader an insight into what is important to keep in mind when working with and towards Deaf persons, a brief introduction to the history of Deaf people may be useful.

In order to understand the background of elderly Deaf persons we need to keep in mind what Deaf people in Norway have been exposed to over time. It must be acknowledged that Deaf people have over time been discriminated, so we must take this into account, especially if being a member of the hearing majority.

A prudent example of the discrimination of Deaf people is that during the census in 1910, Deaf people were counted outside the normal population (Bore, 2006a). The Central Bureau of Statistics explained in the period 1877-1913 that by counting the blind, deaf-mute [døvstum] and insane [sinnssyke] and distributing them over time, and by district, gender and age, the statistics should help to explain how these impairments [lytene] arose (Bore, 2006b). In this quote, Deaf people are put in the same box as, among other things, insane people. The quote also suggests that Deaf people are also assigned muteness only on the grounds that they are Deaf.

The fact that Deaf people were considered a group outside society is evident in several ways. Among other things, it was not allowed for Deaf people to drive a car until as late as 1933 (Stub-Christiansen, 2018, p. 22). Drink-driving, on the other hand, was allowed until as long as 1936 (Sulland, 2016). In addition, Deaf people had to pay as much as 50% higher accident insurance than hearing people as long as 1980 (NDF, 2021).

2.3 Sign language(s)

Sign languages are independent of hearing, as they do not include a sound system (Språkrådet, 2020). That is why people without hearing still have a full-fledged access to a functional language through sign languages (Vonen, 2020). Sign languages are gestural-visual languages which take advantage of the ability to reproduce and show the positions, movements and properties of things through the shape and movement of the hands in front of the body, in combination with the expressions and movements of the head and face (Språkrådet, 2020). Sign Languages are not a back-up solution for those who cannot communicate through spoken language, but full-fledged languages taking advantage of other modalities than those being available through hearing.

Sign language development follows the same phases as spoken language development, and the sign languages has a lexicalised sign repository, duality in the construction pattern of linguistic symbols productivity (Meier, 2002). In the same way as every other language, sign languages have arisen as a result of humans' desire to communicate with each other, and have arisen and been developed in a social context between humans (Vonen, 2020). Naturally sign languages also contain derivational morphology, compound signs and borrowed signs, and have syntactic structures that correspond familiar structures from spoken languages (Vonen, 2020).

Sign languages are minority languages, and most sign language users are multilingual. Through reading and writing, most sign language users are also users of the majority language in the country in which they live. This also has implications for the development of sign languages, as minority languages are often influenced by the majority language used in the country. It is a common misconception that sign language is one international language, or a thought that they should be so. Of course, this is not the case, and there is little reason to believe that it would be any more likely to happen than that all people around the world would speak the same language sometime in the future.

2.3.1 Phonetics in sign language

In sign language, linguistic expressions are produced by means of certain parts of the body, which can be called the sign organs (even though it is not common to call them that) (Vonen, 2020, p. 51). These organs consist of moving parts such as hands and arms, mouth and cheeks, eyes, eyebrows, nose, the whole head, shoulders and the whole upper body (Vonen, 2020, p. 51). In addition to the movable organs, the sign organs consist of relatively immobile organs, such as the forehead and chest (Vonen, 2020, p. 51). In various combinations and ways, all these organs are used in interaction to produce linguistic expressions in sign languages.

2.3.1.1 Manual processes in sign language

It can be useful to divide sign language production into different processes, where the main types are manual and non-manual processes. Manual processes refer to what we do with our hands and arms when we speak sign languages (sign) (Vonen, 2020, p. 51). In sign languages, we vary between using one or two hands when signing. Since the hands are the most flexible sign organs we have, this of course has an impact on how sign languages are built up. Sign languages make great use of the flexibility of the hands, and we distinguish between four different parameters in the description of each hand: handshape, orientation, location and movement (Vonen, 2020, p. 52-53).

2.3.1.2 Non-manual processes in sign languages

The non-manual processes can be sorted according to which moving sign organ is included (Vonen, 2020, p. 53). Among other things, movements and positions in the mouth are important non-manual processes in sign language, as well as movements and positions in the eyebrows (Vonen, 2020, p. 53). The eyebrows can, for example, be neutral, raised or wrinkled/contracted, which is important for the overall linguistic expression. Another non-manual process is movement and positions in degrees of eye aperture, as well as the direction of the gaze/head/upper body (Vonen, 2020, p. 53).

These sign organs are being used in different combinations to produce linguistic expressions which can be perceived by sight (Vonen, 2020, p. 53-54). When communicating by sign language we are therefore completely independent of hearing, because we use our body to express the language, and our sight to perceive it.

2.4 Norwegian sign language (NTS)

The official sign language used in Norway is Norwegian Sign Language [norsk tegnspråk] (hereafter NTS). In 2008 the government presented the report «Mål og meining – Ein heilskapleg norsk språkpolitikk [Goals and meaning: A holistic Norwegian language policy]» (St. meld. nr. 35, 2007-2008). The report was considered and approved by the parliament in 2009, and Norwegian Sign Language was then recognized as a full-fledged language in Norway. According to the Norwegian association of the Deaf [Norges Døveforbund] (NDF, 2020) there is an estimate of 16 500 persons in Norway who use NTS. Exactly how many persons in Norway having NTS as their first language is not known, because Norway does not keep an official track of which language are being used by whom (Vonen, 2020, p. 32). Erlenkamp et al. (2007) estimate that of 16 500 NTS-users, about 5000 are DHH, 10 000 are hearing family or friends of the Deaf community, and that there are about 1500 professionals that use NTS in their profession. This shows that sign languages are being used by way more people than only those being DHH.

2.4.1 Phonology in Norwegian sign language

While phonetics is about the physical mechanisms involved in the production of linguistic elements, phonology is about how the possibilities that phonetics gives us are used in the individual language system (Vonen, 2020, p. 54). Furthermore, phonetics is independent of the sign languages in question, whereas phonology is about the system of using components in a specific language, and different sign languages have different phonological structures.

According to Vonen (2020, p. 54), as of today, only certain parts of the phonology in NTS have been scientifically explored and made generally available through publications. We must manage without a detailed description of the phonological system in NTS, as it has not been documented as of today (Vonen, 2020, p. 54).

2.5 Language impairments and aphasia

In ICD-10, which is a diagnostic system established by the World Health Organization, language difficulties are divided into three main diagnostic groups: expressive language difficulties, receptive difficulties and articulation disorders (Wang, 2012). Expressive language difficulties refer to difficulties in speaking and expressing oneself, while language comprehension is often good (Wang, 2012). If one has difficulties with comprehension, it is often a question of receptive difficulties, which are difficulties in understanding, but one will also be weaker in expressing oneself (Wang, 2012). According to Wang (2012) articulation disorders are about difficulties in expressing the language sounds.

2.5.1 Prevalence of aphasia

In Norway about fifteen thousand people are affected by stroke every year (Qvenild et al., 2010, 24), and approximately 6000-7000 people a year acquires aphasia (Corneliussen et al., 2014, p. 13). The term aphasia is composed from Greek '*a'* which is negative, and '*phasi*s' which means speech (Gjerstad, 2020), and means loss of speech ability (Qvenild et al., 2010, p. 24). Aphasia is a language disorder that occurs after an acquired brain injury, and the most common cause of aphasia is stroke, which includes both cerebral haemorrhage and blood clots in the brain (Qvenild et al., 2010, p. 23). Another cause of aphasia may be external head injuries (Corneliussen et al., 2014, p. 13).

2.5.2 Approaches to aphasia

Aphasia is a complex concept with different definitions and ways of understanding. There are two main approache to aphasia: an impairment-based approach and a consequences-based approach (Qvenild et al., 2010). While the impairment-based approach views aphasia as a linguistic difficulty, the consequence-based approach – on the other hand – focuses on the consequence aphasia has for the aphasic person's ability to communicate. Within the two main approaches, there are also different angles of approaches from different disciplines.

In the neurological (or medical) perspective, aphasia is defined as an acquired language disorder or language impairment due to a limited injury or disease in the brain (Ahlsén, 2008; Papathanasiou, 2017). Anatomy is central in this perspective and the neurological perspective attempt to describe causes to diseases based on the location of the injury. Which parts of the brain that have been damaged, and which nerve cells that have been lost, are decisive factors in defining aphasia from the neurological perspective (Lesser & Milroy, 1993).

In a neurolinguistic perspective medicine and linguistics is combined, and aphasia is defined as a breakdown in specific language domains resulting from a focal lesion (Papathanasiou et al., 2017, p. 4). This perspective is viewing the connections between the location and extent. of damage, in the form of different language deviations within the language components phonology, morphology, syntax, semantics and pragmatics (Papathanasiou et al., 2017). The damage to the brain can affect one, more, or alle four language modalities, which shows the complex relationship between brain and language (Papathanasiou et al., 2017).

Another approach if from a cognitive neurolinguistic perspective. In this perspective, aphasia is considered the selective breakdown of language processing (Papathanasiou et al., 2017). According to papathanasio et al. (2017, p. 4) «Aphasia is considered the selective breakdown of language processing itself, of underlying cognitive skills, or of the necessary cognitive resources resulting from a focal lesion» (Papathanasiou et al., 2017, p. 4). In this meaning the definition indicates that language components may be dependend on a number of cognitive subsystems in cooperation with each other whereas a disturbance in one or more of these system could lead to language deviations (Ahlsén, 2008).

Kagan (1998) defines aphasia as a communicative difficulty in which the inherent competence of the person with aphasia is masked and overshadowed by the difficulty. This is in line with a functional perspective on aphasia (Kagan, 1998). This meaning that the communication difficulties in aphasia mask competence in aphasic persons, that normally would have been revealed through conversations (Kagan, 1998, p. 818). Because this makes it difficult for persons with aphasia to reveal their competence through conversations, they are often being perceived as less competent than they are

In Norway a often used definition of aphasia is in line with Reinvang (1978, p. 11) who describes aphasia as a language defect after a brain injury in individuals who have had normal language development until the time of the injury. The difficulties that arise in a person with aphasia can be of varying degrees and vary in which of the linguistic modalities that is most affected (Corneliussen et al., 2014). The language impairments can be present in all modalities: speaking, listening, reading, writing and signing, and also in all language components: phonology, morphology, syntax, semantics and pragmatics (Papathanasiou et al., 2017). People who get aphasia will in some way have reduced access to their language, and most people with aphasia experience some kind of communication difficulties (Corneliussen et al., 2014).

2.5.3 Aphasia in Sign Language users

Studies with aphasic Deaf signers and fMRI studies indicate that there are many similarities in how spoken language and sign language are organised and processed in the brain. For example, DHH have a dominance in the left hemisphere for both spoken and signed languages, versus a right-hempisphere dominance for visual perception (MacSweeney et al., 2008; Pollard et al., 2007). Case studies with Deaf signings individuals shows evidence that language processing is dominant in left hemisphere for sign language as well as spoken language (Pfau et al., 2012, p. 764-765). And when left hemisphere is damaged, Deaf signers also gets language disturbances (Hickok et al., 2002; Marshall et al., 2004). Right hemisphere damage, on the other hand, does not produce sign aphasia (Atkinson et al., 2005). However, right hemisphere damage can lead to disturbances in visual-spatial abilities, including some abilities involved in sign language processing (Atkinson et al., 2005). Therefore, right hemisphere damage may also have implications for signers in relation to sign language processing. As right hemisphere damages are not the content in this project, I will not go into further details regarding which implications these damages may have in signers.

Studies of Deaf signing persons who suffered from strokes provide evidence that there is a differentiation between motor systems that are involved in non-linguistic gestures and motor systems that are involved in language production (Corina, 1996, p. 633).

A study of Corina et al. (1992) including left-lesioned Deaf signer presents one of the most striking examples to date of the cleavage between linguistic signs and manual pantomime. The study of Corina et al., (1992) finds that the patients suffering from left-hemisphere lesion produced a marked sign language aphasia disrupting both the production and the comprehension of sign language. However, in sharp contrast to the breakdown of sign language, the ability to communicate in non-linguistic gesture was remarkably spared (Corina et al., 1992). The differences observed in the fractionation of linguistic versus non-linguistic gesture reflect differing degrees of compositionality of systems underlying language and gesture (Corina et al., 1992). The compositionality hypothesis receives support for the existence of phonemic paraphasia in sign language production, illustrating structural dissolution which is absent in the production of pantomimic gesture (Corina et al., 1992). This case provides a powerful indication of the left hemisphere's specialization for language-specific functions (Corina et al., 1992).

DHH NTS users are most often bilingual, with sign language as their preferred language, and the majority language in their country as second language. With aphasia in bilinguals there may be differences in how heavily the languages are affected by aphasia. The difficulties can either be parallel, which means that the two languages are damaged in the same way and to the same extent, or the difficulties may occur differently, which means that one of the languages is more damaged than the other (Knoph, 2010).

2.5.4 Co-occurring difficulties with aphasia

After incurring an injury to the brain, it is not uncommon to acquire some co-occurring difficulties in addition to the difficulties with language. It can be useful to be aware of the fact that for many, aphasia is only part of a more complex disease picture (Corneliussen et al., 2014, p. 14). Since the brain is controlling all our body functions there are therefore not unlikely that other difficulties occur after acquiring a damage to the brain. As SLTs it is important to get an overview of our client's overall picture, as the client's history will have an impact on the service which we provide. In the following, is a brief introduction to some difficulties that often co-occurs with aphasia.

According to the Norwegian Directorate of Health [Helsedirektoratet], as much as 80% of everyone who has stroke also gets paralysis (Helsedirektoratet, 2017). This means that getting paralysis is both common and a likely result of having a stroke. As mentioned earlier, aphasia is most often caused by an injury to the left hemisphere of the brain. Our nerve pathways cross from the left hemisphere to the right body part (Qvenild et al., 2010, p. 25) meaning that the left side of the brain controls the right side of the body. This means that right-sided paralysis is likely to co-occur with aphasia in stroke patients. The result of the paralysis may be that one experiences a lack of control and/or a lack of balance (Qvenild, 2010, p. 25). According to Sundet and Reinvang (1988), the extent and degree of the outcome depends on which nerve connections are affected.

Getting paralysis will lead to difficulties with body functions that are affected by the paralysis. Dysarthria is difficulty caused by paralysis, weakness or lack of coordination in the muscles that are in use when speaking (Qvenild, 2010, p. 26). A consequence of this is that speech can be vague, and therefore difficult to understand. In dysarthria, the language function itself is intact, but the phonetic level of language is affected (Howard & Hatfield, 1987). That is, in the case of pure dysarthria, only the speech that is affected, and not the language. A person who is affected by only dysarthria will therefore be able to express himself in complete sentences, and the person's ability to read and write will be as before the stroke (Corneliussen et al., 2014, p. 14). Dysarthria often occurs in stroke patients and is often combined with both dysphagia (difficulty swallowing) (Qvenild et al., 2010, p. 26) and with aphasia (Corneliussen et al., 2014, p. 14).

Another difficulty that often co-occurs with aphasia is apraxia. While dysarthria is about difficulties in performing the phonetic processes necessary to produce speech, apraxia is about difficulties in performing will-controlled [viljestyrte] actions (Corneliussen et al., 2014, p. 14; Qvenild et al., 2010, p. 26). Those affected with apraxia have normal strength and coordination in the muscles, but have problems initiating to perform (Qvenild et al., 2010, p. 26). Different forms of apraxia are speech apraxia [taleapraksi] and oral apraxia. Speech apraxia relates to difficulties with will-controlled movements of the speech organs, while oral apraxia involves problems with will-controlled movements with the mouth, but which are not in relation to language and speech (Qvenild et al., 2010, p. 26). With apraxia will-controlled movements are the challenge, and not the physical execution. People with apraxia will therefore be able to perform movements they are having troubles with initiating if the same moves are being triggered in spontaneous situations.

Vision problems are reported in up to 60% of people among those affected by stroke, according to The Norwegian Directorate of Health (Helsedirektoratet, 2017). A common vision challenge due to stroke is loss of vision in certain parts of the visual field, called visual field outcome [synsfeltutfall] (Qvenild et al., 2010, p. 26). Again, the left side of the brain controls the right side of the body, so for people with left-sided brain damage, it is the right part of the field of vision in both eyes that will be affected (Qvenild et al., 2010, p. 26; Corneliussen et al., 2014, p. 14). Other visual impairments after a stroke may be having double vision due to eye muscle paresis or unstable focusing (Qvenild et al., 2010, p. 26). Struggling with some kind of vision problem can lead to challenges, e.g., in perceiving visual expression. This might have implications for the ability to read and write (Qvenild et al., 2010, p. 26).

