Whose knowledge counts?

Understanding the position of Deaf people within society through their involvement in co-designing of videotelephony

A Master Thesis by
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Summary

This thesis focusses on how the needs of Deaf people can be translated into the design of technology through the form of community-based co-design. The question asked is, *how did the involvement of Deaf people change the design of videotelephony*? The societal justification of this research is found in drawing attention to the exclusion of minority groups – in this case, Deaf people. This practice is harmful to all; it is actively harmful to the lives of Deaf people as everything becomes more complicated than need be, and it is passively harmful to the rest of society as it shows a lack of empathy to those who have non-normative bodies.

The scientific justification lies in the importance of reflection, analysis and discussion regarding technology. In this case: the development of videotelephony, how it was created, which type of videotelephony should become dominant and who is excluded from using it to enrich their life. Analysis of the historical development of videotelephony, in part through a lens of social construction, shows that there are multiple ways to create 'videotelephony'. The chronology shows that the innovation process was a top-down design from men and companies towards the greater public. This reflection is needed to examine the disappearance of the traditional producer/user dichotomy in videotelephony design in the research and design development that happened in the last twenty years in South Africa; a design form termed community-based co-design. The research conducted in South Africa was selected as they had the most extensive, in-depth and long-term research in the development of Deaf videotelephony, both from the beginning of standard design methods until the development of community-based co-design.

The main conclusion found in this study is that Deaf people know what they want and need from technological solutions. By co-designing, they are given the tools to empower themselves. Videotelephony created this way can be employed in all manner of settings,

wherein the design is created explicitly for Deaf people and thereby, more user-friendly. The application of STS research conducted in this thesis can be used for further analysis of this topic. Moreover, it can be applied in regards to other minority groups' development of technological aids and assistance.

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Abstract

This thesis centres on the research question: *how did the involvement of Deaf people change the design of videotelephony*? The focus is on community-based co-design in South Africa. Science, technology and society (STS) approaches named history of technology (HoT), social construction of technology (SCOT), and actor-network theory (ANT) are analysed to format a perspective for the subsequent analysis. A chronology on the development of videotelephony is created through the framework of HoT and SCOT. ANT and SCOT are needed for the STS account of the co-design case study in South Africa. Inequality is discussed to place the problems Deaf people face within a specific context. The potential to negate this is through inclusive design. Two case studies regarding minority/inclusive design are presented. An ANT analysis is conducted on the work of developing communication tools with Deaf people in South Africa. The Deaf co-designers changed the focus of videotelephony on video quality and affordability. Different types of knowledge, stemming from researchers and Deaf people, integrated and merged into co-design. Educational and societal decisions lead to Deaf people having an unequal societal position compared to hearing people. Inclusive design aided this minority group to empower themselves by creating affordable videotelephony solutions.

Keywords: Deaf, historical analysis, video telephone, minority group, community-based approach, co-design

Introduction

Access to housing, jobs, and education creates the possibility for people to begin to live their own life (Reinders, 2008, p. 138), something which people with disabilities are often discriminated against (Kittay, 2011). People with disabilities encounter exclusion from social aspects of life, such as romantic and platonic relationships, as well (Kittay, 2011; Reinders, 2008). This thesis examines how the co-production of videotelephony can create opportunities for Deaf people to become fully included in society. A definition must first be given as to what constitutes as a person being Deaf, and what the difference is between Deaf and hard of hearing. 'Hard of hearing' is defined by the WHO as “the people with hearing loss ranging from mild to severe” ("Deafness and hearing loss," 2020). Furthermore, the WHO states that *“people who are hard of hearing usually communicate through spoken language and can benefit from hearing aids, cochlear implants, and other assistive devices as well as captioning. People with more significant hearing losses may benefit from cochlear implants”* ("Deafness and hearing loss," 2020) Continuing, the WHO states that *“'Deaf' people mostly have profound hearing loss, which implies very little or no hearing. They often use sign language for communication*” ("Deafness and hearing loss," 2020). Following Chininthorn et al. (2016), Deaf is written with capital D throughout this thesis as well, as it pertains to a community whose primary language is sign language.

The place Deaf people have in society is being constructed and reconstructed. During the Covid-19 pandemic, the inequality Deaf people face has come – partially – to the forefront as the Dutch government used a sign language interpreter during its press conferences for the

first time. The sign language interpreter instantly became a viral hit, for signing the word ‘hamsteren’ (hoarding) depicted in Figure 1.

Figure 1 NGT interpreter Irma Sluis signing 'hamsteren', in English 'hoarding'

The response to sign language interpreters being so visible created prolonged exposure for Deafness – something that had never happened before the pandemic. Even during a terrorist attack in Utrecht in 2019, there was no information available through sign language. Even though these press conferences with a live interpretation and viral videos might seem minor, it is a big step forward in generating public awareness of the existence of Deaf people, their language and culture. Video is, after all, *the* medium Deaf people use to communicate.

Social scientists, communication scientists in particular, but also sociologists, psychologists and those interested in business administration have studied videotelephony (Backhaus et al., 2012; Denstadli, Gripsrud, Hjorthol, & Julsrud, 2013; Dudding, 2009; Gemmell, Toyama, Zitnick, Kang, & Seitz, 2000; Gowan Jr & Downs, 1994; Nehls, Smith, & Schneider, 2015; Panteli & Dawson, 2001; Richardson, Christopher Frueh, Grubaugh, Egede, & Elhai, 2009). These academic fields have all explored, at least in some manner, how

videotelephony and its users shape social and organisational relationships (Fish, Kraut, Root, & Rice, 1992; Greenberg & Neustaedter, 2013; Pauleen & Yoong, 2001).

The following statistics showcase the scale of people who are deaf or Deaf. According to the World Health Organization, over 5 per cent of people living on Earth suffer from disabling hearing loss ("Deafness and hearing loss," 2020). 5 per cent of people on Earth translates to roughly 466 million humans with disabling hearing loss. Moreover, the WHO predicts that by 2050 this number would have risen to over 900 million people. Of those 900 million, only a fraction will use sign language as their primary language. The World Federation of the Deaf (WFD) states that *"roughly 56 million deaf people, eighty per cent of the 70 million Deaf people in our world today, receive no education at all, specifically in developing countries' among deaf women, girls, and minority groups" ("Advancing human rights and sign language worldwide," World Federation of the Deaf).* 90 per cent of Deaf children have hearing parents and families that do not learn and use sign language (Mitchell & Karchmer, 2004). The National Institute for Deafness and Other Communication Disorders states that around 324,200 cochlear implants were inserted on the entire globe.

Nearly all nations have recognised Deaf people's right to work and earn a salary ("Advancing human rights and sign language worldwide," World Federation of the Deaf). Continuing, the World Federation of the Deaf states that only a few of these countries have anti-discrimination legislation for corporate contexts protecting those who are Deaf against organisational discrimination. As the schools catering specifically to Deaf children are being closed, which correlates with a significant increase of Deaf people being illiterate and unemployed, and scarcity of sign language interpreters, the reality is, according to the World Federation of the Deaf, vastly divergent. If specialised educational discourses exist, most of them use the term 'hearing impairment'. Brennan (2003, p. 677) states that *"This places the deaf*

pupil within a particular framework or paradigm which, almost by definition, excludes the notion of Deaf identity, at least as understood by Padden & Humphries (1988)".

Over the last two decades, steps were made in terms of documentation providing guidelines and policies which aim to ensure heightened 'inclusion' of deaf and disabled people (Brennan, 2003). Legislation preserves some of these policies. However, even though discourse, speech pattern, vocabulary, and terminology implemented phrases from the equality and rights movement, there is no substantial connection between practice and rhetoric (Brennan, 2003). Developing videotelephony in an inclusive setting crosses this bridge between rhetoric and practice. According to the World Federation of the Deaf, Deaf people must have 1) the opportunity to take up leadership roles so that Deaf people themselves can adequately advocate for their rights, and 2) they need to be actively involved in all decision-making processes concerning their lives. This is reflected in their slogan: 'Nothing about us without us' ("Human rights of the Deaf," 2020).

Policy statements are scattered with hints to rights for the non-normative; most of these policies are based on a medical perspective regarding disabilities and deafness. The progress made by disability rights' movements is in severing the connection between their non-normative bodies and social situation. The real cause of their disability became highlighted: prejudice and discrimination (Brennan, 2003; Shakespeare, 1992). This 'social model of disability' Brennan (2003) writes about does not deny impairment itself, rather societal barriers as well as organisational discrimination were viewed as inherently disabling. Currently, critics have questioned and reinterpreted the social model of disability, saying that *"denying the role of impairment is to deny the experience of individuals themselves"* (Brennan, 2003, p. 669). However, for this thesis, the focus will rest on the social model of disability.

This research aims to explore how co-design of videotelephony did (not) improve the societal inclusion of Deaf people, showcasing the inherent societal exclusion within that

statement. The methodology of this thesis is based on both the actor-network theory (ANT) and social construction of technology (SCOT). The central research question in this thesis is as follows: How did the involvement of Deaf people change the design of videotelephony? Sub questions and follow-up questions to the primary research topic consists of 1) How does the blending of academic and lay-knowledge work within an inclusive design setting, 2) How did participation aid Deaf people, 3) What can be learned about the exclusion or discrimination of Deaf people within society through analysing the process of co-design, 4) What obstacles do Deaf people face in day to day life because others cannot communicate with them and vice versa, 5) How can co-design of videotelephony for Deaf people aid society towards becoming more inclusive towards Deaf people.