According to Reinvang (1978), damage to the brain can also lead to difficulties of a cognitive nature, such as difficulties with memory or concentration. Brain damage may also lead to reduced ability to plan and to show initiative (Qvenild et al., 2010, p. 27). In this context, it is important to emphasise that aphasia is a language difficulty, and not cognitive difficulty. Most people with aphasia have normal cognitive abilities.

The main purpose of this subchapter is to make it clear that aphasia is often a part of a bigger picture. This means that when meeting people with aphasia, one must find out which challenges people live with in their daily lives as a result of the aphasia. The difficulties that are present in the person’s life will necessarily have implications for the SL therapy one can provide. Next, I will give a brief introduction to a model that may be useful to understand functioning and disfunctioning.

2.6 ICF model of functioning

The overall goal of the model for International Classification of Functioning, Disability and Health (ICF) is to create a unified basis of ideas and language to describe health and health-related conditions (WHO, 2006, p. 3). ICF is a multi-purpose classification, designed for use in different disciplines and health services. It must:

- Provide a basis for scientific studies of health and health-related conditions, outcomes and causal factors.
- Be a common language for describing health and health-related issues conditions, to improve the exchange of information between various actors, such as health workers, researchers, politicians and the general public, including people with disabilities
- Allow the exchange of information across national borders, between different health subjects and over time
- Form a systematic code system for health information systems.
  (WHO, 2006, p. 6).

There is a widespread misconception that ICF is only about people having some kind of disability (WHO, 2006, p. 9). However, the ICF model includes all people, and not just people with disabilities, and in this way have an universal application (WHO, 2006, p. 9). It is also important to emphasize that the ICF-model does not classify humans, but human function and restrictions in it (WHO, 2006).

Disability is always an interaction between the features of the person and the features of the overall context in which the person lives. However, some aspects of disability are almost entirely internal to the person, while another aspect is almost entirely external (WHO, 2002).

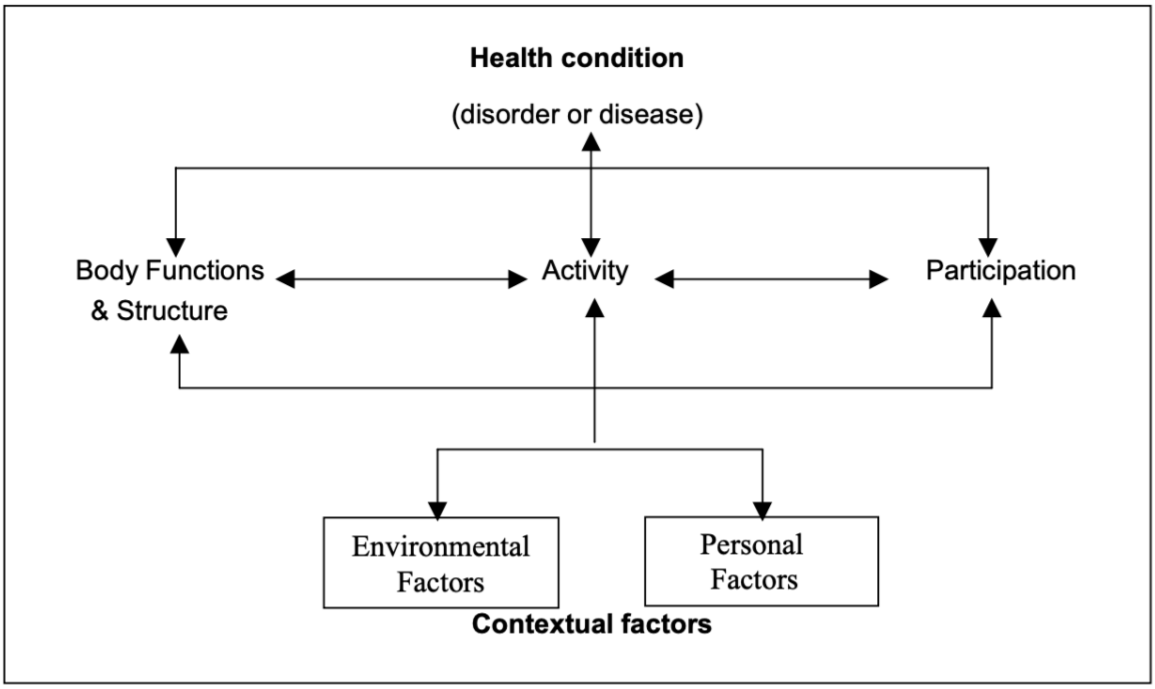

Figure 1: Model of disability. (WHO, 2002, p. 9).

The conceptual basis for the classification includes two main areas: *function and disability* and *contextual factors*. These main areas are then divided into different subject areas (WHO, 2008, p. 10-12):

2.6.1.1 Function and disability:

The subject area body, which is described in the classification first two dimensions (subclassifications) body functions and body structuresThe sub-classification activities and participation includes all aspects of human development, both as an individual and in relationships to fellow human beings.

2.6.1.2 Contextual factors

The last sub-classification, environmental factors is one of them two contextual subject areas in ICF's conceptual apparatus. Environmental factors affect all aspects of function and disability and is arranged in order from the individual's closest environment to more general environmental conditions in society.

Also included in the conceptual factors of the conceptual apparatus are the personal factors, but they cannot be classified in the ICF on due to the great social and cultural variations in the perception of them.

A person's function and disability are perceived as a dynamic interaction between health conditions (diseases, disorders, injuries, etc.) and contextual factors (WHO, 2008, p. 11-12). This builds on an understanding of how the contextual factors around the person are significantly in relation to understand the persons function and disability in everyday life. A person's experienced function and disabilities will always be influenced by the contextual factors in the person's everyday life. This means that a condition or difficulty will be perceived as different for individuals because the contextual factors will have an impact in how this function or disability affects a person’s daily life.

2.7 Rehabilitation for people with aphasia

According to the Norwegian Directorate of Health [Helsedirektoratet] (2017), all patients with stroke in the dominant hemisphere should be screened for language difficulties. Patients with language and communication difficulties should be referred to a survey of language and speech function by a SL therapist (Helsedirektoratet, 2017). Assessment and training in regard to language and communication difficulties in persons with aphasia starts at the hospital, and often requires long-term follow-up by a SLT when the person returns home (Afasiforbundet, 2017). Language training in aphasia after stroke should be specific, initiated in the acute phase and be of sufficient quantity and frequency (Helsedirektoratet, 2017).

Patients with language and communication difficulties should be referred to a SLT for a screening of language and speech function and intensive language training in the chronic phase. In stroke patients with language difficulties (aphasia) in chronic phase, intensive language training is proposed for a limited period of time (Afasiforbundet, 2017). The documentation shows an effect of intensive language training compared to low-intensity language training (Afasiforbundet, 2017). That is why persons who have gotten stroke often are recommended a rehabilitation institution for short (2-3 weeks), but intense periods instead of a few hours here and there.

According to Norwegian Directorate of Health's guidelines (2017) intensive training should include a minimum of five hours a week if one want to achieve a measurable change in language difficulties. Research shows evidence that minimum five hours language training a week is required to give a significant positive effect (Bhogal et al., 2003). There is also evidence that early intervention can promote language improvement (Randall, 1998) and SL therapy should therefore start as soon as possible to obtain a better outcome.

In Norway everyone who gets aphasia has the right to be followed up on their difficulties. The responsibility is divided between the health and education sector and the right to education and treatment is therefore enshrined in the Education Act (Opplæringslova, 1998, § 4A) and in the National Insurance Act (Folketrygdeloven, 1997, § 5-10). The Education Act (1998, § 4A) stipulates that the education must be adapted to the person's needs and have a content and a length that helps the individual to achieve their goals. The National Insurance Act (1997, § 5-10) provides for treatment for language and speech defects, and clients with the mentioned difficulties are entitled to benefits to cover the costs of examination and treatment by a SL therapist or audio educator [audiopedagog]. In order for the benefit to be granted, the person in question must be referred by a doctor and the treatment must be of significant importance to the person's illness and functional ability.

According to the Norwegian Directorate of Health (2017) all municipalities, possibly in unison with other municipalities, shall have a training offer for stroke patients with acquired language and communication difficulties. The offer should be organised in such a manner that the patient is given access to SLT services immediately after discharge from the hospital to ensure continuity in training (Helsedirektoratet, 2017). The Norwegian Directorate of Health (2017) express that research evidence and clinical experience indicate that it is important for the improvement of aphasia that the patient uses language a lot, both in therapy and otherwise. The patient should therefore be encouraged to talk a lot, and both health professionals, family and other relatives should contribute to this, e.g., through motivation and language stimulation, as well as by facilitating a good communication environment (Helsedirektoratet, 2017).

It is the municipalities who are responsible for providing an offer for adults with acquired language and communication difficulties (Afasiforbundet, 2017). People with aphasia should have access to speech and language therapy services immediately after discharge from the hospital, and their right to assessment and training is authorizes in the Educational Act (Opplæringslova, 1998 § 4A-2). Many municipalise in Norway does not have a SLT, and consequently do not have the capacity or competence to provide such an offer. In these cases, the person who have a right to SL treatment after a stroke, often gets treatment by a private SLT. In these cases, the National Insurance Incurance [folketrygden] covers the expenses for SL-treatment (Folketrygdeloven, 1997, § 5-10).

2.7.1 Rehabilitation for aphasia in multilinguals

As mentioned earlier, sign languages are minority languages, and most people who communicate in sign language are bilinguals. In Norway most people who use NTS, also uses Norwegian when writing and reading. When bilinguals acquire aphasia, the different languages are not necessarily damaged in the same way and to the same extent. In some cases, both languages are equally damaged, while others have the greatest difficulty with one of the languages (Statped, 2021; Knoph, 2010). It is difficult to predict which language will be affected and which will respond best to teaching. Possible contributing factors to this are when the languages were learned, how much the person have used the different languages, the structure of the languages, type of aphasia and place of injury (Statped, 2021).

When a person who is bilingual gets aphasia, all languages should be assessed to get an overview of how the different languages are affected and how to plan SL therapy suited for this person (Statped, 2021). A bilingual person with aphasia is usually unable to receive SL therapy in each of their languages, since the SLTs do notnecessarily cover all languages present in the population. Therefore, there might be necessary to use an interpreter while assessing and providing therapy for minorities.

For some bilinguals, therapy and work in one language (e.g., NTS) can lead to improvement in both this language and in other (e.g., Norwegian) untrained languages (Statped, 2021; Knoph 2010). In the event that the person does not improve in the other languages, they will not be harmed by receiving instruction in only one language and not in the others. According to Statped (2021) the municipality and PPT can apply for services from Statped to get assistance in assessment reading measures and guidance about bilingual people with aphasia.

3 Methodology

The research questions in this project regards gathering information about the SL-therapy that are provided for DHH NTS users with aphasia. To explore this, I wanted to include the perspectives of persons having first-hand experience with it. SL therapy among DHH NTS users with aphasia have been explored from both the perspective of a DHH NTS user having aphasia as well as from the perspective of a SLT having experience with providing service for this group.

In this chapter there will be given a description of how I have chosen to conduct the research to answer the research questions. There will be done a brief introduction to the methods being used, and explanation to why I find exactly these methods most suited to answer the research questions. This chapter will give the reader an insight into which steps and considerations that have been made during the conduction of the research project. I will try to explain all the steps as clearly as possible, and as informative as needed. Finally, there will be done a description of how reliability, validity and ethics have been taken into account during this research project.

3.1 Participants

The participants of interest were persons having experience with speech and language therapy among DHH NTS users with aphasia. It has been very important to me that the participants whom the research is regarding were included in the research, having the possibility to give insight into how this phenomenon is experienced. I wanted to get in touch with DHH NTS users with aphasia that were provided therapy from an SLT. I wanted to study those being DHH with NTS as their main communication language, and I therefore did not find it relevant to contact eventual DHH participants mainly communicating by spoken language. To include a professional perspective, I also wanted to include SLTs that provided therapy for DHH NTS users with aphasia. For the SLTs included in the research I wanted the SLTs to be MNLL[1], and to include only SLTs that is approved by the Norwegian speech and language therapist association (hereafter NLL). I mainly wanted to get in touch with SLTs providing

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[1] Member Norwegian speech and language therapist associations (MNLL) https://norsklogopedlag.no

service in NTS, but I was also open to including SLTs who had experience with SL therapy among DHH NTS users using an interpreter.

3.2 Recruitment and accessibility

By working with DHH NTS users, I have gained both insight and interest into the Deaf culture and community. I have also had the opportunity to develop my communication skills in NTS, which makes it possible for me to take part in everyday conversation using NTS. For the researcher to be more likely to get access to the field of research the researcher should be prepared to spend time in the field of research to establish relationships, be accepted, and get contacts within the field (Thagaard, 2013, p. 66-67). The fact of entering the field of research already having some insight in the Deaf culture and history, probably helped me avoid the biggest blunders when entering another culture. Especially in relation to entering a minority culture when I myself am a member of the majority culture. Even though I had some insight into the culture that I was entering, there are probably many elements of interest that I have completely overlooked in that my knowledge about the culture are limited.

My contacts within the Deaf community and my connections to a care home [omsorgsbolig] for DHH have helped me gain access to potential participants and key persons within the field. It has also helped me gaining information from my acquaintances regarding who I should contact. The fact that I was already a member of the Norwegian Association of the Deaf and that my main supervisor is recognised in the Norwegian sign language community has probably also given me some extra weight in terms of not being perceived as a researcher who is completely outside the environment. Having DHH acquaintances have also been important for me and been helpful throughout the project. My acquaintances being DHH have been helpful in contribution to sharing their view and giving me clues as to how my project appears, and whether the project is perceived as meaningful at all. Through my acquaintances, I have also gained access to helpful advice regarding what I as a hearing researcher should keep in mind when meeting with DHH participants in research.

When planning the project, I started with informally contacting the one SLT that I had heard of working with this group. I shared my thoughts and asked some questions regarding this person’s work in relation to what I had in mind for my project. The project took shape and developed in collaboration with supervisors, from various language difficulties among DHH to be limited to SL therapy among DHH NTS users with aphasia. The project was approved by Norwegian Centre for Research Data (hereafter NSD) and considered not to be notifiable by Regional Committees for medical and health research ethics (hereafter REK).

I started to recruit participants by contacting different agencies, organizations and persons who are associated with the Deaf community. Via email I sent information about the research project. In the emails I informed about the research project and about the participants that I wanted to reach out to. I wrote that the project was considered by NSD and REK, and I included the information letter (Appendix C) in the email. I contacted the Norwegian Association of the Deaf with relevant local associations. Some local associations helped me inform about the project through their websites and emails to their members. Norwegian association of speech and language therapists [Norsk logopedlag] and Norwegian association of Aphasia [Afasiforbundet] helped me reach out to potential participants by sharing information about my master's project on their website and in social media.

Recruitment through social media was informed about in my data management plan and approved by NSD, and I followed University of Oslo's strict procedures for recruiting through social media[2]. The project was registered in Forskpro[3] where I uploaded the appendixes from NSD (Appendix A) and REK (Appendix B). In the recruitment text I linked to the project's website in Forskpro, where potential participants could read about the project in detail. I provided my UiO-generated email address as contact information and encouraged anyone who might could help me to contact me via email. I specified that it was important not to tag or write the names of potential participants in the comments section on Facebook and followed up by checking that this was not done.

I used Facebook to publish information about the project in different groups where I found it likely to reach out to potential participants, such as groups for DHH and for SLTs. I sent emails to persons and organisations that might be able to help me get an overview over SLTs and rehabilitation places that offered therapy for DHH NTS users with aphasia, such as

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[2] https://www.uio.no/for-ansatte/arbeidsstotte/fa/regelverk-og-forskningsetikk/kvalitetssystem-helse/rutinebeskrivelser/enheter/med/rutiner/retningslinjer-some-innsamling-forskningsdata.html

[3] https://www.uio.no/for-ansatte/arbeidsstotte/fa/forskpro/prosjekter/uv/isp/logopedisk-oppfolging-for-dove-og-hoyrslehemma-teiknsprakbrukarar-med-afasi/index.html

Sunnaas hospital, Signo, or other persons with experience with aphasia or sign language. I also contacted Statped who helped me get in touch with persons that might could help me, and I asked for their recommendations regarding SL therapy for this group. Of course, I was seeking the assistance of others whose days are filled up with other tasks, and in many cases I did not receive an answer to my second or third inquiry either

I hoped for a larger selection of participants, but I am satisfied with getting participants representing both the perspective of DHH NTS users with aphasia and the perspective from a SLT having experience with SL therapy with DHH NTS users with aphasia.