Two researchers who were part of the studies regarding community-based co-design with Deaf communities were interviewed for this analysis. Dr W. Tucker of the University of Western Cape (UWC) and P. Chininthorn, in affiliation with BANG and TU Delft. These interviews took place via Skype (with Dr Tucker) and face-to-face (with Mrs Chininthorn). The data was written out and analysed using Atlas.ti. A codebook was created and validated through a second coder. Intercoder-reliability was high, at 0.87. The manner of analysis was according to 'the spiral of analysis integrated into the qualitative research process' (Boeije, 2009; Bosch & Boeije, 2010), i.e. the method of coding was open coding, axial coding and selective coding. These three steps were executed iteratively. The codebook can be found in the Appendix.

Chapter 1 starts with an overview of the research methods employed, namely the history of technology, SCOT, and ANT. A conclusion is given what the most appropriated research method for this analysis is. Chapter 2 opens up our understanding of videotelephony by given a historical chronology regarding its invention and innovation. By creating this historical narrative regarding the design and implementation of videotelephony technologies, the trail of patents and designers of said technologies was followed to understand what their initial

considerations. Chapter 3 focusses on inequality towards non-normative people, and wherein inclusive design is presented as a partial solution to this problem. Chapter 4 analyses the case-study of community-based co-design in South Africa. Chapter 5 concludes this thesis by summing up the main points of this argument, as well as answering the research question. Suggestions for further research are given here as well.

Chapter 1

Shaping of society and technology

Introduction

Various articles and books were written regarding disability and new media (Goggin, Newell, & Newell, 2003), the social implications of mobile telephony (Campbell & Park, 2008), and disability and videotelephony specifically (Magnussen, 1997; Magnusson & Brodin, 2004; Renblad, 2000). Facilitating innovation for Deaf user experience (Matiouk, 2016) is the most relevant article to this study, wherein some methods to inclusive design are presented. This thesis focusses on the niche of real-life application of inclusive design *with* Deaf people within an STS perspective.

To understand the scope and perspective of videotelephony and how the exclusion of minorities within society can be analysed through the analysing the design of technology, the methodologies of the methods used must first be clarified. In this chapter, the history of technology (HoT), the social construction of technology (SCOT), and actor-network theory (ANT) are explained and compared to one another. In doing so, insight is gained as to when each approach is useful to employ for my research project. An HoT -approach finds its basis in a critical retrospective of the origin and development of technology X. SCOT could entail the same, though the social context in which construction of technology is vastly more important than the historical approach. The pitfall of classical SCOT is that everything could be reasoned as socially constructed – and thereby saying nothing new at all. ANT was created to 'solve' this drawback through the analysis of the entire network in which technology and other actants are embedded.

The questions leading this analysis and explanation are: 1) how did this approach develop, 2) what are the drawbacks and 3) how does the approach differ from the others in this chapter?

1.1 HoT

"Techniques are ways of creating tools – both new and known – and products of tools", and, according to the Encyclopaedia Brittanica, the capacity for constructing such artefacts is a determining characteristic of humanlike species. Though other species – such as bees building hives and birds making nests – make artefacts as well, these attributes are the consequence of instinctive behaviour and do not alter when faced with rapidly changing circumstances.

Humans can adapt to various environments – from frozen tundras to scorching deserts (Gehlen & Rehberg, 1988). Even though humans do not possess highly developed instinctive reactions to create a hive or a nest, we *can* think systematically and creatively about techniques (Pope, 2005) – the progress in terms of communication technologies attests to this. Humans can more quickly innovate and alter their environment than any other species. Due to their nature as toolmakers, humans are technologists from the beginning.

Twenty years ago, the History of Technology (HoT) was defined as the history of *"making and doing"*; those researching the history at that time of technology found their origin in engineering and wrote history through that lens (Smelser & Baltes, 2001). The traditional ways of thinking about the history of technological development ensured that authors thought in straight lines. The more recent definition shows a shift in perspective, considering the HoT as the history of "*using, experiencing and knowing"* (Buchanan, 2019). HoT currently stresses that history is a web of inter-connections. Moreover, change causes more change (Burke, 1978).

The newer HoT is not only an account of technology. It focuses on the relations of technology beyond mere usage. A significant reason for the shift in perspective is that engineer-

historians no longer define the field. Hughes (1979) states that engineer-historians primarily focused on what was created and used. Professional historians of technology are, by contrast, researching all aspects of history, most notably *"the evolution of technology within complex circumstances shaping, and being shaped by, the doing and making"* (Hughes, 1979, p. 555).

Technological systems and technologies are, according to most historians of technology, socially constructed (Buchanan, 2019). In other words, failure, success, or even mere emergence of technologies are in part due to *"political strategies employed by 'actors' – individuals, groups, and organizations – that have conflicting or complementary interests in particular outcomes"* (Long, Siddiqi, & Post). Almost all historians agree that *"success or failure is contingent on inescapable physical realities"* (Long et al.)

Technological design is formed by social and cultural factors. In other words, *"the shaping of technology is integral to the shaping of society and culture"* (Buchanan, 2019). There is disagreement regarding the role of society and technology. Some say that technology is subservient, i.e. *"impelled by choices made in the context of circumstances"* (Buchanan, 2019). These forms of dispute happen over power manifested in *"registers of politics, gender, race, and inequality"* (Buchanan, 2019; Küng, 2013). Others state that once created, technologies can assert a significant influence on choices; humans and social values are subservient to technology, not the other way around (Kaplan, 2009). Videotelephony itself has not been researched much through the lens of HoT (Fish & Kraut, 1994; Jensen, 2008; Schnaars & Wymbs, 2004).

In sum, European sociologists and anthropologists transformed the field of HoT via the introduction of social construction and actor-network methodologies (Hughes, 2001, p. 6856). The following subchapter will focus on the approach of SCOT.

1.2 SCOT

Scholars in the field of the SCOT (social construction of technology) argue that the employment of technology cannot be grasped without first understanding the way in which technology itself is nested in the social framework. SCOT is typified as a theory or framework in response to technological determinism, which states that technology arises independently from social influences. SCOT uses empirical methods adapted from Empirical Programme of Relativism. This is a method of analysis Bijker, Hughes and Pinch (1987) employed to demonstrate how scientific findings are socially constructed. SCOT can be seen as a theoretical construct that helps understand the development and HoT. In turn, HoT could be viewed as subservient or an aid to SCOT. Historical sociology of scientific knowledge states that *"solutions to the problem of knowledge are solutions to the problem of social order"* (Shapin & Schaffer, 2011, p. 332).

The various steps in development of a *"technological artefact"* can be *"described as an alternation of variation and selection"* (Pinch & Bijker, 1984, p. 411). This leads to a "multidirectional" model, contrasting with the *"linear models used explicitly in innovation studies"* and implicitly in the HoT studies from the 1980s (Pinch & Bijker, 1984, p. 411). A multidirectional view is *"essential to any social-constructivist account of technology"*, as Pinch & Bijker (1984, p. 411) state; with hindsight, it is easy to change the multidirectional model to a more straightforward linear one. However, this lacks the core of Pinch and Bijker (1984) their discussion that the *"'successful' stages in the development are not the only possible ones"* (p. 411). Bijker, Hughes and Pinch (1989) argue against the view of technological determinism, as it merely is a result from looking backwards, and concluding that the process could only have happened in this one way.

According to Bijker, Hughes and Pinch (1989) SCOT posits that to understand the reasoning for accepting or rejecting of technology must stem from analysing 'the social world'. Merely saying that successful technologies are such because 'they are the best' is not enough.

A more in-depth understanding regarding how 'the best' is defined must take place, as well as which groups, stakeholders and actors have taken part in determining 'the best'. Specifically, questions that could be asked in these situations are: 1) Which actor defines the criteria which measures success, 2) How come these criteria are created in this manner and, 3) Which groups or persons are being excluded/included in this process? In asking these questions, the social context from which the technology arose is put in perspective.

Constructivist STS comes, according to Bijker (2015, p. 135), in *"a variety of forms, both mild and radical. The mild versions merely stress the importance of including the social context when describing the development of science and technology."* Examples in the HoT Bijker (2015, p. 135) used include the account of the turbojet revolution (Constant, 1980) and the study regarding the electrification of America (Nye & America, 1992).

Bijker (2015, p. 135) continues stating that *"the radical versions argue that the content of science and technology is socially constructed. […] The 'radicals' claim that the truth of scientific statements and the technical working of machines are not derived from nature alone, but are constituted in social processes."* Bijker (2015) states that radical constructivists of STS share the same background and have similar aims as historians of technology. Studies in these areas have been conducted by the same authors. Multiple case studies have been published regarding the evolution of technologies, arguing that their design was not the outcome of internal, technical logic but rather negotiations between several social groups (R. R. Kline, 2001).

Opponents state that SCOT ignores the consequences of the technologies after it was constructed (Winner, 1993). This results in a form of sociology lacking in perceiving technology in a broader context. Likewise, SCOT fails to account for those design options that never made it to the table. Another criticism how SCOT perceives societies as compositions of groups (Klein & Kleinman, 2002), stating that *"this fails to adequately attend to power*

symmetry between groups" (p. 30). An updated version of SCOT was created in response to this, wherein producers, mediators, and consumers are examined symmetrically, rather than privileging the producers' interpretations of success over that of users (R. Kline, 2003).

The biggest weakness of SCOT consisted of the separation of humans and non-humans, where humans' agency is privileged in social and technological contexts (Baron & Gomez, 2016). Due to SCOT's inherent asymmetry, some STS scholars shifted to what is currently known as ANT.

1.3 ANT

The actor-network theory (ANT) is defined by Baron & Gomez (2016, p. 129) an *"approach which focuses on the description and analysis of associations between natural, human and technological entities (J. Law, 2009)"*. ANT focuses on the connections created between human and non-human entities (Latour, 2005), and in doing so, goes further than SCOT and HoT-approach. ANT argues that items are created for shaping human action and moulding human decisions. The design of these items can act in mediation of human relationships, as well as *"impact morality, ethics, and politics"* (Yaneva, 2009, p. 277).