3.3 Qualitative research

According to Thagaard (2013), having a qualitative approach to the research project can create a good foundation to get a greater understanding of a social phenomenon. The qualitative research methods are well fitted to get thick descriptions in a phenomenon (Cohen et al., 2018), and to understand participants opinions, intentions, involvement and commitment (Befring, 2015). The field of SL therapy among DHH NTS users with aphasia in Norway have not been explored earlier. I wanted to explore this phenomenon in depth to get better understanding of the current state of SL therapy among DHH NTS users with aphasia in Norway. When little research has been done, a qualitative approach may be well fitted to explore and understand a concept or phenomenon (Creswell, 2014, p. 20). I therefore choose a qualitative approach to explore the current state of SL therapy with DHH NTS with aphasia in Norway.

3.3.1 Research design

Because of the potential limited number of participants in this project, the goal was to get two participants who were DHH NTS users with aphasia, and two participants who were a SLT providing service for this group. When only getting one participant within each group, I found qualitative case study as the most suited research design for this project.

Doing a case study, I explored the SL therapy provided for DHH NTS users from different perspectives using different methods to get a greater understanding of the current state. Case studies refers to exploration of few units or cases, where the researcher analyse a great deal of information that the study is regarding (Thagaard, 2013, p. 214). In case studies the researcher develops an in-depth analysis of a case and collect detailed information using a variety of data collection procedures over a period of time (Stake, 1995; Yin, 2009 In Creswell, 2014, p. 14). This case study had an inductive character, where the units of analysis was not planned with a view to a theoretical starting point but aimed to get an understanding that points beyond the project itself (Thagaard, 2013, p. 214). The SL therapy among DHH NTS users was explored from the perspectives of the two participants through observation and multiple interviews. The information from the participants combined with the information gathered when contacting different persons and organization helped me get a broader insight in the current state of SL therapy among DHH NTS users in Norway.

There exists a variety of qualitative methods; however, in this project, I found qualitative semi-structured interviews and observations as the most appropriate methods to use based on the project's participants and research questions. Through semi-structured interviews and observations, the participants have access to participate in the research in the language they prefer, and also makes it possible for the participants to communicate their experiences more broadly than choosing between predefines options of answers.

This is a project that is situated within the perspective of SL therapy and I focused on a group that most SLTs do not know much about. In Norway there have not been conducted research in aphasia regarding DHH or in SL therapy with DHH. In this research study it was important for me to include the participants that the research is regarding to make visible their experiences and view on the current state.

One reason why research within the population of DHH sign language users is lacking, is due to researcher's use of methodology that are inaccessible to DHH sign language users (Anderson et al., 2018). With researchers not being able to communicate in sign language, the researcher and the participants will have difficulties understanding and communicating with each other directly. That the participants are communicating in a sign language will necessarily have implications in choosing methodology that make the research available for the participants and who makes it possible for the researcher and participants to communicate. Traditional qualitative methods have been developed to collect and analyse spoken language, and therefore qualitative methods have to be adapted when working with DHH sign language users (Anderson et al., 2018, p. 1813).

As stated earlier this project wanted to include the perspectives of those having first-hand experience with SL therapy among DHH NTS users with aphasia, and who wanted to share their experiences. The research methods therefore have been chosen and adapted to be accessible for the participants in both spoken and signed language. The research has also been planned for making the participants utterances available for me, getting assistance with translation by a NTS proficient intermediary. Due to covid-19 there also had to be done adjustments to make the data gathering possible in a world where I did not have the opportunity to meet the participants' physically due to strict rules with regard to covid-19. This, of course, lead to some changes from the original plan for conducting the research. I sent a change notification to NSD and got approval to conduct the interviews and observation through Zoom instead of physically.

People with aphasia have come into the background in debates about facilitation for the disabled (Parr, et al., 2003). It is a tendency that people with aphasia have been left out of research in stroke patients, despite the fact that they make up about a third of this population (Carlsson et al., 2007). Therefore, it was important to me that I succeeded making the project available for those it is regarding. Hence, this project purpose was to also make the perspective of DHH NTS users with aphasia visible, the participants having this perspective was of great importance in contributing to this project.

3.4 Semi-structured interview

To be able to capture the width and depth in the research question I found semi-structured interviews an appropriate fit. This was because the semi-structured interview gives the researcher the possibility to get an overview of the general situation, combined with the freedom to go in depth in different phenomena that come to mind in the interview settings (Cohen et al., 2018). The questions in semi-structured interviews are typically open ended, which gives the interviewee the possibility to answer open and freely, and to elaborate when it seems appropriate (Befring, 2015; Cohen et al., 2018). Throughout the interviews I aimed to capture the unique experiences of each participant. I found semi-structured interviews to be an appropriate method that gave me exactly that opportunity.

The focus in the interview with the DHH NTS user with aphasia was meant to elaborate on how the respondents experienced living with aphasia, and which way aphasia has implication in the everyday life. The focus was also on how the participant are experiencing the service provided by the SLT, and in which way the therapy is perceived as helpful and meaningful. The interviews with the SLT were meant to investigate how the SLT are working towards DHH NTS users with aphasia. I wanted to get an overview in which tools are being used for screening and assessment, and which implications a visual gestural language have for the SL therapy. Further I wanted to find out what are the differences between serving hearing persons and DHH NTS users with aphasia, and what the foundation is when providing an effective and meaningful service regarding this group.

The order of the data collection was interview – observation – interview. I chose to conduct the observations between the interviews so that I had the chance to ask questions about what I observed in the second interview. By combining observations and interviews the researcher get the chance to observe elements of what is being said in the interviews, and also to embroider and ask questions about what is being found by observations. This gives the research different sources to investigate the same phenomenon, and also a possibility to assure and discuss own field notes from the observations (Fangen, 2010).

Unlike traditional qualitative research conducted with hearing participants, interviews with DHH sign language user must be videotaped to accurately and fully capture data (Anderson et al., 2018, p. 1818). Therefore, the interviews were videorecorded, providing me with both the original data (the DHH participant's answers in sign language) and the SLT's translation of the DHH NTS user's answers. See chapter 3.4.2 below for an account of how the interviews were conducted.

3.4.1 The interview guides

Because of the differences in the participant's background and starting point I made different interview guides for the two participants. I also made different interview guides for the two interviews conducted with each participant (Appendices D and E). The interview guides differed from one another with having variating themes associated with the perspectives of those being asked. The interview guides were structured thematic, and in a way that were meant to follow the development in the relationship between the interviewer and interviewee. The interview guides were designed as a combination of questions regarding the participant's background, their experiences with speech and language therapy, and with practical questions regarding information and therapy. Open-ended questions were used to make the participants able to answer as freely as wanted. The interview guides were designed to each time start with information and clarification of the project and the participants rights, open for questions from the participants. As a conclusion to each interview, the interview guide was designed so that the participants again got the opportunity to ask questions, and for the participants and me to agree on the next step. The interview guide was not meant to be followed chronological but was designed as a safety net that helped me explore the themes of interest in the interviews.

3.4.2 The interview context

In situations of data collection with DHH sign language user, where the researcher does not sign well enough, it is common practice to use an interpreter (Young & Hunt, 2011). Since I do not concider my own NTS to be good enough to capture the full content in the interviews, I found it necessary to use a translator in the interviews conducted in NTS.

Due to covid-19 and strict rules regarding meeting in person, the interviews had to be conducted by Zoom. Research show that Zoom is found useful in forming and maintaining rapport with the researcher (Archibald et al., 2019). Therefore, I considered Zoom-interviews to be a good solution when not being able to meet the participants in person. The SLT and the client were allowed to meet in person, while an interpreted and me could only meet the participant digitally. When discussing these changes with the SLT, we agreed that it would be more beneficial to have the SLT serving as a translator than to use an interpreter via screen. The SLT, knowing the participant, thought it would be difficult for the participant to take part in the research not having anyone present in the room. The choice of using the SLT as a translator was also done partially because of the DHH participants’ lack of accessibility to digital equipment suited for interviews and observations by Zoom.

Young and Hunt (2011, p. 8) emphasise the importance that the interpreter has to face the person signing to be able to see what is being said. The SLT and the participant was therefore placed face to face during the interviews. From a culturally Deaf perspective, the maintenance of eye contact is of paramount importance because the person with whom they are communicating is primarily visually known, and for the researcher to look away or look down is tantamount to indicating they are not interested in with whom they are communicating (Young & Hunt, 2011, p. 8).

The participant is the person of interest in the interviews, and of course therefore also the person who is naturally to maintain eye contact and focus on in the interviews. Keeping eye contact with the interviewee is also important for the interviewer's possibility to through active listening pay attention to what is not being expressed linguistically, but may be communicated through body language, gestures or hints. Remaining eye contact was challenging by the unaccustomed situation of meeting by screen, and the participant alternated by looking at the SLT and on the researcher. I tried to look at and search for eye contact with the participants whom I was interviewing throughout the interviews.

In addition to making sure that the participant, the SLT and I were able to see each other to follow the conversation there was also important to ensure visual accessibility and avoidance of visual distractions during the interviews (Young & Hunt, 2011). For example, rooms with busy walls, and clothes with busy pattern both create difficult backgrounds against which to read a visual language (Young & Hunt, 2011). Therefore, the interviews were conducted in rooms that was known for the participants, and the researcher wore black clothing which makes the Sign Language more visible.

3.4.3 Relationship and trust

Establishing relationship and trust is in this project was an ongoing process that were present before, during and after the interviews. Providing information about the research project and its intentions and communicating with the participants before meeting them is a way in laying the foundation to a relationship characterised by trust. I met with the participants multiple times, which gave the relationship and trust possible to grow during the project. When I met with the participants I tried to be as transparent as possible and attempt to create trust by explaining my intentions with this project. I stated clearly that this is an academic project where their personal experiences are of interest, and that I will not interpret their answers as representative for all DHH NTS users with aphasia or for all SLTs working with this group.

In the interviews with DHH NTS with aphasia I planned to start the first interview with small talk and present myself in NTS. As it felt natural in the context, I continued throughout the whole first interview with the DHH participant with signing the questions myself. The SLT were helpful when I needed assistance with translations both from Norwegian to NTS and the other way around. Even though it perhaps got a bit clumsy, I found the possibility to share language and communicate as directly as possible as a way to establish a better relationship with the client. I also found the opportunity to communication in sign language as a way to be transparent regarding my own skills in NTS, both for the participants and the SLT. This also made it possible for the SLT and the client to have a perception in how much I probably will understand during the next interview and in the observation who was not going to be translated.

During the second interview in NTS I needed more assistanse from the SLT to translate, which probably affected the intimacy of the relationship. The intimacy is likely to have been affected by the distance between the client and me, given that all communication was filtered through a third person - the SLT. This might have had an impact on the relationship between the client and me, as our relationship – in a greater extent – was dependent on someone else. In addition to the fact that this of course creates challenges concerning how the message to the participants is conveyed to the participant, the presence of the SLT can also be a factor that inhibited the participant's perceived opportunity to communicate freely. Experiences and feelings related to one's own health and experiences are intimate information, and it may simply be that the participant found it difficult to share this, not only with me, but also with the SLT.

3.4.4 Power structure

An interview situation is characterised by an asymmetrical relationship between the participants. The researcher is the one who is defining the research questions, and decides which question are being asked, and which are not. In terms of the research questions the researcher have already chosen what is worth exploring, and also chosen not to explore every other possible phenomenon that also could have been the subject of research. In this there lays a great deal of power.

In the interviews that are conducted in NTS the translator also has a great deal of power, since the clients' utterances are going through the translator. This mean that the participants utterances are being translated from NTS to Norwegian, and when doing so the original utterances are also in some way being interpreted through the SLT's worldview. Since the interviews were video recorded and I have basic skills in NTS myself, the translators' power is reduced, since I afterward had the possibility to work through the video recording and look up the SLT’s speech translation to see if they match the participant's signs, using the Norwegian sign dictionary[4].

Another issue regarding power structure in this project is that the researcher is a hearing individual who have full access to the majority language, while the participant is a user of a minority language. That the interviews are being conducted by using a translator can be seen as an oppression of NTS since this leads the participant to once again having to adapt the majority language and hearing individuals. That the SLT are serving as a translator between the client and me reduces the participant's position further, because the SLT's presence is likely to have an impact on what the participant wishes to convey. In this there lays a great deal of power, that have to be taken into account

In the interviews with the SLTs the power structure may be asymmetrical in terms of the researcher being a student with little knowledge about the phenomena, while the participant is an educated SLT with experiences with providing speech and language therapy regarding DHH NTS users. There are not that many SLTs that are providing Speech and Language therapy with sign language user, which in some ways gives the SLTs that do so the power to define what SL treatment for DHH NTS users with aphasia is.

The asymmetrical relationship in relation to all participants in this project will be characterized by the fact that that I am the one who possesses the power to define what is asked, and how it is interpreted afterwards. While the participants on the other hand, possess the power to decide what to make visible and focus on, regarding their experiences and interpretation of the speech and language therapy regarding them.

3.5 Observation

To get a better understanding in how a SLT session with a DHH NTS user with aphasia can be conducted, I wanted to do an observation of a session between the SLT and the client. Observation is well fitted to get information about relationship, communication and language use between the SLT and the client. It also allowes me to see what the focus in the session is. Observation is according to Løkken & Søbstad (2006) to observe, notice, investigate or keep

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[4] https://www.minetegn.no/Tegnordbok-2016/tegnordbok.php

an eye on something. The observation in this study took place between the two interviews with the participants. A basic principle on which observational studies are based on is that observation of smaller units can provide information about general contexts (Thagaard, 2013, p. 70). Even though a single observation cannot give me a simple answer to how SL therapy among DHH NTS users is conducted, it gives me a view of what may be the content in SL therapy. Combining observation with the other methods being used in the study gives me a greater insight in the current state of SL therapy among DHH NTS users with aphasia and how this is being experienced.

In advance of the observation session, I had a conversation with the SLT regarding what would be the content in the session I was going to observe. Therefore, I had the chance to prepare for the observation session and find the self-evaluation sheet that the SLT and the client was going to go through during the session that I was observing. In forehand, I told the SLT that I wanted them to conduct the observation while paying as little attention to me as possible.

According to Thagaard (2013, p. 70), observation involves selection, as we get a lot of information through observation. It is of importance that the researcher questioning which information is useful and not, an in that way our analytical aim is sharpened (Lofland et al., 2006 in Thagaard, 2013, p. 70). The session between the participants generated a lot of information, and I found it hard to distinguish relevant information from irrelevant information for answering my research questions. I found almost everything that came forward in the observation interesting, and I was not sure what was relevant or not, since I had not decided exactly what I was looking for in advance. This is characterised as an open observation (Thagaard, 2013).

Due to coronavirus the observation also had to be done digitally. The SLT and client was allowed to meet in physically, keeping a distance of two meter, while I had to observe them by watching them on Zoom. Since the SLT and the client was forced to keep a distance by two meters, my view of the participants was not optimal. I met with the SLT in advance, were we placed the camera in a way that made it possible for me to see both the SLT and the client in the observation. Due to the distance between the SLT and the client, the camera was placed apart from both the participants, so that both of them was visible in the Zoom-window. To be able to see both the SLT and the DHH participant it might would have been better to use to cameras instead of one, but I decided that such a move would complicate the situation unduly for the participants.

In the session that I observed the client was going through a formally self-evaluation sheet, not being related directly to having aphasia. I will not embroider further details about the sheet, as I do not see it as relevant for my research questions. In the first interview the client said that he found reading different after the stroke. Therefore, the SLT translated the questions into NTS while the participant had the self-evaluation sheet in front of him. The client answered both in sign, and also by systematically filling out the sheet himself. To observe the session between the client and the SLT and knowing the questions in writing, I also got a view of how the SLT translated the questions into NTS, but also to make them manageable to understand for a client with aphasia. E.g., in some of the more abstract questions, the SLT came up with concrete examples of situations from the client's life.

I had downloaded the self-evaluation sheet in advance, so that I could follow the progress in the session, even though the session was conducted in NTS without an interpreter. Since I have basic skills in NTS myself, it felt ok keeping track on what was going on in the session even though the session was not translated. In advance As I had downloaded the self-evaluation sheet in advance I could easily follow the steps and questions in the sheets.

Through observation the researcher collects data directly through her own senses and writes down narrative descriptions and quotations to describe the phenomenon to be investigated (Løkken & Søbstad, 2006). The observers bias, such as knowledge, background, education etc. will probably affect the observer´s focus and interpretation of the observations (Dalland, 2012), and it is therefore important that the observer’s interpretations and reflections should be kept separate from the concrete descriptions of what actually happened (Vedeler, 2000). The observer should write down ongoing while in the session (Vedeler, 2000), and make clearly what is interpretations and what is descriptions. In this way the observer minimizes the risk of misunderstanding and misinterpreting of the findings in the observations (Bell, 2010). When taking part in the observation I wrote down field notes of what I observed. I wrote down questions I had for the participants after the observation, and thoughts I got regarding what to embroider in the next interview.

3.6 Writing up the findings

According to Thagaard (2013) the process of analysis has already started in the setting where the data was gathered. In this part of the chapter, I will describe the further steps towards the analysis with transcription and coding. There will be done a stepwise introduction to how I have worked with the data material that I have gathered in interviews and observation.

3.6.1 Transcription

After I have conducted the first round of interviews with both the participants, I started with watching a few times through the whole recordings. This was done to get a conception of the information I had gotten in the first interviews. When watching the recordings, I took notes of relevant moments and wrote a time overview of the whole recording. In the time overview I marked what has been the content in the interviews at which time e.g., “13.50-16.00: the SLT’s background” and “00.45-04.00: the client is telling about when he got stroke “. Under the time marks of the content, I also took further notes about the essence in what the participants told under each section. This gave me an overview of the data material before conducting the observation and the second interviews. I also wrote down question that came to mind, that I wanted to ask the participants in the second interview.

To get an overview of the data material I used the same technique when working through the recordings of the observation and the second interviews. When I had written the time overview for all the data material I had I gained a certain understanding of the totality of the data material. This helped me chose which parts of the data material that seemed more relevant for answering my research questions and the questions in the interview guide. These parts were also the first parts to be transcribed.

Next, I chose some parts of the interviews which I transcribed. Transcription is according to Kvale and Brinkmann (2015) something being transformed from one shape to another. In this case meaning transforming recording into text. When transcribing I played the recordings in the program VLC[5]. I chose this program because it gave me the ability to control the playback speed. This was something I found useful, because it gave me the opportunity to

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[5] VLC is a program for playing recordings: https://www.videolan.org/vlc/

play the recordings at a pace that allowed me to write down continuously. When transcribing the interviews with the SLT I wrote down everything the SLT said. In the interviews with the client, I wrote down what the SLT said verbatim. The transcriptions convention that was used was in line with the model of Linell (2009, p. 465-466). I wrote down everything that was said verbatim, and included expression such as *mm*, *ee* and *yes*. I marked when there were overlapping talks, and when there were words that I was not sure of. I included my own sounds when confirming what the participants said, and added it to the participants' utterances, e.g., *"that was also very useful to see [yes]*. I highlighted words that the participants put extra pressure on, and I included small pauses in the speech flow. To avoid huge amounts of transcription notes I only included the participants' body language when I found it especially relevant to include e.g. "*It was very (.) ((shows signs for square))".*

When transcribing I only wrote down what was being said. I tried not to assume anything about the participants' opinions, and I therefore wanted to include as little as possible of my own interpretations in the transcripts. I also did not want my own first thoughts to be forgotten. Therefore, I wrote down my owns thoughts and reflection in another document while transcribing.

While watching the recordings and transcribing the interviews I became more aware about myself as an interviewer. I became aware of that I at some places interrupted the participant's answers with further questions and tried to be wore aware of not doing this in the second interview. Another thing was that I got very curious and also asked about things what might not was relevant for my thesis. I also discovered that I actually managed to keep silence and wait for the participants answer they had answered the questions to give them time to tell more if they wanted. This is especially important for persons with aphasia to give them enough time to perceive and understand the question and to formulate an answer (Papathanassiou et al., 2018).

When transcribing, I listened through the interviews and observation many times both in slower and full speed. I worked a lot with the transcript to make them as detailed as needed, but still making the data amount manageable. This was challenging and very time consuming because I found it difficult deciding which parts of the data material that was relevant This led to that I transcribed almost everything, being afraid that I left out something important. It also found it demanding deciding how detailed I wanted the transcription to be to include all the information that might was relevant. All the details included in the transcription may not have been necessary to capture the content in the interviews.

3.6.2 Analysis

After transcribing the data material, I had a huge amount of data material to work with. I found it challenging choosing categories to organise the transcriptions by. While watching the recordings and transcribe I wrote down some words or themes that was often mentioned by the participants, that I wanted to include in the analysis. When organising the material, I first organised it by questions or themes from the interview guide to get an overview. I defined some labels from the interview guide, such as e.g., “Assessment tools” and “rehabilitation”.

The interviews were initially conducted in Norwegian and Norwegian Sign Language (NTS). The excerpts that are included in the thesis is translated from Norwegian/NTS to English. When translating the excerpts that have been included in the thesis, I have been aware of trying to maintain the original meaning. The participants’ utterances have been translated from their original language and the clients’ utterances have also been translated from NTS to Norwegian by the SLT. Therefore, some of the participants’ sense might have been lost in translation. To minimise this, I have made a form with the Norwegian utterance with translations into English translation with all the quotes used in the thesis (Appendix F).

When analysing the transcription, I used the program NVivo to code the transcriptions. This program made it possible for me to also write memos regarding my own thoughts when analysing. This was helpful as it made it easier for me to find back to exactly which utterances that had triggered my reflections.

According to Thagaard (2013, p. 158) coding data is about denoting sections of data with terms that express the meaning content of the text. When starting to categories the data material I started with making codes from my research questions and from the content of the interview guide. This is what Bratberg (2017, p. 97) describes as a deductive strategy for analysis, as the codes has been prepared before it was applied to an empirical material. My first step was to categories the data material within the three different research question getting an overview of the balance in the material and in which way the material answered my research questions. Next, I coded the material by codes that developed from the content in the interviews, and new codes emerged. This is in line with what Bratberg (2017, p. 97) describes as an inductive analysis strategy, where the model gradually emerges through the analysis (Bratberg, 2017, p. 97).

3.7 Quality in research

In this project I wanted to get a greater understanding of a social phenomenon. In qualitative research the researcher are an important person and a big part of the research throughout the whole research process (Cohen et al., 2018). The researcher's interpretation can therefore have a big impact in which understanding and conclusions that are being drawn from the research (Thagaard, 2013). Therefore, it is important that the researcher make the research process visible from start to finish in order to strengthen the credibility of the study and empirical findings (Thagaard, 2013).

3.7.1 Validity

Validity in research refers to truthfulness of the data obtained and how well-founded and credible the study and the result from it are (Vedeler, 2000, p. 106). A key concern to obtain validity is to eliminate sources of error and condition which may threaten the validity. The validity can be made visible through accounts of how the data has been interpreted, transparency, and by questioning if the interpretations that have been made reflect the reality (Thagaard, 2013). The project's validity is present during the whole research process (Kvale & Brinkmann, 2015) and have been taking into account every step of the way. In this chapter I have accounted for how the analysis have been conducted, and in which way the results of the study have emerged. The analysis is based upon the participants' experiences of SL therapy with DHH NTS users with aphasia. It is to a big extent the participant's personal utterance regarding their experiences in the topic that have been analysed and interpreted in this project. The project has to a great extent gained information regarding the participants' experiences at the current state, but may not generalisable due to small amount of participants.

3.7.2 Reliability

Reliability in means in which way someone else could have gained the same results by following the same steps in the research (Thagaard, 2013; Kvale & Brinkmann, 2015). In qualitative research studies this can be hard to accomplish, because of the uniqueness of the data gathering Qualitative research builds on the premises of interaction with different people. Since dynamic between people influence the results, it will be hard to accomplish the same results multiple times, since both the interviews and the observation would probably be different when conducting it again. To argue for reliability in qualitative research the researcher has to explain how the data developed throughout the research process and be transparent in what have been done in the research (Thagaard, 2013). According to Thagaard (2013) reliability is about convincing the critical reader in terms of the quality throughout the whole research process, and in that way also argue for the value of the results.

Throughout this chapter I have tried to describe all parts of the research as concretely and clearly as possible, to give the reader insight into the processes, choices and interpretations that have been made along the way. With help of the software NVivo I have kept a project journal, where I have logged activities that have been done along the way with timestamps. I have done this to be able to document all steps in the process, and to keep track of what has been done when and in which order. In this chapter I have described and accounted for every step that have been done and made the process transparent to the reader.

3.8 Ethical considerations

The ethical considerations have been an ongoing process throughout the whole project. According to The National Comitees for Research Ethics in the Social Sciences and Humanities Comitees (herafter NESH), the duty of confidentiality is important in relation to research, which means that all information must be treated with care, and it must be ensured that no unauthorised persons have access to information (NESH, 2018). These are guidelines that I have followed in my master's project, and the I am the only person who have had access to information regarding the participants. Personal information is information that directly or indirectly can be traced back to individuals (Gisle, 2018).

One problem of interest is that I do not consider my own NTS as good enough to catch up all information in the interviews, and I therefore used the SLT as a translator in the interviews with the client. That the SLT herself was a participant in the project might have impacted the clients answer. This of course may have been experienced as uncomfortable for the client, if the client did not want the SLT to know everything about how the SL therapy have been experienced by the client.

Another consideration this research arises, is the importance of getting the participants free and informed consent. According to NESH (2018) that means that the participants voluntarily participate in the research, and that the respondents is informed about the project´s purpose, methodology, planned dissemination and expected result. The consent should be in writing, and it is also important that the consent informs about the informant's opportunity to withdraw at any time if they want (NESH, 2018). The DHH participant received in advance of our first meeting, and the consent was also translated in NTS to the client. To be abselutely sure that the client was consenting, I went through we went through the consent form once more in the second interview.

Since this project was gathering personal information about the participants. I therefore had to apply NSD[6] to get my master's project approved. In addition to NSD the project was considered by REK to be sure that everything was done correctly. The project was noted as not notifiable by REK. When conducting the project, I made sure that I only gather the information that is required to answer my research question. I also made sure that the data material was kept safe during the project and that the transcriptions did not include name, gender or name of organisations that could identify the participants. All recordings and transcriptions will be deleted after the master’s thesis are approved.

Another important aspect of informed consent when working with and within Deaf communities concerns the small size and closeness of the community. Familial, social and professional networks amongst Deaf people (and some hearing people who might be insiders to different extents) are very tight and overlapping (Young & Hunt, 2011, p. 16). Due to the small conditions within the deaf community in Norway, some details in the case study have been omitted from the master's thesis, in order to safeguard the participants' privacy. Therefore, information that is not highly necessary to answer the research questions have not

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[6] Norwegian Centre for Research Data
https://www.nsd.no/en/about-nsd-norwegian-centre-for-research-data/

been included in the thesis. The descriptions of the participant have been read and approved by the SLT in order to maintain the participants privacy.

4 Results and discussion

The purpose of this project is to raise awareness and contribute to knowledge about SL therapy among DHH NTS users with aphasia. This will be achieved with exploring the current state of SL therapy provided for DHH NTS users with aphasia. If one acquires aphasia in Norway, one has the right to be provided service by a SLT. As this is a right that applies to everyone with aphasia, my attention has been to explore what kind of service DHH NTS users with aphasia receive in Norway. Furthermore, I wanted to investigate the current state of knowledge and awareness regarding SL therapy for this group.

The content in the SL therapy has been explored through interviews and observation with persons having experience with SL therapy among DHH NTS users with aphasia. I wanted to gain insight into how SL therapy is experienced from the perspective of an SLT and the client who takes part in the therapy process. Last but not least, I wanted to explore and point out some factors that are meant to help SLTs provide meaningful service for DHH NTS users with aphasia.

The main research questions that are to be answered in this chapter are as follows:

- What is the current status of speech and language therapy provided for Deaf and hard of hearing Norwegian Sign Language users who are affected by aphasia?
- How is the speech and language therapy experienced from the perspective of a client within the group of Deaf and hard of hearing?
- How is the speech and language therapy experienced from the perspective of a speech and language therapist providing service for this group?
- How can speech and language therapists contribute to meaningful service for Deaf and hard of hearing Norwegian Sign Language users who are affected by aphasia?

In this chapter an explanation to my interpretations regarding the data material will be given. The chapter begins with a brief introduction of the participants, to give the reader relevant information regarding the participants' background and knowledge. I will then present some findings that go slightly beyond SL therapy for DHH NTS users with aphasia. With a holistic approach to SL therapy, I believe these findings are of great importance for understanding the consequences that the stroke has had for the patient's life, beyond his language difficulties.

Furthermore, I will present the main findings of the study, organised by the research questions that the study aims to answer.

4.1 Participants

In this paragraph, I will briefly present the participants that this case study is built upon. I will give a brief description of the relationship between the participant and me, and of the relationship between the client and the SLT. Because of the small size in the Deaf community, some information about the participants will be left out to maintain the participants' anonymity. Only information that is absolutely necessary to get an understanding of the participants in relation to answering the research questions, will be given. To create an orderly and clear structure, the two participants will be referred to as *client* and *SLT*. To separate the participants in the text, the participants have been assigned two different hypothetical genders. The client will be referred to as *he/him,* while the SLT will be referred to as *she/her*.

4.1.1 Relationships

The two participants are known to each other in advance of this case study. The relationship between the participants are client and therapist. They have had a client-therapist relationship for approximately two years. The participants do not see each other on weekly basis but meets regularly for short but intense periods of SL therapy.

When it comes to the relationship between the SLT and me, we had a little knowledge about each other in advance of the data gathering. In the process of planning the project, I contacted the SLT directly because I knew she was working within the field of SL therapy among DHH. Before the first interview we had already established a certain relationship through short telephone conversations and email correspondence.

As to the relationship between the client and me, we did not know each other in advance. When I started recruiting participants for my project, the SLT mentioned that she knew a potential participant that could help me answer my research questions. Due to her duty of confidentiality, the SLT could not share any information about potential participants so that I could reach out to them myself. Instead, she helped me get in touch with the client and asked him if he wanted to take part in the study. When he accepted the invite, she helped me schedule the interviews with the client. The first interview with the client was therefore the first meeting between the client and me.

4.1.2 Client

The client is an older person who lives in a small city in Norway. He is Deaf, and at several points in the interviews, expresses that "*I am deaf. I cannot hear*". NTS is his first language and preferred communication language. He says that he needs others to sign if he is to be able to take part in the communication. The client has acquired aphasia after he suffered from a stroke approximately three years ago. He is retired from work, which he was in advance of the onset of aphasia. The client says that his life has changed after the stroke, and that there are many things he used to do before the stroke that he cannot do anymore. For example, before the stroke the client used to live in an apartment by himself, and he drove a car to visit people whenever he wanted. The client says that he has not been allowed to drive after he got the stroke, and that he consequently cannot visit people whenever he feels like it. He says that he had to move after he got stroke, and that he is now living in a care home for elderly people. In the care home where he lives, he says that he is the only person who is Deaf and that neither the residents nor the staff knows NTS. Once a week, for four hours, the client meets with a support contact [støttekontakt] with whom he can communicate in NTS.

4.1.3 Speech and language therapist (SLT)

The SLT has a background from working in the Deaf community for many years before she became a SLT. She has knowledge about the Deaf community and history, which she also emphasises as important when working with DHH. She has been working with Deaf colleagues and service users for many years and in different positions. The SLT took her master's degree to become a SLT after she had already been working with Deaf colleagues and service users for several years. After she completed her SLT education she went back to a previous workplace, where she - little by little - established her role as a SLT. She is now working as a SLT who provides SL therapy for DHH, among other things. The SLT emphasises that she - because of her background - has a very holistic approach to her work. For this reason, she says, she is not working as a "*typical speech and language therapist.*" This is also something that I witnessed in the observation, as the content of the observation goes beyond a typical approach to persons with aphasia. She says that the typical one-to-one therapy is not her main mandate at her current workplace. In regard to her NTS skills, the SLT says that "*I guess I am regarded as being at the higher level"* and says that she has taken a basic subject [grunnfag] in NTS. She also says about her NTS that: "*I am broken [gebrokken]"* and that one *"(...) can see that I am not (.) born into a (...) family with sign language."* The client, on the other hand, said that when he first met her, he thought she was Deaf.

4.2 Access to a linguistic and social community

Before I answer my research questions in relation to SL treatment among DHH NTS users, I will present some findings that go somewhat beyond the purpose of this project. These findings were not something I was looking for or was prepared to find when I planned the project, and the content and strength of the client's story came as something unexpected to me. After thorough reflections and ethical considerations both with myself and with my supervisors, I have come to the conclusion that it is relevant to publish the content of the client's story in my thesis, as it also is a contribution to making visible the current status regarding DHH NTS users with aphasia.

With respect to the client and his history, it is important to emphasise that this does not necessarily have to be the case among other DHH NTS with aphasia. It is nevertheless the client's truth about his life situation as a result of him being hit by a stroke. As the client has chosen to tell me this during our interviews, I see it as my task to pass it on to the reader of this paper.