ANTs material-semiotic approach means that relations that are simultaneously material (i.e., between things) and semiotic (i.e., between concepts) are tracked (John Law & Singleton, 2014). Because of this, ANT is a research methodology on how to study phenomena, as well as a critique of traditional sociology (Bruno Latour, 2005). The research methodology of ANT is employed in the focal case of this thesis, as it enables an analysis that unearths the network formed through the case of co-designing videotelephony with Deaf people.

ANT outlines the way connections between actants create new entities that are more than the sum of the two. The 'gunman example' exemplifies this fusion of actants (Bruno Latour, 1999): a man and a gun can create a new entity when they are connected: the gunman.

ANT researchers focus on the linking of the man and the gun. A gunman can shoot someone or something and therefore differs from a man and a gun. Through this thought experiment, the conclusion can be drawn that war is caused by neither guns nor humans.

According to Latour (2008, p. 151), sociotechnical systems are developed *"through negotiations between people, institutions, and organizations"*. However, Latour (2008, p. 151) also states that *"artefacts are part of these negotiations as well"*. Latour does not state that *"machines think like people do and decide how they will act"* (p. 151), but rather he reasserts that *"their behaviour or nature often has a comparable role"* (p. 151). Through this argumentation Latour makes the argument *" that the material world pushes back on people because of its physical structure and design"* (p. 151).

Users can freely have their own interpretation what an artefact means. However, it is impossible to *"tell an automobile engine that it should get 100 miles per gallon"* (p. 151). This is due to restrictions imposed by laws of nature, as well as design specifics, limit how artefacts can be integrated into a sociotechnical system (p.151). Artefacts are sometimes deliberately created as replacements of human actions, as well as other people's containment and shaping of activities. *"People can 'act at a distance' through the technologies they create and implement and, from a user's perspective, technology can appear to determine or compel specific actions"* (p. 151).

'Actor' is misplaced, as this theory does not focus on the networks of people exclusively. An actor can be non-human as well, such as the gun mentioned before. The word actant is more applicable and used where possible (De Assis & Giudic, 2017). An actant is "*that which accomplishes or goes through an act" (p. 147)* . As De Assis & Giudic (2017, p. 147) state: *"An actant can be a human, but it can also be an animal, an object, or even a concept, as long as it accomplishes or undergoes an act within a network."* By using the word 'actant', all

entities are treated equally, and the focus shifts to actions of the entity rather than the entity itself (Dankert, 2012).

The 'network' part of actor-network concentrates on the consequence of the aforementioned actions. An *actant-network* is formed, when actants connect (Dankert, 2012, p. 8). According to Dankert (2012, p. 8), *"a network is always an actant-network"*. By looking from afar, an actant-network appears as one actant as the connections within the network cannot be observed. Vice versa, by zooming in on an actant, connections come into view, and the actant can be seen as a part of its network.

Actants have the power to change other actants, i.e. '*agency'* (Dankert, 2012, p. 6). 'Acting' is always by interacting with others. As a *result* of processes taking place between actants in networks a scientific claim can be developed about a distinction between the natural and the social, and consequently about the function of the social for scientific practices (Pickering, 1992, p. 310-311).

Actor-networks are inherently unstable and appear dynamic to a high degree (Greenhalgh & Stones, 2010). ANT tries to preserve the connections of actants through *"translation, which involves the four stages of problematisation, […] interessement, […] enrolment […] and mobilisation"* (Greenhalgh & Stones, 2010, p. 1287). Translation is defined as *"the constant shifting of power between technology and society"* (Sasvari, 2013, p. 8). In this thesis, a *Callonian, analytical approach* coming from his research on the scallops is used. A network entails relations and translations between steady actors; thereby deciding the hierarchy of the actants within the network. Once a network has been set up to endure, it implies closure preventing other actants or relations from taking part in the network (Detel, 2001). The network remains the same, ensuring the process of translation can happen and therefore opening the possibility of the aggregation of scientific knowledge (p. 14265). Actor-networks construct and reconstruct throughout the connecting and reconnecting of actants. In terms of stability:

"As long as the actants keep interacting, the actant-network will look stable from the outside. The connections between their constituting actants will hold." (Dankert, 2012, p. 8). The actor-network will break down upon ending of the interaction.

In sum, ANT traces connections and reconnections of human and non-human actants. These connections could be used for empirical analysis. ANT focuses on how connections were established. The ANT perspective is useful in this thesis as it traces how actants formed a network to create videotelephony tools for Deaf people.

1.4 Application of these methods

In this thesis, inequality is the focus. These methods are employed to understand, discuss and analyse inequality inherent to the construction and design of videotelephony. Chapter 2 focusses on videotelephony, not as a modern invention but rather, traced back to its inception in the late 18th century. Through a historical lens, clarity is given on how this invention could progress. In creating this chronology, SCOT is also used to aid the examination of how videotelephony could be created in various formats and through various actors – the process of creating videotelephony was not linear. This HoT-perspective, paired with SCOT, creates an analysis of videotelephony as a technology created in societies with great inequality.

The question asked in Chapter 4 of this thesis is not only about actants, but also on the dynamics of these actants, and the influence each has on this process of developing videotelephony. The case study is not reconstructed completely, but rather an analysis is given on a certain level of accounts – published work in peer-reviewed journals, as well as interviews. This creates a narrative reconstruction on the accounts of the researchers on what happened.

ANT vocabulary gives the opportunity of a broader research perspective, a criticism regarding ANT is that it fails to provide explanations for social processes (Whittle & Spicer, 2008). Moreover, according to Greenhalgh & Stones (2010, p. 1287-1288) ANT reduces

"humans to comparable status to technologies places human motives, desires and virtues beyond the analytic frame and evades ethical questions" (Greenhalgh & Stones, 2010, p. 1287-1288). SCOT helps to alleviate this drawback.

For this thesis' case study, this entails that combining these two approaches will analyse the co-designing of videotelephony for Deaf people through the lens of human agency shaping technology – within its network and together with all actants. Both theories reside within the sphere of STS and are best employed for studies attempting to grasp societal relationships with technology. As Baron & Gomez (2016) state: *"There is not a single widely used paradigm, which has synthesised the various schools and theories dealing with technology and society"* (p. 10). 'Actors' are the vocal point of both theories, however there is a definitional divergence regarding said actors between SCOT and ANT.

Diverting SCOT, Latour *"re-affirmed that ANT did not limit itself to solely human individual actors but extends the word actor – or actant – to non-human, non-individual entities"* (Baron & Gomez, 2016, p. 134). This is precisely why ANT is the primary research approach in this thesis as it creates understanding of the socio-technical interactions inherent to co-design of videotelephony. Within this research, a combination of SCOT and ANT is necessary to understand the influences of social contexts in designs of videotelephony, but also the inequality that underlies these social contexts and influences. ANT asserts the importance of the network but does not consider how the network – and possible inequalities – came into being, which is why SCOT is used.

This thesis will use all three research approaches in mixed variations. Table 1, on the following page, shows where each research approach is used in this thesis.

Method	In this thesis
HoT	Chapter 2
SCOT	Chapter 2 & 4
ANT	Chapter 4

Table 1 Overview of research methods used in this thesis

Chapter 2 focusses on the social construction of videotelephony, through a historical narrative of the development of videotelephony as a whole. Specific notice is already given in the influence of the Deaf community in this chronology in chapter 2.3. Chapter 4 uses a Callonian-interpretation of ANT to analyse the case study of inclusive design with Deaf people after SCOT was employed to understand the underlying inequality creating the need for inclusive design.

Chapter 2

Historical analysis

Introduction

The history of videotelephony could be a subchapter on the history of innovations and inventions. In order to create a clear timeline on videotelephony, popular website entries such as videos from YouTube, Wikipedia and blogs were used as a starting point. Relevant sources mentioned in both the videos, blogs and the Wikipedia article on (the history of) videotelephony were accessed and referenced as such. However, before videotelephony as an invention can be discussed, a clear definition on 'inventions' needs to be given.

The definition of inventions used in this thesis is as follows: *"Inventions combine components – whether they be simple objects, particular practices or steps in a manufacturing process – in new and useful ways"* (Fleming & Sorenson, 2003, p. 16). Continuing on page 16, Fleming & Sorenson (2003) state that *"An inventor can create novel products either by rearranging and refining existing components or by working with new sets of them."* New technological creation arises from recombining and synthesising existing technologies (Fleming & Sorenson, 2001). Versatility and creativity of humans and technology is a key connection, according to Fleming & Sorenson (2001) and therefore, inventions are a combination of existing and new technologies. A design is thereby considered by Fleming & Sorenson (2001, p. 1020) *"to be either a new synthesis of existing and new technological components or refinement of a previous combination of technologies"*.

This framework enables the invention process to be a combined quest searching for enhanced configurations and combinations of existing technologies (Fleming & Sorenson, 2001). Using the perspective of HoT and SCOT explained in the previous chapter, this section

will show how videotelephony came into being – from fantasy to physical object, through social influences changing the path of innovation, to the point of mainstream application for both hearing and non-hearing people.

Videotelephony is defined as *"a means of simultaneous, two-way communication comprising both audio and video elements"* (McGraw-Hill, 2002). Continuing, McGraw-Hill (2002) states that: *"Videotelephony software has been developed and made widely available that permits real-time collaboration and conferencing, including multipoint and point-to-point conferencing"*. A videophone is a device capable of audio-visual transmission between users in real-time. Videoconferencing , according to Muhlbach, Bocker, & Prussog (1995, p. 291), entails that *"groups of people meet in videoconferencing studios, employing a point-to-point connection"*, thereby being usually situated in an organisational context.

The existence of videotelephony changed the way people communicate, as well as reimagine their work and private life. Already in the early 20th century, imagined applications for videotelephony ranged from a salesperson showing a dress through a video stream to relatives speaking across time zones. Videotelephony was deployed commercially between 1930 and 1940, 1980 and onwards, including the so-called "image phones". These devices would use conventional telephone lines to transmit still images every few seconds. The development of more powerful central processing units (CPUs), advanced video codecs, and the availability of broadband Internet allowed users synchronous, high-quality interactions nearly anywhere on Earth.

However, to understand the complexity of videotelephony, we must first look at the beginning of its conceptualisation.

2.1 Origin

The earliest audio-video device and wide-screen television was labelled the telephonoscope. Popular magazines had created this design shortly after the telephone was patented in 1876. 'Le vingtième siècle; la vie électrique' (Robida, 1890) and other science-fiction works written by Robida showcase a 'videophone'. Videophones were implemented in various cartoons, most notably those drawn by George du Maurier. Figure 2 showcases one such drawing, where the global idea of workings of a videophone can be seen.

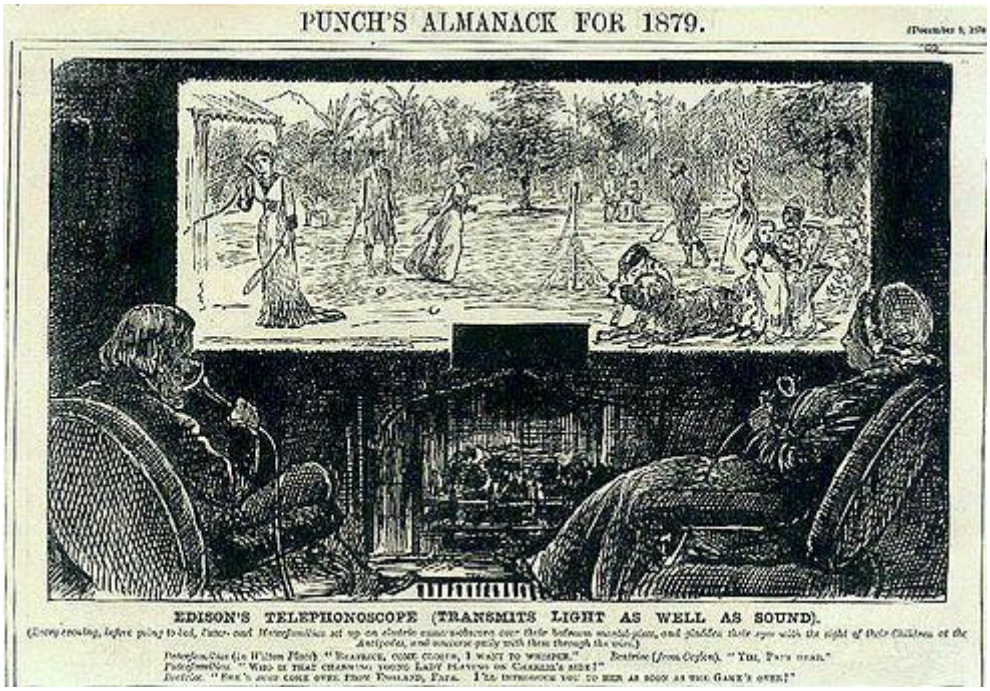

Figure 2 A conceptualisation of a videophone, drawn by G. du Maurier. Source: Punch magazine, 9th of December, 1878.

French writer and publisher Mr Figuier coined the term telectroscope in 1878 to popularise an invention falsely thought to be real (Peters, 1938). One newspaper article speculated that: *"By means of the electroscope merchants will be able to exhibit their goods, or samples of them, to any customer supplied with the same instrument, whether in Liverpool, London, Paris, Berlin, Calcutta, Peking, San Francisco, or New Orleans"* (N.N., 1877).

Before 1935, ‘video telephone’ was no standard term with multiple expressions being used; there were around 20 terms in English alone. All these terms would convey the description of a technology combining radio, telegraph, television and telephone technologies (Kennedy Jr., 1930). The evolution of the idea of videotelephony in Germany and the US is analysed in the following section.

Europe and the United States

The ancestry of videophones can be traced back to telegraphic image transmitters, stemming from several companies, e.g. AT&T's Bell Labs’ transmission of photographs (N.N., 1924), which is an ancestor of fax machines. These first transmissions of images were in their turn founded on earlier activities done in the 19th century. However, Germany had developed the first long-distanced, fully operational video telephone system in the years leading up to the Second World War.

Germany 1936 - 1940

Germany's *Gegensehn-Fernsprechanlagen,* the first working public video telephone service, was created in 1936 by *Fernseh-AG*'s R&D department (Rich, 2011). Figure 3 depicts the German videotelephony system as it was in 1936.

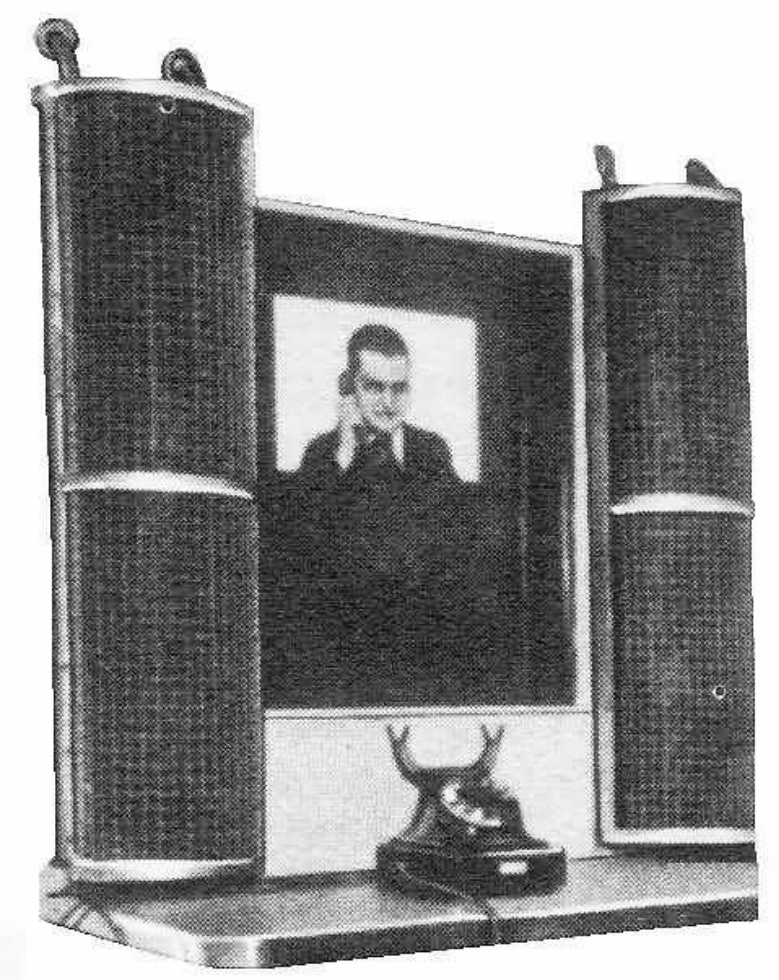

Figure 3 The 'Gegenseh-Fernsprechanlagen' at work

This videotelephony service was created by the German *Reichspost,* i.e. the national postal service, and began between Leipzig and Berlin, connecting two postal offices 160 km apart.

Fernseh-AG's R&D department based this videophone service on the research done by Gunter Krawinkel in the latter part of the 1920s and had been presented at the Berlin International Radio Exposition in 1929 (Goebel, 1953).

In this initial trial-phase, Berlin was connected via broadband coaxial cable lines to Leipzig. In July 1938, two years of active use, the system was broadened from Leipzig to Nuremberg, as well as Munich, as well as Berlin to Hamburg. At its peak, this system formed a web spanning over 1000 km. Public areas had videophones in the form of two videophone booths per city. Costs of this service was high, with a call between Berlin and Leipzig priced at RM3½, about $1/15^{th}$ of the average weekly wage ("Public Television in Germany," 1936).

The videophone used in Berlin had been invented and implemented by the *Reichspost*'s Laboratory. All other video telephone systems in the remaining cities were developed by Fernseh A.G. (Goebel, 1953). The videophone system was in continuous change through development and tests, resulting in an advance in quality of communication (Goebel, 1953). Though modern videotelephones have upgraded significantly, the German videotelephones were reviewed as 'impressive' ("Public Television in Germany," 1936).

The general public could use the videophone service through visiting the post office video telephone booths simultaneously in respective cities (L.S., 2010). Ambitious plans, extending the videophone network to other major cities, were announced but never fulfilled due to the outbreak of WWII (von Weiher, 1983). The videophone system, using expensive broadband cables, was shut down in 1940 and the cables were converted to lines for telegraphs and television services (Muhlbach et al., 1995).

Germany Post-WWII

World War II would set video and television back in popularity, before gaining the interest of the general public mid-1950s. The Deutsche Bundespost would, decades after WWII, create Broadband Integrated Glass-Fiber Optical Network (BIGFON), which was a videotelephony network connecting several major German cities (Muhlbach et al., 1995).

The United States 1927 - onwards

AT&T had developed the ikonophone by 1927 (Roberts, 2019). The ikonophone, later also named the teleostereograph, as depicted in Figure 4, was big: *"The contraption took up half a room, delivering a moving picture at 18 frames per second"* (Mäkinen, 2007, p. 37).