In the interviews with the client, it emerged that as a result of being hit by a stroke, he had to move from his apartment to a nursing home[eldrehjem]. He says that he was forced to move after the stroke and that after the hospital "*(...) then move (.) to a nursing home. And I did not say (.) did not say I was going there. I was moved there (.) what? I was shocked* ." He said that he did not understand that he had to move, so when he realised he had to move permanently to the nursing home, he was shocked. He says that *"It is boring there. It does not fit to live there".*

In the nursing home where he now lives, the client says that he is the only Deaf person. *"I live in such a (.) nursing home [eldrehjem], but that is boring. Do not like. I feel (.) they are just talking and talking. Deaf, none. Signs, none. It is terrible. Future, I do not want",* he says about his living situation. He tells that neither the other residents nor the staff at the nursing home knows how to communicate in NTS and that this leaves him to not have anyone to communicate with in his everyday life. "*Home is not good (.) there are nobody with signs. Terrible",* he says. The client says that he does not have access to an interpreter and that he therefore cannot understand what is being said. He says that he does not want to life there any further, and that he wants to move to a place with other Deaf persons. The other persons where he lives are just *"Talking talking talking (...) I do not get peace. They are lacking signs".* He says that he cannot hear, and therefore cannot understand what they are saying. This is something he emphasizes as uncomfortable, and which does not give him peace.

He tells that not having anyone to communicate with makes him feel alone, and that he misses having someone talking with. When the persons where he lives is only talking the client tells that *"I'm getting tired. Can't hear, I say. I give up (.) and then I do not bother about them. Other seniors just say hello (.) do not talk. It's boring (.) Awful. I'm thinking of the future, what? My life. It is impossible.* This client is clear about how he feels about his living situation, and that he is not comfortable with it. He says that it makes him feel lonely not having anyone communicating with, and that he is tired of the other person who is just talking and talking while he cannot hear, and therefore not take part in the conversations emerging. *"One room (.) And bedroom. Boring. Walks (.) do not sit for long and watch TV. I get up and walk and walk, back and forth and around and around. It's awful. Missing someone to talk to. Yes, alone",* the client says.

"I walk alone. It is like a prison. I feel (..) that I do not have life, that it isn't anything", he says about his own situation. In the interviews the client is clear in his statements and leaves little doubt about how his living situation affects him and makes him feel. He states clearly that he does not like being the only Deaf person living in the nursing home, and that he misses having access to sign language. The client has been living at the same place since he got moved after the stroke, and his statements regarding his situation are exclusive of negative nature. With this as a basis, I will further present my findings in relation to the project's research questions.

4.3 The current state

The first question the project was meant to answer was:
What is the current status of speech and language therapy provided for deaf and hard of hearing Norwegian Sign Language users who are affected by aphasia?

When asking this question, I expected that the question would be possible to answer with the data material gathered through interviews and observations with a few participants having experience with this. Since everybody who is affected with aphasia in Norway has the right to get therapy by a SLT, I wanted to find out how this was being fulfilled in regard to DHH NTS users as well.

As I tried to reach out to potential participants, both SLTs and clients, it became clear to me that it seemed to be little awareness regarding what this group are being offered and who is offering it. In advance, I expected that either the speech and language therapist association or the aphasia association could help me get in touch with SLTs who provided service for DHH NTS. I sent them an email and asked if they had an overview of SLTs who provides service for DHH NTS users in Norway, so I knew who to contact for study. However, either the speech and language therapist association or the aphasia association did have an overview of which SLTs providing service for whom. They did not know of any SLTs who provides service for DHH NTS users either. The aphasia association did not know if they had any members who are DHH and/or NTS users.

The Speech and Language Therapist Association's [norsk logopedlags] website provide an overview of privately practicing SLTs in Norway. On their website one can find SLTs sortet by location and a short description in regard to which areas of difficulty the SLTs provide therapy for. As I searched through the entire list, I could not find any SLTs who informed that they offered treatment for DHH and/or NTS users. When I afterwards clicked through all treatment centres in Norway that have an agreement with the specialist health service, I also could not find any treatment centres that wrote that they offer rehabilitation after stroke that is adapted for DHH and/or NTS users. This off course does not mean that it does not exist, but it gives an insight in how difficult it is to find it if one does not know of any.

The SLT that participated in this research is not mentioned on the SLT overview at NLL's website. She told me that she at the current state did not have the capacity to offer SL therapy for more clients that is DHH NTS users. Therefore, she had not actively gone out and informed about herself and what she could offer either. Through conversations with the SLT, it also emerged that she also did not know of any more SLTs than herself who offers SL therapy for DHH NTS users with aphasia either. She said that she did not have a network with other SLTs who worked withing the Deaf community.

When I contacted the Deaf association with relevant local groups, I also gained some insight into their attention with this group in mind. They themselves said that they did not know of any of their members that this could apply. According to the SLT in my study, she believed that several elderly people had a connection to the Deaf association, and that she therefore said that the Deaf association could probably be an important channel for information regarding aphasia among DHH. In their website, the Norwegian Association of the Deaf's website they write as follows about themselves: *"The goal of the Norwegian Association of the Deaf is to achieve full participation and equality for the Deaf and hard of hearing in society"* (NDF, 2021).

Including the DHH in research is, as I see it, one step of the way to achieve participation and equality for DHH. Considering that elderly people have a stronger connection to the Deaf association, I therefore thought that I could probably get in touch with some potential participants by informing about the project through their channels. When informing the Deaf associations about the project, I wrote that I hoped the project would contribute to raising awareness to equal health care for everyone. I emphasized the importance in including persons having experience with SL therapy among DHH NTS users with aphasia themselves in the project. Unfortunately, the secretariat of Norwegian Association of the Deaf, did not have the capacity to assist me with informing about my project. Still, some of the local teams affiliated with the Deaf Association helped me share information about my master's project to their members. It did not lead to any participants. But at least the members in the local teams that shared information regarding the project had the opportunity to take part in the project and got information about that the project exists.

Sending emails to key persons withing the field of SLT led to contact with a key person a person at Sunnaas hospital. This person responded to my referral regarding SL therapy among DHH NTS users and wrote that there were so few patients this was regarding that they did not see a need for a larger system around this group.

As I contacted several key people who I thought would help me with information that could help me answer my research questions, it dawned on me that I did not receive no such information. I therefore contacted Statped and asked if they had an overview of SLTs who offers SL therapy for DHH. As they could not provide me with such an overview, I used the "ask-us" [spør oss] function at Statped. I asked questions in relation to their recommendations for SL therapy among DHH NTS with aphasia. They emphasised that none I their aphasia-team had expertise knowledge regarding aphasia in NTS users. Statped's recommendations was to follow the same principles in SL therapy as for SL therapy among other multilingual persons with aphasia. as for SL therapy.

So, by going through the network of the Norwegian speech and language therapist association, the aphasia association, Statped and Sunnaas in addition to search through relevant websites, I did not succeed in getting in touch with a single SLT who offers service for this group.

What emerged in my study was that there is little awareness about the SL therapy service available for DHH NTS users with aphasia at the current moment. I see my master's project as a small, but hopefully important step in raising awareness about marginal groups that also have the right to get access to a SLT if acquiring aphasia. Most SLTs in Norway do not know NTS, which is the same case when meeting persons with other preferred language than Norwegian in therapy. That I did not succeed in getting in touch with a single SLT despite my effort was something that was quite surprising to me. I advance I thought that I would succeed in finding an overview in SLTs that provided service for DHH in NTS with aphasia. Going through this whole process when trying to find these SLTs made me aware of the process one would have to go through if one is in need of an SLT who can provide service in NTS. Also, that the one SLT in participating in this study did not knew of any other SLTs that provided service for this group indicates that if these SLTs excist, they are not very visible even for those working in the same field.

4.4 The client's perspective

The second question I wanted to answer through this project was how the SL therapy are being experienced from the perspective of a client that is DHH NTS user with aphasia. This question I am not sure that I have gotten an answer to at the current state. In the interviews with the client there was so many things that came up that was outside my expectations. This led to what I wanted to find out was probably not what was most important to the client.

4.4.1 At the hospital

In the interviews the client openly talked about the moment when he got stroke. He remembered the exact moment of the stroke, and explained it step by step. Many times, during the interviews the clients said again that "*before, I was normal. But suddenly I got a stroke*". He tells about the experience that *"it was terrible"*. He says that he was sent to the hospital with ambulance in a rush, and that *"I was lucky".* The client said that he got scared, and that he did not understand what was happening to him. When he came to the hospital, he says that he did not have access to an interpreter, and that he did not understand what the staff at the hospital said. He said that what was difficult at the hospital was that "*It was, there was no sign (.) Was* ***just*** *talking. It was* ***not*** *easy. I said lacking (.) they lacked an interpreter (..) and then no interpreter came. So, I was disappointed".* He said that none of the staff at the hospital tried to explain him what had happened, with either pictures, writing or with gestures. *"They were just talking. And I cannot hear, so I did not understand",* he says about the situation at the hospital. He said that he did not understand what had happened to him, which made him feel afraid. *"I was afraid. Was afraid. What had happened? What was wrong? So I was ill".* He says that *"the nurses just came in and did their job, and then they left. They did not say anything".*

Getting a stroke often happens unexpected and suddenly (Corneliussen et al., 2014, p. 13). It is therefore a traumatic experience for the one who are affected with a stroke, since one is not understanding what is happening. As the client said regarding that he was normal and then suddenly got a stroke is in line with how stroke often occurs. He said that he was scared afterwards and afraid that it might happen again. When not having access to information regarding what has happened to him, the process with processing what has happened did not start. That the staff was talking, and he did not understand what they were saying about him, made the client even more scared, he said. According to the client, he was sent from the first hospital to another hospital nearer where he lived after approximately one month. Also, at the second hospital the client says that no one explained what had happened to him and that he was not provided an interpreter there either.

In the interview with the client, he commented several times that the doctor at the hospital had written on a note to him that he was Deaf-mute [døvstum]. This was something that seemed outrageous to the client, as he mentioned several times during the interview that the doctor *"(...) writes on note (.) deaf-mute (.) wrong. Doctor, deaf-mute, no. I got mad. Deaf (.) Only Deaf. Terrible. Old days (.) it was finished*. The client's strong wording about this, describing it as terrible and that it made him mad shows that this was something that clearly made a negative impression on him. Deaf-mute is an outdated term, which was removed from the legislation in 1915 (Winther, 2019). The doctor's use of the outdated term evidently suggested to the client an attitude of attributing muteness to the client because he is Deaf. The client's strong reaction to the doctor using this term might be because of the association to the times when NTS was not recognized as a language. The client might have felt oppressed by the hearing doctor, regardless of what was the doctor's intention. Even though the term is outdated, the client's experience at the hospital testifies that it is still in use as late as a few years ago, also among highly educated persons within our own health system.

When I asked the client regarding his experiences at the hospital, he did not recognize when I described procedures at the hospital that is common for people who have suffered from a stroke. I described common methods in both formal and informal assessment for language difficulties after a stroke, such as storytelling and elements from different aphasia tests. The client did not recall being assessed with any tests of this kind. He says about the staff at the hospital that "*they said nothing. They just took care of me (.) and then they left. They did (.) they did what they were supposed to (.) and then they left. Did not talk".* Again, he emphasised that he did not have access to an interpreter, and that he could not understand the staff who were just talking and talking.

The client told that after the stroke he was not able to eat by himself, and that he therefore received nourishment through PEG. He could not recall that anyone in the hospital had evaluated his swallowing function, either while he had PEG or when the PEG was removed. *"Went up the nose (.) And straight down. Huff, that was awful",* the client said about when he tried to swallow.

Of course, there might have been the case that the staff tried to conduct language assessment and check the client's functions even though the client did not perceive it that way. But if there were no interpreter at available at the hospital, it is also not unlikely that this was not checked. The client says that the staff at the hospital could not communicate in NTS, and also did not have access to an interpreter. Without knowledge in NTS, the staff has probably not had access to the client's communication. Without skills in NTS, they probably have not had the opportunity to make their communication available to the client either. What the client says about his hospital stays testifies that important assessment that is intended to secure the patients after a stroke has not been carried out because the staff and patient have not had the opportunity to understand each other.

4.4.2 Difficulties

Paralysis in the opposite side of the body is frequently occurring together with aphasia. For one being a user of a gestural language, this naturally have implication in the person's ability to communicate using the right-hand side. A signing person with aphasia having a right-sided paralysis will also having troubles with communicating with their hands because of the right-hand paralysis. In NTS the right hand normally is the active hand, and the one who doing most of the signing when using both hands. In my study the client said that he suffered from right hand paralysis after the stroke, who made signing difficult for him. He said that *"Det var umulig å få den opp (.) det gikk ikke. Den var helt slapp. Det var før. Én hånd som jeg brukte (.) nå er det to".* He said that the right-hand paralysis also made drawing and writing difficult for him, so that he could not communicate through writing and drawing either. He also said that he had difficulties with the balance, which made it hard for him to walk. At the point of the interview, he suffered no longer from paralysis, and said that it was better now.

In relation to having aphasia, the client explains that it was difficult for him to find the words after the stroke and describes symptoms of word-finding difficulties. *"I know word (.) and the stroke, after stroke, words where? Where are the words? What is this and this called? That was difficult. Disappointed".* Almost everyone who gets aphasia will have some kind of word-finding difficulties and struggling with finding the words. The client describes that he knew what he wanted to say, but that it was difficult to find the words he needed to communicate it. *"I want to talk, but (.) but I was prevented (.) I was not able to. Before (.) before the stroke, then I talked and talked (.) it went perfectly well (.) And suddenly everything (.) after the stroke. Yes (.) No, there was a significant difference with the signs. That was weird".*

The client says that it was impossible to find the words after he got a stroke. He said he was looking for the words but that *"The brain sort of (.) it miss and miss".* The client says that he works with the SLT and that it is easier for him to find the words and understand the words when they draw and uses pictures. He says that it is mostly the SLT who are drawing, since he himself finds it difficult after the stroke. When talking about his language difficulties the client says that he finds it difficult both producing utterances himself, and with perceiving others. He also says that reading was different after the stroke, and that he is not perceiving all the words in e.g., the newspaper. In the interviews the client says that he is having some difficulties with remembering and that the words are missing. "*Practice practice (.) must practice (.) write. The brain is working. Something easy to forget. Is easy. What is forgotten (.) what? I have to remember. Mm. Not funny,"* he says.

When I ask the client open-ended questions about what he and SLT have been working with together, he cannot recall much of what they have been working with in the therapy. *"Important that with the stroke. Tells stories. ((raises his hands repeatedly and looks like he should start saying something)) I do not remember. Do not remember"*, he says about the content in the SL therapy. The client says that they have been talking about the stroke and what has happened to him. When the SLT assist him with drawings from one of their first meetings, the client is able to talk more about what they have been working with. The client said that when he first met with the SLT he was a bit nervous. *"was angry and (.) why me? I was frustrated (.) I was scared",* he says about his thoughts the first time he met with the SLT.

4.4.3 In the rehabilitation

When the client is talking about the implication the meetings with the SLT have had in his life, he describes the meetings with the SLT as very positive and social. He says that: *"Now [I'm] here (.) Then it will be (.) Then it is absolutely great (.) It is top".* He says that he is allowed to meet with the SLT four times a year in periods ranging from 2-3 weeks at the time. This the client describes as great, as he gets the opportunity to communicate in signs.

Even though the client cannot recall very much of what the SLT have been working on with the SLT, he states clearly that the meetings have been of great importance for him. *"If I had not come here, I might have been dead. Luckily, I get to come here (.) and luckily, I still have* *continued to come here",* he says. The client mentions several times the importance of being met with someone who knows how to sign. He says that he likes it when he meets up with the SLT because, in his own words: "*Then we get to talk (.) And that is important. Important with signs (.) Oh, that is important. Mm. Important to live with signs (.) It is important. Mm. It is important that two talk together. That is life, that. It is important*". He emphasises the importance of being met with signs which made it possible for him to take part in social intercations. *"Felt I lived (.) got life (.) got a life",* he says about when he first met up with the SLT.

In the interview with the client, he stated several times the importance of being met with signs and that the SLT knows NTS. Considering the client's life situation, where he is daily excluded from social and linguistic interactions with other people, he gives an impression of being able to communicate with others is something he is very grateful for. In the interviews, I found it somewhat challenging to obtain detailed descriptions of what the SLT and he have worked on. The client says that he does not remember, but that he recalls more information about their work when the SLT shows him drawing from earlier meetings. He also says himself that this is helping him remember better. The client clearly states that he appreciates the meetings with the SLT and that their meeting is fortunately something he will continue with. The client tells that they have worked with talking about the stroke, which he clearly remember and can tell exactly what happened. That this is something the client remember that they have done is something that indicates that this have been of significant importance to the client. He tells about all the feelings in regard to the stroke, and talking with the SLT about this have probably helped him process it. Since the client did not get any information about what had happened to him at the hospital, probably led to a delayed processing of his new life situation. The meetings between SLT and the client make visible a holistic approach to SL therapy.

4.5 The SLT's perspective

The third research question this project aimed to answer was:
How is speech and language therapy among DHH NTS users with aphasia experienced from the perspective of a speech and language therapists who provide therapy for this group?

4.5.1 How does this SLT work?

In the interviews with SLT, I want to get a picture of her view of the SL therapy offered to DHH NTS users with aphasia. I want to get a picture of her experiences with SL therapy with this group and find out how she works with the clients in the therapy. Already early in the first interview, the SLT clarifies that when talking about SL therapy among DHH NTS users, there are not many people we are talking about, only a few. She says that this is something she believes has implications for what one can say about the therapy, because as SLT you always meet individuals. The SLT also says that although she has worked for many years in the field, she has not met many DHH NTS users with aphasia, and she emphasize repeatedly that her experiences must not be interpreted as a conclusion on how DHH NTS users are.

The SLT says that since Deaf people both are a minority and that the situation does not apply to many, the battles for Deaf people are extra though to handle because they most often are only a few that are fighting the battle. E.g., there is not likely that it is a big group of DHH NTS users that will fight for better rights and an equal service towards them, because there are simply not many people this applies to.

In the interviews with the client, it appears that he has not been given access to an interpreter at the hospital, and in that sense the hospital has not given him access to information regard what has happened to him. The SLT says that this is also something she has experienced with previous patients. She says that her experience is that it is important to use time with the clients talking about what have happened to them. Her experience indicates that the clients have probably not fully grasped what has happened to them when they come to her, and that they therefore seem to need to talk about the damage and its extent. The SLT says that she with stroke patients can see that the clients state a clear distinction between before and after the stroke occurred. She also says that her experience is that clients can clearly remember and talk about exactly the moment when the stroke occurred.

The SLT says that she has a holistic approach to her clients, and that she is concerned with finding out the consequences and impact of aphasia on clients' lives. She says she has a holistic approach to SL therapy and says that she believes it is important that we as SLTs evaluate the implications of the injury in the clients' lives. She says that it is important to look at the consequences the injury has led to in the client's life, and that it is only then that we can assess which measures and therapy can be useful for the clients. She emphasizes that she is concerned with finding out what is important for each and every client in order for them to get better lives.

Regarding how the SLT meets DHH NTS with aphasia in SL therapy, she says that she bases the same principles as for hearing with aphasia. She says that at an early stage she tries to map the clients' difficulties and what implications it has in their everyday life. She also says that she is also trying to find out who the patients were before they got aphasia. As for assessment tools, she says that she relies on assessment tools that have been developed for the hearing, such as the Norwegian Basic Test for Aphasia [Norwegian Basic Test for Aphasia]. *"I do not have language tools. That is what is a challenge. We could have had one of those (..) I could have wished for it ((laughing)). But it is not available in signs (.) not in Norwegian Sign Language (.) and there will probably never be so either. So, it is more (.) what (.) what are the test looking for",* she says.

When lacking assessment tools that are adapted to NTS users, the SLT says that she finds it useful to rely on those tools developed for hearing individuals with aphasia. She states clearly that she knows that the test results are invalid whereas the test is not adapted to NTS. However, the SLT says that she is trying to adapt the test into the context it will be used. She says that she knows which language aspect the tests are looking for and tries to adapt this to be suitable in NTS. She says that the results of the test give her some indications about the clients' difficulties, which helps her to form a basis for further work.

4.5.2 The overall offer

In the first interview with the SLT I told her that it had been difficult for me getting in touch with potential participants for my study. I asked the SLT where she thought these clients were, and what they were being offered. She said that: "*I do not think they get that much. (.) Maybe they get the offer to get training with an interpreter? (...) They may opt out because (...) it might be too strenuous".* The SLT says that she does not know what DHH NTS users with aphasia is being offered. She says that she maybe someone gets an offer to get SL therapy using an interpreter. The SLT says that sometimes this, of course, may be the best we can provide when not having access to a SLT with NTS skills. Anyhow, she states that this is something that might is being perceived as too strenuous for the clients, since the communication is always going through an interpreter.

Another thing the SLT is saying is that she has met with people providing service for persons with aphasia, meaning that getting a rehabilitation offer together with only hearing individuals are a sufficient offer. She also says that this might be, and that this might be something that some clients wish for themselves. But she says that she also has experience with this offer being provided on the basis of the staff utterances with the content *"It has worked before (.) he is a good lipreader*". The SLT says that this is unfortunately an attitude she has experience with, and which she says is an indication to being ignorant to the effort it takes for people to stand in a situation where they have to read lips. *"So much extra energy they have to spend on standing in a situation where they have to lipread (.) I think it's just sad (.) very sad. (.)",* the SLT says about this phenomenon.

It is a common misconception that Deaf people are all good lip readers (ALTA, undated, In Yung & Hunt, 2011, p. 7). According to the SLT this is also a misconception that she is familiar with in other persons providing service for DHH NTS users. Only around 30-40% of speech is lip-readable and individuals' skills and abilities as lip-readers vary considerably (ALTA, undated, In Young & Hunt, 2011, p. 7). There is therefore reason to believe that for someone with aphasia in addition, it will probably be demanding to get the content of everything that is said. The SLT emphasizes, however, that she also has experience with some clients who prefers such an offer.

4.5.3 When meeting with DHH NTS users

The SLT says that there is one thing that she experiences as more difficult for her clients who are DHH NTS users and that *"(...) is paralysis (..) especially of the hands. It is a huge challenge."* She says that when the clients with aphasia get paralysis in the dominant hand, it makes it difficult for them to express themselves through NTS. She says that it makes it difficult for the clients to use their arm at all, and that it is an additional barrier for NTS users. Hence NTS users are highly dependent in their hands since NTS is a visuo-gestural language, where one is in need of expressing oneself using the hands.

Another issue that the SLT states in the interview is that she sees it as important that DHH NTS users with aphasia are being met with someone familiar with their situation and language. She says that *"(...) those who are sign language users, they know something about history as well. One is concerned with their background. One is concerned (.) with ee (.)*

understands what it is like to be deaf (...) So the history of Deaf people (.) I think it is very important to know." She says that this is something she think is important when the SLT meets with DHH NTS users with aphasia. She says that this is *" also very essential to know, and think: how was they before? (.) and for some of them, it is not a given that they were on an abstract level (.) before they got aphasia."* This is she saying in the context of that people with aphasia are often elderly, which means that they are likely to have a background where they have experienced being discriminated on the grounds that they are Deaf.

The SLT also expresses that when working towards DHH NTS users with aphasia it is important to be aware of the clients' possibilities to be a part of a linguistic community. She says that she might not think the situation as for the client in this study is that unique when it comes to having access to NTS.

4.6 How can we make it better?

How can speech and language therapists contribute to meaningful service for deaf and hard of hearing NTS users who are affected by aphasia?

To get a view of what Statped recommended for SL therapy among DHH NTS users with aphasia, I sent a question to their “Ask-us-service” and asked what they would recommend when providing service for this group. They said that none of them working at the Aphasia team at Statped have top expertise in sign language and aphasia, and that they do not have an overview of SLTs providing therapy for this group. Further, Statped said that they did not have separate recommendations for DHH NTS users with aphasia. Their recommendations were to follow the same guidelines as for other multilingual aphasics when working with DHH NTS users with aphasia. Ideally, one should find a SLT who knows NTS, otherwise one must use an interpreter. The same principles are used as in the case of minority language speakers with a spoken language other than Norwegian spoken language. For example, that *"e.g., tests developed for one language cannot be translated directly and used in another".*

The SLT says that when not being familiar with NTS or Deaf community one should try to show interest in NTS when meeting with these clients. She says that one could try to learn a few signs in NTS that are common, even though this is not anything being expected from us. When using interpreters in SL therapy, the SLT says that *"(.) one must not take for granted that the interpreter knows what we are looking for."* When assessing the clients, we should, according to the SLT, be clear on what we are looking for in e.g., tests and try to adapt it to NTS. The SLT also says that interpreters may not be familiar with communicating with people having aphasia. Therefore, it is important that we instruct the interpreter in communication with persons having aphasia, the SLT expresses.

Through the interviews with the SLT she says that she wants to encourage everyone who is a SL therapist and has knowledge of NTS or the Deaf community to *"go ahead [kjøre på]"* with providing therapy for DHH NTS users. She says that even though one may not have such a high level in NTS, it is valuable that one have knowledge of Deaf culture and its history, as well as the basic structures in NTS that are important for assessing the clients' language and language use.

5 Conclusion and future direction

5.1 Summary

The purpose of my master's project was to explore the SL therapy provided for Deaf and hard of hearing Norwegian Sign Language users who have been affected with aphasia. As everyone being afflicted with aphasia has the rights to be provided therapy with a SLT I wanted to find out how this applies for DHH NTS user with aphasia.

The results of this study show that no available information as of today in regard to an overview of the SL therapy offer available for DHH NTS users with aphasia in Norway. Despite diligent efforts, I have through this project not succeeded in getting an overview of which SLTs or rehabilitation institutions that provides SL therapy for DHH NTS users with aphasia. Furthermore, my results show that the consequences of aphasia have been of large consequences for the client in this study. As a result of the stroke, the client had to move to a nursing home with only hearing people, which has had a negative impact on his opportunities for participation in linguistic and social communities. The client does not have access to NTS in his everyday life. He is offered SL therapy four times a year, for periods of two to three weeks at a time. The client describes the importance of being offered SL therapy as extremely valuable, as this gives him the opportunity to communicate on NTS. Regarding the SLT's perspective on the current state of SL therapy offered for DHH NTS users with aphasia, the results of the study show that the SLT is not sure what these clients are offered either. Among those who receive SL therapy from her, they are met with a holistic approach to aphasia with roots from what is known for aphasia rehabilitation in hearing persons.

5.2 Limitations

A limitation to this study is that it is a qualitative study based upon very few participants. The results of this study may therefore not represent the current status regarding SL therapy with DHH NTS users with aphasia. Even though my study is qualitative and narrow I believe it is of valuable impact in giving an insight in the current status regarding SL therapy provided for a DHH NTS users which have been available for participation in this study.

Further research is needed on the subject to contribute to raising awareness the health care situation in DHH NTS users.

5.3 Further recommendations

I believe this master's thesis have contributed to raising awareness in SL therapy with DHH NTS users with aphasia. To provide a better offer there are some things as I would SLTs in Norway to do.

If one is familiar with NTS or DHH I ask you to raise your hand and make yourselves available for providing SL therapy for DHH NTS users with aphasia.

Further, an overview of SLT that provide service for DHH NTS users and other bilinguals in Norway would have been preferrable. Would be of great help in finding the best speech therapist for each client. I think such an overview would be of great importance in finding SLTs that can offer suited service

Last but not least, I would like to encourage SLTs raise awareness of minorities who are in need for SL therapy.

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Appendices

Appendix A: Approval letter NSD

NSD NORSK SENTER FOR FORSKNINGSDATA

NSD sin vurdering

Prosjekttittel

Logopedisk oppfølging for døve og høyrslehemma teiknspråkbrukarar med afasi

Referansenummer

130872

Registrert

30.01.2021 av Maria Haldorsen - marhald@uio.no

Behandlingsansvarlig institusjon

Universitetet i Oslo / Det utdanningsvitenskapelige fakultet / Institutt for spesialpedagogikk

Prosjektansvarlig (vitenskapelig ansatt/veileder eller stipendiat)

Kari-Anne Bottegaard Næss, k.a.b.nass@isp.uio.no, tlf: 92240741

Type prosjekt

Studentprosjekt, masterstudium

Kontaktinformasjon, student

Maria Haldorsen, marhald@uio.no, tlf: 99414190

Prosjektperiode

01.03.2021 - 30.06.2021

Status

22.03.2021 - Vurdert

Vurdering (2)

22.03.2021 - **Vurdert**

NSD har vurdert endringen registrert 22.03.2021.

Det er vår vurdering at behandlingen av personopplysninger i prosjektet vil være i samsvar med personvernlovgivningen så fremt den gjennomføres i tråd med det som er dokumentert i meldeskjemaet med vedlegg den 22.03.2021. Behandlingen kan fortsette.

OPPFØLGING AV PROSJEKTET
NSD vil følge opp underveis (hvert annet år) og ved planlagt avslutning for å avklare om behandlingen av personopplysningene er avsluttet/pågår i tråd med den behandlingen som er dokumentert.

Lykke til videre med prosjektet!

Tlf. Personverntjenester: 55 58 21 17 (tast 1)

11.02.2021 - Vurdert

Prosjektleder skal innhente godkjenning fra Etisk godkjenning fra Regionale komiteer for medisinsk og helsefaglig forskningsetikk (REK). Vedtak fra REK lastes opp i meldeskjema når det foreligger. Dersom vedtak fra REK medfører endringer i prosjektet må dette meldes til NSD ved å oppdatere meldeskjemaet.

Det er vår vurdering at behandlingen av personopplysninger i prosjektet vil være i samsvar med personvernlovgivningen så fremt den gjennomføres i tråd med det som er dokumentert i meldeskjemaet den 11.02.2021 med vedlegg, samt i meldingsdialogen mellom innmelder og NSD. Behandlingen kan starte.

MELD VESENTLIGE ENDRINGER
Dersom det skjer vesentlige endringer i behandlingen av personopplysninger, kan det være nødvendig å melde dette til NSD ved å oppdatere meldeskjemaet. Før du melder inn en endring, oppfordrer vi deg til å lese om hvilke type endringer det er nødvendig å melde: https://www.nsd.no/personverntjenester/fylle-ut-meldeskjema-for-personopplysninger/melde-endringer-i-meldeskjema
Du må vente på svar fra NSD før endringen gjennomføres.

TYPE OPPLYSNINGER OG VARIGHET
Prosjektet vil behandle særlige kategorier av personopplysninger om helseforhold og alminnelige kategorier av personopplysninger frem til 30.06.2021.

LOVLIG GRUNNLAG
Prosjektet vil innhente samtykke fra de registrerte til behandlingen av personopplysninger. Vår vurdering er at prosjektet legger opp til et samtykke i samsvar med kravene i art. 4 nr. 11 og art. 7, ved at det er en frivillig, spesifikk, informert og utvetydig bekreftelse, som kan dokumenteres, og som den registrerte kan trekke tilbake.

Lovlig grunnlag for behandlingen vil dermed være den registrertes uttrykkelige samtykke, jf. personvernforordningen art. 6 nr. 1 bokstav a, jf. art. 9 nr. 2 bokstav a, jf. personopplysningsloven § 10, jf. § 9 (2).

PERSONVERNPRINSIPPER
NSD vurderer at den planlagte behandlingen av personopplysninger vil følge prinsippene i personvernforordningen om:

• lovlighet, rettferdighet og åpenhet (art. 5.1 a), ved at de registrerte får tilfredsstillende informasjon om og samtykker til behandlingen
• formålsbegrensning (art. 5.1 b), ved at personopplysninger samles inn for spesifikke, uttrykkelig angitte og berettigede formål, og ikke viderebehandles til nye uforenlige formål
• dataminimering (art. 5.1 c), ved at det kun behandles opplysninger som er adekvate, relevante og nødvendige for formålet med prosjektet
• lagringsbegrensning (art. 5.1 e), ved at personopplysningene ikke lagres lengre enn nødvendig for å oppfylle formålet

DE REGISTRERTES RETTIGHETER
NSD vurderer at informasjonen om behandlingen som de registrerte vil motta oppfyller lovens krav til form og innhold, jf. art. 12.1 og art. 13.

Så lenge de registrerte kan identifiseres i datamaterialet vil de ha følgende rettigheter: innsyn (art. 15), retting (art. 16), sletting (art. 17), begrensning (art. 18) og dataportabilitet (art. 20).

Vi minner om at hvis en registrert tar kontakt om sine rettigheter, har behandlingsansvarlig institusjon plikt til å svare innen en måned.

FØLG DIN INSTITUSJONS RETNINGSLINJER
NSD legger til grunn at behandlingen oppfyller kravene i personvernforordningen om riktighet (art. 5.1 d), integritet og konfidensialitet (art. 5.1. f) og sikkerhet (art. 32).
Prosjektet skal bruke tolk. Tolken vil være databehandler i prosjektet. NSD legger til grunn at behandlingen oppfyller kravene til bruk av databehandler, jf. art 28 og 29.