Figure 4 A 1927 Bell Labs videophone prototype

AT&T's ikonophone/teleosterograph was in experimental use by 1930. This was possible due to continued research into two-way television-telephones during the 1930s, intending to create two-way videotelephone for telecommunication and broadcasting (Buckley & Darrow, 1956). Other creations of 'two-way television-telephone' systems in the 1930s happened as well, mostly to compete with AT&T (Mäkinen, 2007, p. 37). However, no other could resolve technical issues, e.g. signal compression; Bell Labs could. The fundamental issue for transmitting low-resolution video through telephone lines was signal compression, or the lack there of. In 1964 AT&T produced the Picturephone (Mäkinen, 2007, p. 37), showcasing the first commercial videotelephony system at the World Fair of the US in 1964 and video conferencing service for groups in the decade after. All these products failed commercially, but were heralded as technical successes.

People had no use for audio-video communication, and widespread use of video telephones was unlikely to succeed (Noll, 1992). One reason is that *"current generations of videotelephony are nothing new in these recent attempts at reinventing PicturePhone for face-to-face video communication: they will only replicate the past with the same results, namely, market failure"* (Kraut & Fish, 1995, p. 699). What this chronology has already shown, is that videotelephony was created through multiple attempts and failures – showcasing the multidirectional model of the construction of technology mentioned in chapter 1. It was the technological advancement of other areas that sparked the interest of creating videotelephony (Burke, 1978).

AT&T published their research, which enabled competitors to develop videophones as well. AT&T's videophones was met with coverage in public news, science journals, as well as popular culture.

2.2 The 21st century

Interdependence *"in the technological context"* implies *"coupling between components"* (Fleming & Sorenson, 2003, p. 16). Innovation or inventions with modular design has the option that alteration in one element of a product has *"relatively little influence on the performance of other parts, or the system as a whole"* (Fleming & Sorenson, 2003, p. 16). Continuing on page 16, Fleming & Sorenson (2003) state that *"In a nonmodular, or "coupled," design, the components are highly interdependent, and the result is non-linear behaviour."* To put simply, a small compononent changing can create dysfunction of the entire system. A change in decoupled, modular inventions has fairly limited 'dramatic' results (Fleming & Sorenson, 2003).

The rise of digital compression methods in the 21st century gave way to new methods of creating videotelephony. As Fleming and Sorenson (2003) would say: the nonmodular design

of videotelephony technologies ensured that a change in video compression lead to financially accessible videotelephony in the early 2000s.

Japanese image-phones

In Japan, significant progress regarding a portable videophone was made. Mitsubishi's *Lumaphone* was designed in 1985. The Lumaphone costed $1,500 upon introduction in the US (Booth, 1988). The Lumaphone's design consisted of a video display of 4 centimeters in size and a video camera (which could be blocked for privacy reasons) next to the screen.

Although promoted as a 'videophone', its operations were more alike to the 'still image' phone of 1956, as every 3 to 5 seconds an image was sent over analogue telephone lines. Though meant as a mobile phone, the Luma LU-1000 could connect to a regular TV or monitor, as well as be hooked up to a printer for improved teleconferencing.

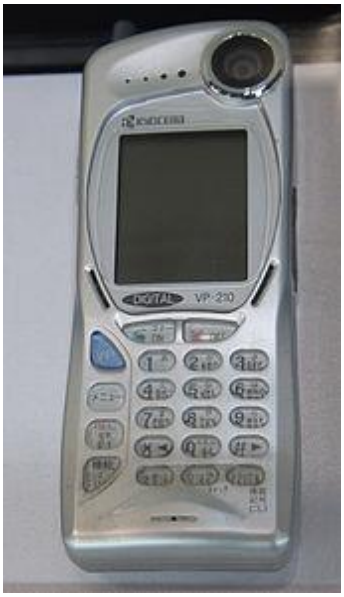

Figure 5 The Kyocera VP-210 Visual Phone

Fast-forwarding ten years, the Kyocera Corporation, released the VP-210 VisualPhone; this mobile phone could send *"a Shaky-TV-style color image to a small screen on the other*

party's telephone – assuming that it too is a video phone" (WuDunn, 1999, p. 2). Figure 5 is a photo of this mobile phone. At the time, this was an expensive, high-tech video phone costing US$325 in 1999. *"The tiny amount of memory and the relative crudeness of the camera make it a museum piece today, but at the time having that functionality […] was nothing short of revolutionary"* (Yegulalp, 2012, p. 1).

Commercial release ensured that mobile videotelephony became internationally profitable. The implications were vast; videotelephony could become available everywhere this phone would have reception. Through the development of the mobile phone, leading to the smartphone, videotelephony has now become a 'normal' way of communicating with others across vast distances and time zones. In this process of normalization of videotelephony, the applications for this form of communication expanded as well.

Applications of videophones

People with non-normative bodies, the elderly and those living in remote places have embraced the possibility videophones give. It must be noted that those who live in non-normative are the ones benefitting greatly of video telephony's existence. Telecare was enhanced through videophones in the form of various medical services, e.g. diagnostics and consultation (Doughty, Cameron, & Garner, 1996). Mediated diagnostics were taken a step further as telemedical services have developed a new technology which can be viewed as 'medical' videophones, which are capable of performing diagnostics. These videophones *"are capable of transmitting voice, data and video over standard telephone lines or [...] broadband data lines"* (N.H., 2004). Videophones, in the way of 'baby watch', were even employed by the Royal Dutch Telephone Company to create a connection between parents and their premature babies, who were lying in the hospital (Oudshoorn, Brouns, & van Oost, 2005).

Corporate teleconferencing is another context of use for videotelephony; a context of use available through specifically designed, publically accessible rooms. Telepresence is possible in these setting – which is a richer form of videoconferencing where top notch telecom technologies are employed to give the impression that there is no barrier between users.

The general workings of videophones are still used today through video calls using smartphones and PCs through cheaper parts. TV cams are one such development where people make "videophone" calls without a PC.

2.3 Implications for Deaf people

Before the 1960s, Deaf people couldn't communicate with another unless they were in the same physical space. Kinner & Kinney (2015, p. 4) state that Deaf people *"also relied on neighbours to make calls for them. Those who had a telephone at home would ask their children to make calls for them, and these repeated requests sometimes put a strain on the relationship between parents and children"*.

Because of this restriction of communicating over long distance, the Deaf community had a prominent place in developing cheap, but high in quality videotelephony. A critical player in this developmental process was Jonathan Hodson. Hodson had proposed multiple times the idea of video relay services (Kinner & Kinney, 2015). Notoriety for inexpensive video-compressing technology came through Hodson's continued push on this subject, gaining traction within Deaf organizations and state relay administrators. The effect was significant. *"Thus, Deaf organizations and state relay administrators lobbied Federal Communications Commission to include the video relay service into telecommunications relay service infrastructure"* (Kinner & Kinney, 2015, p. 26).

In Figure 6, Hodson is shown using the VRS. “In 2003, Sorenson became the first VRS provider to develop a videophone specifically for Deaf people, which it licensed to Deaf users at no charge. The technology began changing lives” (Hossler, 2017, p. 41).

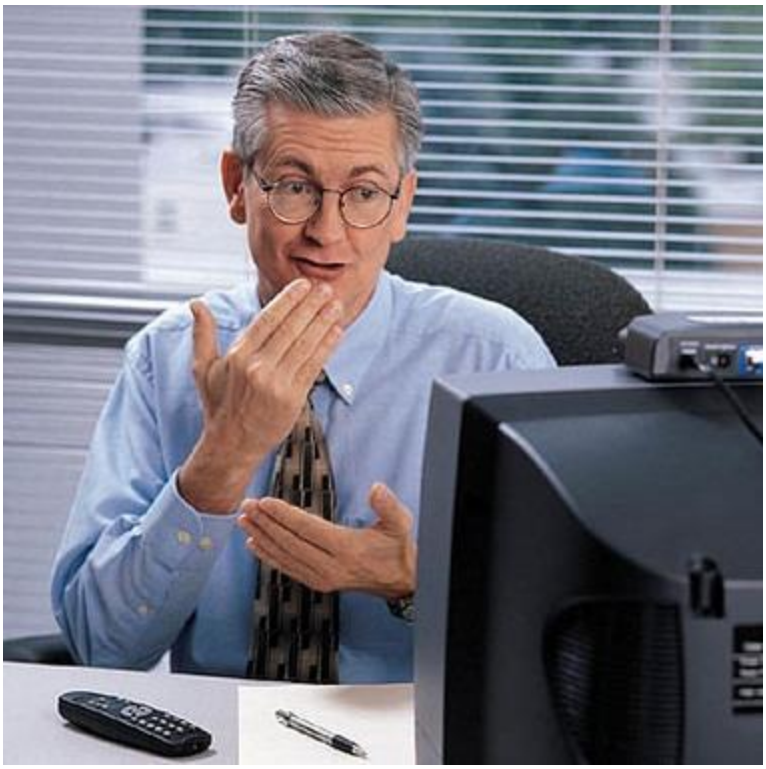

Figure 6 Hodson shown using the VRS, from The Salt Lake Tribune, July 14, 2004

This video relay service was created with a separate TV receiving the output of its video in order to make it financially accessible to the general public but also to enable users in having remote control, a higher quality of video compression to upgrade video quality, as well as ease of use.

The technology became widely used at Deaf education centres, spreading to the Deaf, mute and hard-of-hearing community. VRS for the Deaf grew in the US due to easy access to high-speed Internet, higher quality videophones and sponsored VRS (Fitzgerald, 2003).

High-speed Internet connections, with a more approachable price-quality, were becoming more common; videotelephony followed suit. Video display and capture technology

also became cheaper, at last partially through Hodson's push towards accessible VRS and this process' consequences. Private videotelephony via webcam, software compression, a PC and broadband Internet was continuously becoming more affordable for all. Hardware has also improved in quality, while the prices were lowered. Freeware, such as MSN messenger, made software-based videoconferencing accessible.