For å forsikre dere om at kravene oppfylles, må dere følge interne retningslinjer og eventuelt rådføre dere med behandlingsansvarlig institusjon.

OPPFØLGING AV PROSJEKTET
NSD vil følge opp ved planlagt avslutning for å avklare om behandlingen av personopplysningene er avsluttet.
Lykke til med prosjektet!

Tlf. Personverntjenester: 55 58 21 17 (tast 1)

Appendix B: Consideration from REK

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	Saksbehandler:	Telefon:	Vår dato:	Vår referanse:
REK sør-øst C	Claus Henning Thorsen	22845515	25.02.2021	244487
			Deres referanse:	

Arnfinn Muruvik Vonen

244487 Logopedisk oppfølging for døve og høyrslehemma teiknspråkbrukarar med afasi

Forskningsansvarlig: Universitetet i Oslo

Søker: Arnfinn Muruvik Vonen

Søkers beskrivelse av formål:

Formålet med dette forskingsprosjektet er å løfte fram og synleggjere noverande status for det logopediske tilbodet som tilbys døve og høyrslehemma (DHH) teiknspråkbrukarar som har blitt ramma av afasi. Forskningsspørsmåla er: Kva er dagens status for logopedisk oppfølging for døve og høyrslehemma teiknspråkbrukarar som er ramma av afasi? Korleis opplevest denne oppfølginga frå perspektiva til klientar innanføre denne gruppa, samt frå logopedar som følgjer opp denne gruppa? Korleis kan logopedar bidra til meiningsfull oppfølging for døve og høyrslehemma teiknspråkbrukarar som er ramma av afasi? Dette prosjektet vil inkludere DHH teiknspråkbrukarar som er ramma av afasi i forskinga, og synliggjere deira synspunkt som eit bidrag til dagens kunnskapsstatus. Ved å også inkludere erfaringar frå logopedar som følgjer opp denne gruppa, vil forskingsprosjektet synleggjere ulike perspektiver og innhente breiare kunnskap om den noverande praksisen kva gjeld logopedisk oppfølging.

REKs vurdering

Vi viser til innsendt skjema for fremleggingsvurdering for ovennevnte prosjekt *Logopedisk oppfølging for døve og høyrslehemma teiknspråkbrukarar med afasi,* mottatt 17.02.2021. Leder av REK sør-øst C har nå vurdert henvendelsen, med tilhørende dokumentasjon.

Slik komiteen oppfatter prosjektet, er formålet å undersøke det logopediske tilbudet som finnes for døve og hørselshemmede tegnspråkbrukere med afasi. Det er klientenes og logopedenes opplevelse av oppfølgingstilbudet som er i fokus. Komiteen mener, basert på den dokumentasjonen som er fremlagt, at studien således ikke har til formål å skaffe til veie ny kunnskap om sykdom og helse, slik dette forstås i helseforskningslovens § 4.

Prosjektet er derfor ikke fremleggelsespliktig, jf. helseforskningslovens §§ 2 og 4. Studien kan gjennomføres uten REK-godkjenning.

REK antar for øvrig at prosjektet kommer inn under de interne regler for behandling av opplysninger som gjelder ved ansvarlig virksomhet. Søker bør derfor ta kontakt med enten forskerstøtteavdeling eller personvernombud for å avklare hvilke retningslinjer som er gjeldende.

Vi gjør oppmerksom på at avgjørelsen av spørsmålet om fremlegging er å anse som veiledende jfr. forvaltningsloven § 11.

Vedtak

Ikke fremleggspliktig

Med vennlig hilsen

Claus H. Thorsen
Seniorrådgiver

Appendix C: Information letter

Vil du delta i forskingsprosjektet

«Logopedisk oppfølging for døve og høyrslehemma teiknspråkbrukarar med afasi»

Dette er eit spørsmål til deg om å delta i eit forskingsprosjekt der formålet er å undersøke det logopediske tilbodet som finnes for døve og høyrslehemma teiknspråkbrukarar med afasi. I dette skrivet gjer me deg informasjon om måla for prosjektet og kva deltakinga vil innebere for deg.

Formål
Eg er mastergradstudent ved institutt for spesialpedagogikk ved Universitet i Oslo, med fordjuping i logopedi. I mitt masterprosjekt ynskjer eg å undersøke det logopediske tilbodet som tilbys døve og høyrslehemma teiknspråkbrukarar som har blitt ramma av afasi. Afasi er språkvanskar etter erverva skade i hjernen, og kan føre til ulike typar språk- og kommunikasjonsvanskar, avhengig av skadens omfang og lokalisasjon. Logopedar har kompetanse til å hjelpe personar med afasi, og i Noreg har alle som har blitt ramma av afasi rett til logoped. Gjennom dette forskingsprosjektet ynskjer eg å bringe fram kunnskap om logopedisk oppfølging for døve og høyrslehemma teiknspråkbrukarar som har blitt ramma av afasi. Eg ynskjer å undersøke kva innhaldet i den logopediske oppfølginga kan være, og korleis oppfølginga oppleves for personen som har blitt ramma av afasi, men også frå logopedens perspektiv. Ved å delta i dette forskingsprosjektet kan du hjelpe meg å frambringe kunnskap om dagens status, og bidra til å skape medviten om logopedisk oppfølging for døve og høyrslehemma teiknspråkbrukarar med afasi.

Kven er ansvarleg for forskingsprosjektet?
Universitetet i Oslo er ansvarleg for prosjektet.

Kvifor får du spørsmål om å delta?
Det er to grupper som er aktuelle deltakarar i dette forskingsprosjektet:

1. Døve og høyrslehemma personar med Norsk Teiknspråk som førstespråk som er ramma av afasi, og som har oppfølging av logoped.
2. Logopedar MNLL som arbeider med døve og høyrslehemma personar med Norsk Teiknspråk som førstespråk og som er ramma av afasi.

Kva inneber det for deg å delta?
Dersom du vel å delta i prosjektet inneber det at du deltar i to intervju, og at du lar prosjektstudent observere ei økt mellom klient og logoped. Intervjua vil vare omlag ein time kvar gong, og det er ynskjeleg å gjere videoopptak av intervjua som føregår på teiknspråk, eller lydopptak av intervjua som føregår på talespråk. Det vil bli brukt teiknspråk-tolk i intervjua som gjennomføres på teiknspråk. Spørsmåla i intervjua vil i hovudsak handle om dine tankar og erfaringar kring logopedisk oppfølging for afasi i møte med døve og høyrslehemma personar med Norsk Teiknspråk som førstespråk. Observasjonen vil finne stad mellom dei to intervjua, og du vil få høve til å kommentere eller stille spørsmål før, under og etter intervju og observasjon. Det vil ikkje føregå innsamling av opplysingar om deltakarane i studien frå andre kjelder enn deltakaren sjølv. Du vil få høve til å lese gjennom og korrigere sitater frå intervjua, samt få tilbod om ein avsluttingssamtale der me gjennomgår og snakker om oversettingane og funna i prosjektet, dersom det er ynskjeleg.

Det er frivillig å delta
Det er frivillig å delta i prosjektet. Du kan når som helst trekke ditt samtykket utan å oppgje grunn, og alle dine personopplysingar vil då bli sletta. Det vil ikkje ha nokon negative konsekvensar for deg dersom du ikkje ynskjer å delta i prosjektet, eller dersom du seinare vel å trekke deg.

Ditt personvern – korleis me oppbevarer og bruker dine opplysingar
Opplysingane om deg vil berre bli brukt til formåla som er opplyst om i dette skrivet. Me behandler opplysingane konfidensielt, og i samsvar med personvernregelverket. For å ivareta din konfidensialitet vil datamateriale som kan bidra til å identifisere deg behandlast i samsvar med personregelverket, og være lagra på sikkert prosjektområde hjå Tjenester for Sensitive Data (TSD). I framstillinga av masteroppgåva vil du og det du fortel være anonymisert.

Kva skjer med opplysingane dine når me avslutter forskingsprosjektet?
Opplysingane anonymiseres når prosjektet avsluttes og oppgåva godkjennes, som etter planen er 31.06.2021. Videoopptak/lydopptak og personopplysingar vil då bli sletta.

Dine rettigheiter
Så lenge du kan identifiserast i datamaterialet, har du rett til:

- innsyn i kva personopplysingar som er registrert om deg, og å få utlevert ein kopi av opplysingane,
- å få retta personopplysingar om deg,
- å få sletta personopplysingar om deg, og
- å sende klage til Datatilsynet om behandlinga av dine personopplysingar.

Kva gjer oss rett til å behandle personopplysingar om deg?
Me behandler opplysingane om deg basert på ditt samtykke.

På oppdrag frå Universitetet i Oslo har NSD – Norsk senter for forskningsdata AS vurdert at behandlinga av personopplysingar i dette prosjektet er i samsvar med personvernregelverket.

Kor kan eg finne ut meir?
Dersom du har spørsmål til studien, eller ynskjer å nytte deg av dine rettigheiter, ta kontakt med:

- Universitetet i Oslo ved Maria Haldorsen (prosjektstudent) på e-post: marhald@uio.no eller på telefon: 99414190.
- Arnfinn Muruvik Vonen (ekstern rettleiar) på e-post: arnvon@oslomet.no
- Luca Tateo (rettleiar UiO) på e-post: luca.tateo@isp.no
- Vårt personvernombud: Roger Markgraf-Bye på e-post: personvernombud@uio.no

Dersom du har spørsmål knytta til NSD si vurdering av prosjektet, kan du ta kontakt med:

- NSD – Norsk senter for forskningsdata AS på e-post: personverntjenester@nsd.no eller på telefon: 55 58 21 17.

Med venleg helsing

Maria Haldorsen
(student)

Samtykkeerklæring

Eg har motteke og forstått informasjon om prosjektet *Logopedisk oppfølging for døve og høyrslehemma teiknspråkbrukarar med afasi*, og har fått høve til å stille spørsmål. Eg samtykker til:

- ☐ å delta i intervju
- ☐ å delta i observasjon
- ☐ at det blir gjort videoopptak av meg under intervju/observasjon

Eg samtykker til at mine opplysingar behandles fram til prosjektet er avslutta

----

(Signert av prosjektdeltakar, dato)

Appendix D: Interview guides, client

Intervjuguide 1 - klient

Introduksjon:

- Takk!
- Informasjon om frivillig samtykke, anonymitet og konfidensialitet
- Informasjon om forskingsprosjektet
- Avklare rammer i intervjuet etter deltakarens ynskje:
  Bruk av tolk, teikning, skrift, bileter, peiking, ja/nei, stopp, neste spørsmål osv.
- Kan du fortelje litt om bakgrunnen for at du vart med på dette prosjektet?

Om deltakarens bakgrunn:

- Kan du fortelje om deg sjølv og din bakgrunn?
  Eks. Utdanning/yrke, interesser, familie/vener/pårørande, kva er viktig for deg.
- Kan du fortelje litt om din språklege bakgrunn?
  Eks. Teiknspråk, skriving og lesing på norsk, andre språk.
- Kva opplever du som den beste måten for deg å kommunisere på?

Afasi og logopedisk oppfølging:

- Korleis kommuniserer du med logopeden din?
  Eks. Teiknspråk, via tolk. Skrift, teikning, andre kommunikasjonshjelpemidler.
- Kva er viktig for deg for å skape ein trygg relasjon med logopeden din?
- Kan du fortelje litt om kvifor du vel å gå til logoped?
- Kva opplever du at logopeden kan hjelpe deg med?
- Kva har du arbeida med saman med logopeden din fram til no?
- Kor ofte går du til logoped?
- Kva er dine mål for arbeidet saman med logopeden?
- Korleis opplever du at den logopediske oppfølginga hjelper deg med å nå dine mål?
- Kva er hovudfokus i den logopediske oppfølginga no for tida?

Avslutning:

- Har du noko du ynskjer å legge til?
- Har du nokon spørsmål?
- Informasjon om observasjon og neste intervju

Intervjuguide 2 - klient

Introduksjon:

- Informasjon om frivillig samtykke, anonymitet og konfidensialitet
- Korleis har du hatt det sidan sist?

Sist gong me var saman fekk eg observere ei økt mellom deg og logopeden din.

- Er det noko du ynskjer å fortelje eller stille spørsmål ved i forbindelse med observasjonen?
- Avklaringar og spørsmål i forbindelse med observasjonen

Tilgang på informasjon:

- Kva visste du om afasi før du sjølv vart ramma?
- Opplever du at du har fått tilstrekkeleg informasjon om afasi og oppfølging?
- Gjennom kva kanalar har du tileigna deg informasjon om afasi og oppfølging?
  Eks. Skriftleg/munnleg. Via afasiforbundet, døveforbundet, sjukehuset, familie/vener/pårørande, logoped, andre kanalar osv.
- Kva opplever du som den beste måten for deg å tileigne deg informasjon på?
  Eks. Skriftleg, munnleg, bileter, teikning, kroppsspråk, andre.
- Kva tiltak tenker du kunne vore gjort for å gjere det lettare for deg å få informasjon om afasi og oppfølging, og svar på det du lurer på?

Afasi og logopedisk oppfølging:

- Omlag kor lenge er det sidan du vart ramma av afasi?
- Kan du fortelje litt om korleis det opplevdes for deg å bli ramma av afasi?
- Kan du fortelje litt om korleis afasien har påverka deg?
  Eks. Kjensler, kommunikasjon, ordleiting, tilleggsvanskar, familie, jobb osv.
- Kva opplever du som den største utfordringa med å ha afasi?
- Korleis arbeider du for å møte denne utfordringa?
- I kva rekkefølgje ynskjer du å arbeide med dine utfordringar?
- Korleis opplever du at logopeden legg til rette for å arbeide med det som oppleves som meiningsfullt for deg i tida de har saman?
- Kva personlege mål og ynskjer har du for framtida?
- Korleis planlegg du å arbeide for å nå desse måla?

Appendix E: Interview guides, SLT

Intervjuguide 1 - logoped

Introduksjon:

- Takk!
- Informasjon om frivillig samtykke, anonymitet og konfidensialitet
- Informasjon om forskingsprosjektet
- Kan du fortelje litt om bakgrunnen for at du vart med på dette prosjektet?

Om deltakarens bakgrunn:

- Kan du fortelje litt om deg sjølv og din bakgrunn?
  Eks. Utdanning, arbeidserfaring, arbeidsplass(ar), kva er viktig for deg som logoped, kvifor logoped, interesseområder innanføre logopedien.
- Kva type arbeidsplass arbeider du på no?
  Eks. Sjukehus, rehabilitering, vaksenopplæring osv.
- Kva områder innanføre logopedien arbeider du i hovudsak med?
- Kan du fortelje litt om din kjennskap til Norsk Teiknspråk og til døvemiljøet?

Rammer for oppfølginga:

- Kan du fortelje litt om ditt inntrykk av det logopediske tilbodet som tilbys døve og høyrslehemma teiknspråkbrukarar med afasi?
  Eks. Saksgang, kven følgjer opp, innhald osv.
- Kva er dine tankar kring dette tilbodet?
- Kva tiltak meiner du hadde vore hensiktsmessig for å legge til rette for betre oppfølging?
- Korleis blir du sett i kontakt med dine klientar?
- Kva er rammene for den logopediske oppfølginga du kan tilby dine klientar?
- Korleis opplever du rammene for det tilbodet du kan gje dine klientane?
  (Økonomi, tid, ressursar, relasjon, kunnskap)

Startfasen og logopedens oppgåver:

- Korleis kommuniserer du med dine klientar?
  Eks. Teiknspråk, via tolk. Skrift, teikning, andre kommunikasjonshjelpemidler.
- Korleis arbeider du for å skape ein trygg relasjon med dine klientar?

- Kva ser du på som di viktigste oppgåve i den logopediske oppfølginga av døve og høyrslehemma teiknspråkbrukarar som er ramma av afasi?
- Korleis arbeider du for å ivareta dette? (ref. førre spm)
- Korleis går du fram for å finne ut kva som er behovet til klienten i den logopediske oppfølginga?
  Eks. Kartlegging av vanskar, samtalar, mål.
- Korleis arbeider du for å hjelpe klienten til å sette opp mål for den logopediske oppfølginga?
- Korleis opplever du klientens høve til å være deltakande i å sette opp mål for oppfølginga?
- Kva områder opplever du som særleg viktige for dine klientar?
  Eks. Informasjon, kommunikasjon, kjensler, vanskar osv.
- Kva opplever du at du kan hjelpe dine klientar med?
- Kva har du arbeida med saman med klienten/klientane dine fram til no?
- Kva er hovudfokus i den logopediske oppfølginga no for tida?