Whereas VRS is considered as a support of communication between a Sign Language user and a speaking user, videoconferencing can be employed without third-party mediation between two Deaf users. All mobile phones that support the universal mobile telecommunications system networks can become videophones through the usage of its internal camera. Labelled 'smartphones', these phones can video call other users anywhere on the planet – as long as there is an internet connection.

Pew Research concluded that as of 2010, seven per cent of Americans had connected via a mobile video call (Carter, 2010). Mid 2010, there were 790 million UMTS users on 134 networks, existing in 59 countries ("Worldwide number of UMTS subscribers from 2007 to 2011 ", 2010), and in theory there is the same amount of potential videophone users. Smartphones can use Internet, both through cellular phone networks or Wi-Fi connections, to enable videotelephony with any other user.

2.4 Summary

This chapter showcases that technological artefacts are not created linearly, as multiple possible designs for videophones were invented, created, disregarded or further developed. The design that finally resulted from this process could have been different (Klein & Kleinman, 2002). The first videotelephony was created in the form of videophones, dating back to the 1927 trial phase of AT&T, and conceptually dating back to George Marrier's conceptual drawings (as was depicted in Figure 2, page 22). Late 1930, the central hubs of videophone connections in Europe

existed in the form of post offices, initiating a videophone service for user-to-user communication. Currently, smartphones and videophones are mostly employed for user-to-user connections.

AT&T, which developed their Picturephone service in the ‘70s, enabled users to connect via videoconferencing for the first time since WWII. Short distance-communication was covered through analogue transmissions, but converted to digital signals for longer distances. Nowadays, digital ISDN and IP transmission modes is used by corporations in order to transmit the larger quantity of data generated by high-end microphones and cameras.

For the first time, Deaf people have found exciting new possibilities to communicate with one another over long distances synchronously. This brought opportunities for further involvement and participation in society. However, in all these cases, the dichotomy between producers and users maintains – something that Edgerton (1999) states is no longer adequate. Current research shows the need to move beyond the equation of 'user' with 'consumer’ since videotelephony can be employed in different ways according to the needs, interests and purpose it has for its users (Ensmenger, 2018; Van Dijck & Nieborg, 2009).

The next chapter will showcase inequality towards non-normative people as a deep-rooted issue and videotelephony is not excluded from this. This chapter shows time-appropriate ‘state of the art’ videotelephony, usable only to those with access to sufficient funds. Most Deaf people were – and are – not so fortunate and experience inequality in some form in their lives. To understand what inequality means, Chapter 3 focusses on defining and exploring inequality for non-normative people, with a focus on Deaf people. A solution to inequality and the traditional dichotomy between producers could be found in inclusive design methods.

Chapter 3

Inequality and inclusive design

Introduction

In recent years, inviting minority groups to co-design technology has become more recognized as a design method (Blume, Galis, & Pineda, 2013; Galis, 2011; Heylighen & Bianchin, 2013). Several established research journals have now given a place to ‘disability design’, going further than mere designing for disabled people and instead focusing on the benefits of designing with (Bieling, 2010; Brodersen & Lindegaard, 2016; Rajapakse, 2018; Waller). In this chapter, two examples are given regarding the process of researchers, designers, experts and minority groups co-designing, or at least, furthering progress. The first study is based on Rabeharisoa & Callon (2004) in which French citizens with muscle dysmorphia create new research based on their lay-knowledge. Activism and inclusivity of all types of knowledge are the basis of this movement. This case showcases how minorities can influence societal norm. Moreover, this presents a basis of comparison for co-design, and inclusive design procedures are created by and for Deaf South Africans. The study by Rabeharisoa & Callon (2004) will provide insight into how the community-based co-design of videotelephony for Deaf people in South Africa follows along or differs from a specific pattern.

3.1 Inequality

Inequality has come in several shapes and forms and has been defined as such as well. The ethicist's perspective on inequality is that the *"people's demand for equality - whether of rights, resources, opportunity, welfare, capabilities - is, at bottom, a demand to be accorded the equal dignity due to all"* (Kittay, 2005, p. 97). Economic inequalities are shown explicitly by people's different positions within the commercial distribution, i.e. in their wealth, income, and pay. People's economic positions are related to other characteristics, e.g. ethnicity, disabilities and gender (Gurría, 2011). Closely linked to economic inequality is social inequality, which is the perspective most useful for this thesis as it implies the lack of equality of access to opportunity (Caves, 2005). These opportunities consist of social rights, including access to the labour market, health care, a source of income, education, freedom of speech, political representation, and participation (Hunt, 2017, p. 7). Economic inequality is an oft studied type of social inequality, frequently described as the unequal distribution of income or wealth (Guidetti & Rehbein, 2014).

The rejection of equality for women and people of dark skin may come to mind first of all. This inequality was based on 'natural' inequality and an inherent difference from Caucasian males. This exclusion following from this inequality has since been recognised as subjective, and any alleged inferiority is now viewed as resulting from imposed political and social inequality (Bertrand & Mullainathan, 2004; M'charek & van Oorschot, 2019). It was only that *"until recently, impairment alone has seemed indubitably a 'natural' source of inequality, quite unlike the arbitrary social disadvantage of class, gender, or race"* (Kittay, 2005, p. 97). Exclusion because of disabilities spans over race and skin colour. Humans are not limited to appearing in one shape or size; the same goes in terms of (in)capacities and (dis)abilities (Kittay, 2005). Some of these factors are scattered over the years, whereas others are allotted differently

by birth or by circumstance. Kittay (2005, p. 97) states that disabled people *"have convincingly argued that disability is itself a social, not a natural, category"* of inequality.

The disability that is related to bodily and sensory impairment stems from social norms privileging specific bodies and minds compared to others (Kittay, 2005). Due to this notion, lives are constructed wherein specific capacities are allowed to flourish in some humans, but not in others. However, flourishing of capacities is possible in everyone. As Kittay (2005, p. 98) says: *"Given adequate support and access, people with disabilities can live lives that are as full and as worthy as those whose bodies are not similarly impaired"*. The social model of disability (Brennan, 2003), which was mentioned on page 6 of this thesis, reiterates how disability comes out of social prejudice combined with a lack of social impartiality towards the needs of various capabilities and physical demands (Kittay, 2005).

People with sensory impairments, those with non-normative bodies, people with mild retardation, as well as people with a variant on the scale of autism spectrum disorder have all shown their capability to uphold *"self-sustaining employment, to live on their own, to have families, to exhibit leadership and to produce objects of artistic merit. In short to live 'normal' lives"* (Kittay, 2005, p. 98).

It must be noted how human (non)-normative bodies even become classified and categorized as such. This is done through scrutinizing medical knowledge (Foucault, 1977). Conrad & Barker (2010, p. 69) showcased this as follows: *"Expert knowledge about human 'normality' and 'abnormality', which is not objective, is the principal form of power in modern societies. […] Foucault stressed how medical discourse constructs knowledge about the body, including disease."* A disease's ontology has become the result of medical discourse (Turner, 1995). Vice versa, people's behaviours are influenced through medical discourse, impacting subjective experiences of embodiment, the shaping of identities, legitimating interventions within the medical contexts, and create further inequality (Foucault, 1975, 1977)

There is a conceptual differentiation between disease and illness, in the way of respectively being the biological condition and social definition (Eisenberg, 1977). Not all illnesses are treated equally, with some having stigmas, some considered disabilities, and some contested (Conrad & Barker, 2010). What is essential for Conrad & Barker (2010, p. 69) regarding these differentiations is "*that they exist for social rather than purely biological reasons. These cultural meanings have an impact on the way illness is experienced, how illness is depicted, the social response to illness, and what policies are created concerning illness"*.

Nussbaum (2002) puts a capabilities' list essential for living a dignified life. The capabilities of humans, and what it means to be technologically supported in these capabilities is the framework for the argument in this thesis. How non-normative people are capable, supported through additional means to increase capabilities, and inherent value they have in societal contexts, the chance to participate in society – it is this that what should be focussed on.

Nussbaum's capability list is created to be seen as a number of rights intrinsically part of being human. This list is diverse. Included are actions such as exercising sense, our imagination, play, engaging politically, involving ourselves with the non-human world, sexual fulfilment, affiliation, and the integrity of our body (Nussbaum, 2002). Humans do other humans an injustice when they are not given full access to what is necessary for them to obtain the abovementioned capabilities. In addition to that, Nussbaum's list of capabilities can serve as a source of humans claiming space for their dignity. That is to say: *"It is because humans can have these capabilities that their life is a life worthy of distinctively human dignity"* (Kittay, 2005, p. 108). The entire build-up of this argumentation can be summarized by stating that it is the task of a just society to enable all its members in developing the capabilities they inherently should have.

Studies focussing on disability consider the potential for a life well lived in what Mauldin (2014, p. 1) calls *"non-normative bodies and pushing back against the imperative that bodies should conform to normative ideas in the first place.[…] For example, living well could mean having access to transportation and education, being employed, being able to live in the community and place of their choice"*. In recent years, the legislature regarding the rights of disabled people was created. In the US, it is the Disabilities Act (ADA), enacted in July 1990, which states that *"The Nation's proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic self-sufficiency for such individuals"* (ADA, 1991, § 12101 (a)(7)). Despite creating legal assurances in individual democratic nations, activism is needed to argue for implementation of policies to ensure equal dignity for all humans regardless of their disability or ability (Kittay, 2005).

Not only in the United States but in all other nations as well, a vast number of people with disabilities are unable to access basic structural needs. This is not due to a disability, but rather a consequence of things like the way that social systems are organized and created (Mauldin, 2014).