Avslutning:

- Har du noko du ynskjer å legge til?
- Har du nokon spørsmål?
- Informasjon om observasjon og neste intervju

Intervjuguide 2 - logoped

Introduksjon:

- Informasjon om frivillig samtykke, anonymitet og konfidensialitet

Sist gong me var saman fekk eg observere ei økt mellom deg og klienten din.

- Er det noko du ynskjer å fortelje eller stille spørsmål ved i forbindelse med observasjonen?
- Avklaringar og spørsmål i forbindelse med observasjonen

Tilgang på kunnskap:

- Kva kanalar har du brukt til å tileigne deg kunnskap om afasi blant døve og høyrslehemma teiknspråkbrukarar?
- Korleis opplever du høve til å finne informasjon om logopedisk oppfølging av døve og høyrslehemma teiknspråkbrukarar som er ramma av afasi?
- Kan du fortelje litt om kva du har funnet ut om afasi blant døve og høyrslehemma teiknspråkbrukarar?
- Er det noko spesielt du tenker det er særleg viktig å tenke på med tanke på logopedisk oppfølging for døve og høyrslehemma teiknspråkbrukarar med afasi?
- Opplever du at du har tilstrekkeleg kunnskap om afasi og oppfølging av denne gruppa?
- Kva tenker du at kunne hjulpet deg i din jobb med oppfølging av døve og høyrslehemma teiknspråkbrukarar med afasi?
  Eks. Faglege nettverk, informasjon, kurs, vidareutdanning, osv.
- Kva grep tenker du kunne vore gjort for å bidra til eit betre tilbod for døve og høyrslehemma teiknspråkbrukarar med afasi?

Kartlegging og behandling:

Sist intervju snakka me litt om korleis du går fram for å finne ut kva som er klientens behov i den logopediske oppfølginga, og korleis de set opp mål for behandlinga. Denne gongen ynskjer eg å stille nokon spørsmål angåande kartlegging og behandling.

- Kva verktøy bruker du for å kartlegge klientens vanskeområder?
  Eks. NGS, BAT, HAST osv.
- Kva metodar bruker du for følgje opp og arbeide med klientens vanskar?

- Er det nokon vanskar som du opplever som meir framtredande blant døve og høyrslehemma teiknspråkbrukarar med afasi?
- Er det nokon vanskar tilknytta afasi som du opplever som mindre framtredande blant døve og høyrslehemma teiknspråkbrukarar med afasi?
- Kva tenker du om kartlegging og behandling av afasi blant døve og høyrslehemma teiknspråkbrukarar?
- Kor finn du støtte/inspirasjon/hjelp til å finne fram til og tilpasse den logopediske oppfølginga for døve og høyrslehemma teiknspråkbrukarar med afasi?
- Er det nokon verktøy og tilpassing du kan anbefale andre logopedar som arbeider med denne gruppa?

Afasi og logopedisk oppfølging:

- Kva opplever du som den største utfordringa med å følgje opp døve og høyrslehemma teiknspråkbrukarar med afasi?
- Korleis arbeider du for å møte denne utfordringa?
- Korleis legg du til rette for at klienten skal oppleve oppfølginga som meiningsfull?
- Kven samarbeider du med i oppfølginga av klientane?
  Eks. Pårørande, andre fagpersonar.
- Korleis opplever du at du har høve til å hjelpe klienten i den logopediske oppfølginga?
- Korleis er rammene for den logopediske oppfølginga du kan tilby?
- Korleis har du kome i kontakt med klientane som får oppfølging hos deg?

Logopedisk oppfølging og språk:

- Kva tenker du er viktig å tenke på for logopedar som følgjer opp døve og høyrslehemma teiknspråkbrukarar som er ramma av afasi?
- Kva råd vil du gje til logopedar som i framtida skal følgje opp denne gruppa?
- I kva grad opplever du det som viktig at afasiramma med teiknspråk som førstespråk møter teiknspråklege logopedar?

I Noreg har alle som er ramma av afasi rett til logoped. Diverre kan dei færraste logopedar teiknspråk, så det kan være utfordrande med tilgang til teiknspråklege logopedar.

- Korleis tenker du at ein ikkje-teiknspråkleg logoped på ein god måte kan følgje opp døve og høyrslehemma teiknspråkbrukarar som har afasi?

- Kva råd vil du gje til logopedar som ikkje kan teiknspråk for å hjelpe dei med å likevel kunne tilby god oppfølging for døve og høyrslehemma teiknspråkbrukarar som er ramma av afasi?

Avslutning:

- Har du noko du ynskjer å legge til?
- Har du nokon spørsmål?
- Tilbod om samtale for gjennomgang av transkripsjon
- Takk!

Appendix F: Translated quotes

Quotes from the client

Jeg bor i sånn eldrehjem, men det er kjedelig. Liker ikke. Jeg føler (.) de bare prater og prater. Døve ingen (.) Tegn ingen. Forferdelig. (Fremtid, jeg vil ikke).	I live in such a (.) nursing home [eldrehjem], but that is boring. Do not like. I feel (.) they are just talking and talking. Deaf, none. Signs, none. It is terrible. (Future, I do not want).
Jeg er jo døv. Jeg kan jo ikke høre.	I am deaf. I cannot hear.
Før var jeg normal. Og så plutselig slag.	Before, I was normal. But suddenly I got a stroke.
Morsomt her (.) fint. Hjemme, ikke bra (.) ingen med tegn. Forferdelig (...) går alene. Det er som et fengsel. Jeg føler (..) at jeg ikke har liv, at det ikke er noe.	It is fun her (.) nice. Home, not good (.) there are nobody with signs. Terrible (…) I walk alone. It is like a prison. I feel (..) that I do not have life, that it isn't anything.
Jeg glipper og glipper (.) plutselig så glipper jeg. Før (.) så var jeg normal (.) og plutselig så fikk jeg et sånt fall, plutselig. Selv (.) ja. Forferdelig, det er grusomt.	I miss and miss (.) Suddenly then I miss. Before (.) I was normal (.) And suddenly I had such a fall, suddenly. Even (.) Yes. Terrible, it's cruel.
(...) det er ingen døve der. Jeg er eneste døve (.) huff. Jeg mangler tegn. Det er ingen.	(…) there are none deaf there. I am the only deaf (.) Oh. I am missing signs. There are none.
(...) skriver på lapp (.) døvstum (.) feil. Legen, døvstum, nei. Ble sur. Døv (.) bare	(...) writes on note (.) deaf-mute (.) wrong. Doctor, deaf-mute, no. I got mad. Deaf (.)

døv. Forferdelig. Gamle dager (.) det var ferdig.	Only Deaf. Terrible. Old days (.) it was finished.
Da får vi pratet (.) og det er viktig. Viktig med tegn (.) åh, det er viktig. Mm. Viktig å leve med tegn (.) det er viktig. Mm. Viktig at to sammen prate. Det er liv, det. Det er viktig.	Then we get to talk (.) And that is important. Important with signs (.) Oh, that is important. Mm. Important to live with signs (.) It is important. Mm. It is important that two talk together. That is life, that. It is important.
Nå her (.) da blir det, da er det helt supert (.) det topp	Now here (.) then it becomes, then it is super (.) it is great.
før (.) hadde bare en arm, den andre var lam. Å skrive (.) vanskelig (.) og bedre å skrive nå. én (.) én arm kunne bruke (.) bare med én, tegn med én hånd (.) den andre var lam. Nå går det bra. Jeg har trent og trent.	
Jeg var redd. Var redd. Hva var det som har skjedd? Hva var galt? Så jeg var syk	I was afraid. Was afraid. What had happened? What was wrong? So I was sick.
Nå her (.) da blir det (.) da er det helt supert (.) det er topp.	Now [I’m] here (.) Then it will be (.) Then it is absolutely great (.) It is top.
Tungvint å skrive (.) å, det var tungvint. Ordene (.) å, det var vanskelig (.) med ordene.	Cumbersome to write (.) Oh, it was cumbersome. The words (.) Oh, it was difficult (.) with the words.
Det var det var ingen tegn (.) var **bare** prating. Det var **ikke** lett. Jeg sa mangler (.)	It was, there was no sign (.) Was **just** talking. It was **not** easy. I said lacking (.)

de manglet tolk (..) og så kom det ikke tolk. Så jeg var skuffet.	they lacked an interpreter (..) and then no interpreter came. So I was disappointed.
Jeg vet ord (.) og slaget, etter slag, ordene hvor? Hvor er ordene? Hva heter det og det? Det var vanskelig. Skuffet. øve øve (.) må øve (.) skrive. Hjernen arbeider. Noe lett å glemme. Er lett. Hva glemt (.) hva? Jeg må huske. Mm. Ikke morsomt.	I know word (.) and the stroke, after stroke, words where? Where are the words? What is this and this called? That was difficult. Dissapointed. practice practice (.) must practice (.) write. The brain is working. Something easy to forget. Is easy. What is forgotten (.) what? I have to remember. Mm. Not funny.
Det var vanskelig å finne et tegn selv (.) å oppfatte var ikke lett. Jeg oppfattet ikke. Slaget (.) jeg oppfattet ikke. Det var vanskelig.	It was hard to find the signs myself (.) and to perceive was not easy. I did not perceive. The stroke (.) I did not perceive. It was difficult.
(...) så flytta (.) til eldrehjem. Og jeg sa ikke (.) sa ikke at jeg skulle dit. Jeg ble flyttet dit (.) hva? Jeg fikk jo sjokk.	(...) then move (.) to a nursing home. And I did not say (.) did not say I was going there. I was moved there (.) what? I was shocked.
Prater prater prater (...) Jeg får ikke fred. De mangler tegn.	Talking talking talking (...) I do not get peace. They are lacking signs.
Er kjedelig der. Passer ikke å bo der	It is boring there. It does not fit to live there.
De kan ikke tegn. Det er ingen som kan tegn. De bare prater. Hvis jeg hører ikke, og	They do not know sign. There is no one who can sign. They're just talking (...) I’m

de prater og prater. Jeg blir lei. Hører ikke, sier jeg. Jeg gir opp (.) og så får de være. Andre eldre sier bare hei (.) prater ikke. Det er kjedelig (.) forferdelig. (5) Jeg tenker fremtid, hva? Mitt liv. Det er umulig. Ett rom (.) og soverom. Kjedelig. Går (.) sitter ikke lenge og ser TV. Jeg står opp og går og går, frem og tilbake og rundt og rundt. Det er forferdelig. Mangler noen å prate med. Ja, alene.	getting tired. Can't hear, I say. I give up (.) and then they get to be. Other seniors just say hello (.) do not talk. It's boring (.) Awful. I'm thinking of the future, what? My life. It is impossible. One room (.) And bedroom. Boring. Walks (.) do not sit for long and watch TV. I get up and walk and walk, back and forth and around and around. It's awful. Missing someone to talk to. Yes, alone.
Sa de ingenting (.) de bare stelte meg (.) og så gikk de. De gjorde (.) de gjorde det de skulle (.) og så gikk de. Pratet ikke.	Said nothing (.) they just took care of me (.) and then they left. They did (.) they did what they were supposed to (.) and then they left. Did not talk.
Hjernen liksom (.) den glipper og glipper	The brain sort of (.) It misses and misses
Viktig det med slaget. Forteller historier. ((tar opp hendene gjentatte ganger, og ser ut som han skal starte å si noe)) Jeg husker ikke. Husker ikke.	Important that with the stroke. Tells stories. ((raises his hands repeatedly and looks like he should start saying something)) I do not remember. Do not remember".
Jeg har lyst til å prate, men (.) men jeg ble jo forhindret (.) jeg fikk det ikke til. Før (.) før slaget, da pratet jeg jo i vei (.) det gikk jo helt greit (.) og plutselig ble alt (.) etter slaget. Ja (.) nei, det var veldig forskjell med tegnene. Det var rart.	I want to talk, but (.) but I was prevented (.) I was not able to. Before (.) fefore the stroke, then I talked and talked (.) it went perfectly well (.) And suddenly everything (.) after the stroke. Yes (.) No, there was a

	significant difference with the signs. That was wierd.
Gikk opp i nesa (.) og rett ned. Huff, det var fælt.	Went up the nose (.) And straight down. Huff, that was awful.
Hvis ikke jeg hadde kommet hit, hadde jeg kanskje vært død. Heldigvis så kommer jeg hit (.) og heldigvis har jeg fortsatt å komme hit.	If I had not come here, I might have been dead. Luckily I get to come here (.) and luckily I still have continued to come here.
Var jo sint og (.) hvorfor jeg? Jeg var frustrert (.) jeg var jo redd	Was angry and (.) why me? I was frustrated (.) I was scared.
Følte jeg levde (.) fikk liv (.) fikk et liv	Felt I lived (.) got life (.) got a life.

Quotes from the SLT

Original quote:	**Translated quote**
(...) ikke den typiske logopeden	(…) not the typical speech and language therapist.
Jeg tror ikke de får så mye. (.) Kanskje de får tilbudet om å få opplæring med tolk? (...) Men det kan godt hende at de velger det bort fordi at (...) kanskje det blir for anstrengende?	I do not think they get that much. (.) Maybe they get the offer to get training with an interpreter? (…) They may opt out because (…) it might be too strenuous?

(…) grunnfag i tegnspråk [ja] (.) det har jeg ee (.) men (.) så jeg blir vel ansett som å være på det høyere nivået (…) Jeg blir ikke tatt (.) jeg blir vel ikke av alle tatt for å (.) jeg er gebrokken. Ser vel at jeg ikke er født (.) født til en (.) inn i familie med tegnspråk	(…) basic subject in sign language [grunnfag] (…) so I guess I am regarded as being at the higher level (…) I am probably not taken (.) I am probably not taken by everyone to (.) I am broken. I see that I was not born (.) borned into a (.) into a family with sign language
det var også veldig nyttig å se [ja]”.	that was also very useful to see [yes].
det var veldig (.) ((viser tegn for firkant))”.	It was very (.) ((shows signs for square))
Jeg har ikke språkverktøy, det er jo det som er en utfordring, da. Vi kunne gjerne hatt en sånn (..) jeg kunne ønsket meg det ((ler)) [ja]. Men det finnes ikke på tegn. [Nei]. Ikke på norsk tegnspråk (.) og det kommer nok aldri til å være heller [nei] så da er mer (.) hva (.) hva er testen på jakt etter? Så prøver å omforme det. (.)	I do not have language tools. That is what is a challenge. We could have had one of those (..) I could have wished for it ((laughing)). But it is not available in signs (.) not in Norwegian Sign Language (.) and there will probably never be so either. So it is more (.) what (.) what are the test looking for? And then try to reshape that.
det har fungert før (.) han er så god til å avlese (.)	It has worked before (.) he is a good lipreader.
så mye ekstra energi de skal bruke på å stå i en situasjon hvor de skal avlese (.) jeg synes det bare er trist (.) veldig trist. (.)	so much extra energy they have to spend on standing in a situation where they have to lipread (.) I think it's just sad (.) very sad. (.)
(...) de som er tegnspråklig, de vet noe om historien også. Man er opptatt av bakgrunnen deres. Man er opptatt (.) av ee (.) forstår hvordan det er å være døv (...) Så	(...) those who are sign language users, they know something about the history as well. One is concerned with their background. One is concerned (.) with ee (.) understands

døvehistorien (.) det tror jeg er kjempeviktig å kjenne til	what it is like to be deaf (...) So the history of Deaf people (.) I think it is very important to know
det også veldig vesentlig å vite, og tenke: hvordan var de før? (.) og for noen av de, så er det ikke gitt at de var på et abstrakt nivå (.) før de fikk afasi	it also very essential to know, and think: how was they before? (.) and for some of them, it is not a given that they were on an abstract level (.) before they got aphasia
(.) man må ikke ta for gitt at tolken vet hva vi er på jakt etter	(.) one must not take for granted that the interpreter knows what we are looking for
Det er lammelser, da (..) særs av hender. Det er jo en kjempeutfordring (...)	It is paralysis (..) especially of the hands. It is a huge challenge.

Various/from the literature

Original quote:	**Translated quote**
(…) ved å telle blinde, døvstumme og sinnssyke og fordele dem over tid, og etter distrikt, kjønn og alder, skulle statistikken bidra til å forklare hvordan disse lytene oppsto.	(…) by counting the blind, deaf-mute and insane [sinnsyke] and distributing them over time, and by district, gender and age, the statistics should help to explain how these impairments [lytene] arose.
Målet for Norges Døveforbunds arbeid er å oppnå full deltakelse og likestilling for døve og hørselshemmede i samfunnet.	The goal of the Norwegian Association of the Deaf is to achieve full participation and equality for the deaf and hard of hearing in society.

(...) feks. at tester utviklet for ett språk, ikke kan oversettes direkte og tas i bruk på et annet.	(...) e.g. tests developed for one language cannot be translated directly and used in another.