If all human beings are deserving of equal dignity (Kittay, 2005), equal economic distribution (Caves, 2005) and equal opportunity (Guidetti & Rehbein, 2014); whether under it being a human rights law (Peiris, 2018), creation of themselves (Della Mirandola, 2012), an innate ability of acting and becoming an autonomous moral being (Kant, 2013), or being a part of societies with fair social co-operation in the form of a member with self-respect (Rawls, 2009), then those with a disability have showcased their right for equal dignity in full (Kittay, 2005). As Nussbaum (2002) showed, the capabilities of humans should be the deciding factor for inclusion. Technological enhancing or supporting of these capabilities should not be

undermined – describing inequality is not enough, something should happen as well. This thesis will focus on social and economic inequality.

The focus of this thesis is on the co-design of videotelephony with Deaf people, the underlying mechanisms for social and economic inequality against the Deaf community, how their involvement changed the product, and how this works to alleviate social and economic inequality. We must, therefore, gain insight on technological development for those with non-normative bodies.

In some cases, technology is essential in facilitating the imperative to live well in a non-normative body. The use of technology, however, most often starts with problematizing people's body, rather than focussing on the problems created in and through society and societal norms. Such a line of reasoning goes against the foundational tenets of disability studies (Mauldin, 2014). This way of design and usage of technology, with the body being presented as the problem, is used to critique *"the ethos of technology and medicine"* (Mauldin, 2014, p. 2) that Colligan (2004) questioned as "the moral imperative to fix" (Colligan, 2004, p. 46), meaning that there is a correlation between 1) intervention through medical and scientific means on bodies (p. 49), 2) the consequent moral imperative perceived to 'fix' those non-normative bodies (p. 46), and 3) the lack of accommodating and creating space for those who have disabilities, which in turn means that those with non-normative bodies are systemically excluded and discriminated (p. 47).

In short, our societies are getting enamoured with technological possibilities aiming to fix non-normative bodies rather than reforming societal values and social structures that exclude people with disabilities (Colligan, 2004, p. 85). Most importantly, it has to be noted that the 'fix' of Deaf people in the form of cochlear implants does not work. Brennan (2003) states that those born to Deaf parents usually amass their respective sign language parallel to their hearing peers learning the spoken word.

However, comparatively there is a marginal group of deaf children born in a family that hears that grow up learning Basic Sign Language, even when deaf children learn their respective sign language as quickly as hearing people learn a spoken language (Brennan, 2003). As Brennan (2003, p. 672) states: *"This results in a situation whereby deaf children exposed only to English are typically delayed in their acquisition of the language. Even those children who are given cochlear implants very early are recognised, even by the proponents of implantation, to be delayed in their development of spoken English"*.

A concise literature review of and subsequent argumentation regarding inequality was needed to frame this study's scope. It has become clear that inequality is a concept with multiple perspectives, and solutions can be vast and different as well. Deaf people encounter inequality in their lives, regardless of where they live, in some measure – whether it be in rights, opportunity, social status or in some other form. In recent years, those with non-normative bodies have gained traction in mobilising and creating legal rights supposed to create equality for all. Design of technology has followed this movement. In the following section, the 'moral imperative to fix', mentioned on this page, has a top-down procedure of design. This will be contrasted in the following section with inclusive design methods wherein end-users are given more say in the matter.

3.2 Design

Design is – ideally – a dialogic or deliberative enterprise that involves designers as well as the people they design for (Heylighen & Bianchin, 2013). However, the question designers and scholars alike should first ask is: *"Whose knowledge counts?"* (Haraway, 1988). For Haraway, this alluded to a shift in a white men-dominant viewpoint, towards inclusive, female and other minorities' ways of thinking and knowing. For designing technologies, the same method of reasoning can be applied. In other words, as Heylighen and Bianchin (2013, p. 93) put it, the

questions to be asked are: *"Who is to decide the standards? Should the norms of anything be determined by the best knower or is it to be decided by the people, however ignorant they might be?"* Designers themselves cannot, or at least up to a certain point, judge for themselves what is right without taking into account other people's point of view. Laypeople's point of views should not be arbitrary and can thus be questioned in respect of its appropriateness. As Heylighen & Bianchin (2013, p. 106) state: *"People can go wrong in interpreting their own response"*.

What is relevant in this sketch Heylighen and Bianchin (2013) present, is that the format of 'good design' is available and subjective for everyone. Others claim that domain-specific knowledge and general process knowledge is necessary for creativity; subsequently for design as well (Christiaans & Venselaar, 2005). Heylighen and Bianchin (2013) go against this argumentation by stating that good design can be created through deliberative collaboration of designers and lay-people discussing relevant issues. Therefore, inclusivity is not depicted solely as a matter of convergence of different perspectives.

On the contrary, it is in the definition of good design that there is cooperative integration of those different perspectives. Inclusive design means that the technology's creation stems from utilization of *"information and competences at the disposal of the designer and the people she designs for in qualified circumstances"* (Heylighen & Bianchin, 2013, p. 93), and not when merely the designer and consumer appreciate it (Blake & Tucker, 2006).

One key aspect of inclusive design is the engagement of diverse groups of people to work within the design process. Reed & Monk (2011, p. 295) argue that *"this objective can only be achieved through a move from a view of inclusive design as solely concerned with individual capabilities to a view of inclusive design set within a social context"*.

One such method of knowledge production by Callon & Rabeharisoa (2003) is named *research in the wild*. This form of knowledge production focusses on the influencing of or

collaboration between experts and laypeople. Callon and Rabeharisoa (2003) observed that laypeople are being included more through consultation, participation, and public debate, thereby shifting the relations between said laypeople and experts. At the same time, there are two booby-traps when the relationship between technical and professional experts are addressed: the idea of lay-people's ignorance set against the argument of superiority of lay expertise in its greater realism (p. 196). To circumvent this, Callon and Rabeharisoa (2003) proposed adopting a symmetrical pose. Through a symmetrical perspective, knowledge of professional and technical experts, as well as that of lay-people *"are not contradictory but complementary"*, it is a *"mutual enrichment"* rather than a competition or substitution (Callon & Rabeharisoa, 2003, p. 196). When using a symmetrical perspective, no assumption about intrinsic difference between lay and professional and technical knowledge can be made.

This section shows that inclusive design can create a significant benefit to both the designers, as well as the intended-users. For this latter group, the benefits can become higher than the initial expectations. The skills needed to create new design through inclusivity means that the lay-participants develop skills not only to aid in the design process but to further their situation in life in general as well (Blake, Tucker, & Glaser, 2014). This is why inclusive design is relevant to explain in regards to the focal point of this study, which is a version of inclusive design, namely community-based co-design.

The following two sections showcase the principles of inclusive design, i.e. how the influence of minority groups can aid in the development of technology relevant or sometimes even sorely needed by these actants to live a full life with dignity.

3.3 Muscle dysmorphia

Scientific and medical knowledge used to be regarded as the realm wherein experts know all. The general public and patients would be merely passively imparted by this knowledge. There

has, however, been a shift in the realm of knowledge, and whose knowledge counts. The following case demonstrates Callon & Rabeharisoa's 'research in the wild. The case centres on how a French patient organisation actively began producing knowledge regarding the disease called muscular dysmorphia (MD). The following section gives an overview of how the AFM came into being, defines what emergent concerned groups are and exemplifies how lay-experts and minority groups can change their position within society through their initiative.

Emergent concerned groups can, if certain conditions are met, enforce new interaction between scientific research and political identities, when the subject of academic research and subsequent results are linked to the emergent group's place in the greater collective (Rabeharisoa & Callon, 2004). The case of MD patients, and the Association Française contreles myopathies (AFM) are an illustration of Rabeharisoa & Callon's (2004) emergent concerned group. It exemplifies how patients with MD reconstructed their individual and collective identities, i.e. altered the way they perceive themselves, their illness and their community. AFM's engagement towards scientific and technological research activities was intensive, which in turn enabled patients with MD to change their ontological status (Rabeharisoa & Callon, 2004).

A few families who had family members suffering from MD created the organization 'AFM' in the 1950s. During this period in time, those who had severe forms of MD were not regarded as being human. Testimonies exist in abundance (Barataud, 1992; de Kepper, 1988), with words such as *"errors of nature"* and monster. The individual was not at all seen as an human being, a person separate from the disease from which s/he was afflicted. As there was no professional community centred around this affliction, life as a person with MD became an ontological state which was defined as inherently being excluded from culture and society (Callon, 2006).

Few professionals and researchers invested time and energy in this disease. Because of that, there had been no cure nor research conducted, no causal relationships as a base to create solutions and no established facts; there were only questions and concerns. The lack of a professional organisation towards the research of MD resulted in parents of children with MD creating the AFM. In doing so, they changed the lives of their children and others afflicted forever. In 1950, MD patients were not recognised as human beings. In the late 1950s, they were MD patients, wherein they were still excluded from society. Since the 1980s, they are merely humans with a particular affliction that cripples their bodies and shortens their lifespan (Rabeharisoa & Callon, 1999). People with MD had won themselves the right of being seen as humans.

AFM is an innovative and vital player in France, specifically within the domain of medicine and science, and most notably in the domain of politic and economy (Rabeharisoa, 2006). Via their annually recurring TV programme, Le Téléthon, AFM is able to gather significant amounts of money: cumulatively they managed to gather €700 million in 27 years' time. Figure 7 depicts an advertisement for the 2019 television programme. About seventy per cent this money is dedicated to supporting biological and clinical research. AFM became a vital actants in genomic and genetic research due to these significant funds (Rabeharisoa & Callon, 1999).

Figure 7 Example of a Téléthon advertisement

In terms of technological support furthering the human genome sequencing project, AFM designed and financed the 'Généthon', a technology platform that has proven vital. Consequently, AFM's support towards creating and developing highly specialised teams regarding neuromuscular diseases has proven successful on an international scale. When comparing the progress of public research organizations, AFM has pushed the research agenda to venturing into new research areas, e.g. AFM's decision of moving the primary focus of research towards the area of gene therapies (Givernaud & Picard, 2001).

This decision was made because AFM's president at the time, Bernard Barataud, found that research regarding the human genome was not going fast enough. Tambourin (2005) states that this conclusion lead to the decision for AFM to invest in research focusing on more detailed knowledge of the human genome.

Due to the work of AFM, the world has changed for patients with MD. Disabilities and problems created by MD are now related to genomes that are flawed, which the research conducted by AFM's funding uncovered and characterized. The AFM's history suggests that, given the rights circumstances, emergent concerned groups can push innovation in a specific

directions, as well as imposing new ways of connecting scientific research with political debate. In AFM's case, they did this through creating a direct link between the problems found in research content and the subsequent research results to the role of people with MD in society. Additionally, AFM has been demonstrating the breadth of their influence via its influential position in the government of France in the form of launching a national program for the production of 'Genopoles'. AFM's contribution consists of various aspects, e.g. the donation of equipment and facilities through the Généthon (Tambourin, 2005).

AFM has financed clinical research, as well as creating a consulting network specifically catering to people with MD, thereby becoming more than a fund for research regarding genetics (Rabeharisoa, 2006). AFM assisted diffusion and popularization of genetic knowledge through technical publications for both laypeople and professionals and the Téléthon. The AFM has spread out from its primary focus of research and medicine, as it has become actively involved in the economic sector through its support of start-ups and industrial partnerships. The outlook of AFM has always been international: whenever it was unable to find allies or solutions in France, whether in the field of science or economics, AFM would look across borders. Finally, the AFM has contributed significantly in the area of disabilities (Winance, 2001), e.g. they helped in the design, creation, and implementing of new forms of assistance for disabled people (p. 495).

Uncertainties remain for those with MD, primarily on the prevention of diseases and the rapidity of uncovering new therapies. However, multiple successes reshaped the lives of people with MD (Callon & Rabeharisoa, 2008). It is now possible to *"define options and to elaborate strategies. Professional networks - researchers, doctors, occupational therapists, and care officers - have been established, and patients with their families have formed groups to work together. Neuromuscular diseases are finally on the list of those covered by Social Security. People suffering from them have gone from a situation of passive exclusion to one of*

active inclusion." (p. 235). AFM's history is an excellent example of the '*emergent concerned group'* Rabeharisoa and Callon (2004) described.

Alluding to a 'concerned' group is a way of accentuating the reality of humans feeling bound by a matter of concern experienced by all that are part of this group, while being expressed with (for them) familiar words. Characterizing groups as 'emergent' means there is an inherent implication that nothing is stable: the group identity and member identity is problematic. In the case of AFM there was even a radical ontological question regarding the people with MD being considered 'human'. The interests, aims and goals important to emergent groups are undeveloped, dynamic, and, most importantly, defined by third parties, in AFM's case, parents and friends. The cause of the creation of an emergent group is not identity or interests, rather identity and interests spring forth from the action of forming an emergent group (Callon & Law, 1982).

Understanding how AFM created its identity came from focussing on and analysing *"patients' and their families' engagement in the research undertaking that was to spawn new entities: the genomes responsible for the disease"* (Callon, 2007, p. 236). These genomes supported the development of a specific identity and indirectly gave patients and their families the financial and rhetorical means that were necessary to defend that identity publically. The motions and actions of emergent concerned groups are not understandable without the nonhumans-actants that arise through their investigation (Rabeharisoa, 2006).

Similar to the videotelephony for Deaf people case, the social context in which the patient is situated, as well as the patient themselves should change. A double movement, the first via realm of scientific research, and the second via political advocacy enabled this. Rabeharisoa Callon (2008, p. 236) state that to understand *"how emergent concerned groups are sometimes capable of constructing stabilized identities, goals, interests, or preferences,*

it is necessary to examine all the investigations, inquiries, and research studies that these groups undertake to find solutions to the problems they face".

Using this perspective, the case of AFM is an excellent example, since the strategy they want to employ was stated from the beginning. Rabeharisoa and Callon (2004) iterate that this is most likely because of the radical character of the concern for AFM: being recognised as fully developed human beings. To construe this approach AFM assigned money early on out to two courses of action, namely the way to a cure and the line to citizenship. The first path directed AFM to focus on proteins, stem cells, and genes. The second path propelled AFM in the *"fight for the recognition of all handicapped people's rights and to propose appropriate compensatory sociotechnical prosthetic devices"* (Rabeharisoa & Callon, 2008, p. 236). These double courses of action met each other continuously and eventually aided in constructing a genetic identity which eventually shifted into 'genetic citizenship' (Callon & Rabeharisoa, 2008; Heath, Rapp, & Taussig, 2004; Rose & Novas, 2005). All due to laypeople taking matters in their own hands.

There are aspects to this case study that are similar to the focal point of this study: laypeople becoming experts, those 'inflicted' wanting to change the narrative about them, flattening the curve of inequality towards those with non-normative bodies, ensuring that their problems get recognised by the government and legal rights were created. There are also notable differences: videotelephony was not created by Deaf people, though some aspects such as Hossler (2017) shows on p. 36 were tweaked and improved through the involvement of the American Deaf community. The focal case study of community-based co-design in South Africa is not created by the Deaf community but instead came into being through academia. Money was not generated, but rather, it was awarded through grants by the EU, Canada, and telecommunications organisations. These differences showcase that videotelephony specifically designed for and by Deaf people are not yet as commercialized and operationalized

as the results of the AFM. The following section will lay out the case study of community-based co-design.

3.4 Co-design with Deaf communities

When focusing on emergent concerned groups, the case of Deaf communities in various countries arises. Similar to the case of patients with MD, Deaf people are, more often than not, passively excluded from society. Through organising themselves, Deaf people are putting their problems on political agendas. The analysis of co-design of technology can unearth the exclusion and discrimination that Deaf people face. The following section focusses on the South African Deaf community and their participation in community-based co-design of videotelephony.

Telephony for the Deaf always consists of some form of videotelephony; there is no other way. Deaf people nearly exclusively communicate through visual cues and signs and have, therefore, different needs when it comes to videotelephony than Hearing users (Blake, Tucker, Glaser, & Freudenthal, 2011). Rather than looking at long-term goals, the case-study by Blake et al. (2011) shows the incorporation of societal values that in turn determine the current needs of Deaf South-Africans, e.g. the need for increased skills in literacy, as well as digitally.

Multiple prototypes of video chat, both synchronous and asynchronous, browser-based and mobile video centred, were designed and evaluated. The aim of this research was to *"identify an acceptable video communication technology for Deaf people"* which they *"would like to use in their day-to-day life"* (p. 46). Indirectly, they hope that the *South African government* would realise that technology and the low cost of ICT could as easily replace the need for human interpreters, who are not large in number and therefore costly (p. 46).

Blake et al. (2011) designed and tested various ways of telecommunication for Deaf people, both in regards to communication between two Deaf people, as well as one hearing and the other being Deaf. During the time of their research, they built up the amount of community-based co-design, starting from using an interpreter to talk to the Deaf community, and ending with the research team learning sign-language – with an interpreter as a back-up – and active participating of the Deaf community in the progress of the design.

There were video quality-problems with when mobile phones used real-time video communication. Alternatively, text-based communication on mobile phones worked well enough, but *"results from other research studies show that Deaf people prefer using sign language to communicate with each other rather than text"* (p.35). One part of the project focussed on the implementation of an interface based on gestures for asynchronous video communication. The mobile phone would record, cancel or send a video based on gestures made by the person – therefore negating the need to use a mouse or keyboard of a laptop. Users liked this way of interacting, as they thought it created ease of use for communicating using video. There were, however, video quality problems when users signed too fast.

When looking at synchronous video communication, there were already some options available during the period of 2004-2011 (p.4). Though Skype was available, South-African Deaf people preferred using Camfrog. Skype, at that time, had chosen quality of audio over the quality of the video, rendering it useless to Deaf people. Moreover, Camfrog was internationally known as a video chat service used by Deaf people. This image of the video chat ensured that Deaf people would instead use the one other Deaf people used primarily. Privacy was an issue when using Camfrog, for those who worried about this, namely that it was an open-access programme (p. 33).

During the latter part of their research, between 2008 and 2011, Blake et al. (2011, p. 2) their concept of 'community-based co-design' was redesigned through "fusing action research,

industrial design approaches, education and other societal measures". User experience was a vital element of this approach. Before the active designing of new technology started, Blake et al. (2011) reflected on an earlier study which focusses on the design of a telecommunication solution to enable Deaf people to communicate (Glaser, 2000). A thorough investigation was, therefore, first conducted in the form of knowing whether the right question was being asked; a broad, general perspective was used to study the communication problems of the Deaf community. A literature review on what Deafness in South Africa entails, field research about the South African context, context mapping with generative tools, cultural probes, and analysis of data were all conducted. As the designer was Dutch, the cultural examinations and ethnography were needed for him to gain insight of the South African context. The literature review was necessary because of this as well.

Blake et al. (2011) found that *"there is a need for telecommunication between Deaf people, but that most of the problems pointed out had to do with communicating with hearing people"* (p. 43). Most problems uncovered were related to being Deaf, but it was society specific as well. Two examples given were regarding bus taxi's that would not stop at the correct place, and doctors who were wearing masks before their mouth which lead to Deaf people not being able to understand the facial expressions. An asynchronous, video recording and conversion system were designed to help Deaf people and hearing people communicate with one another in the context of a pharmacy. The interface would translate South African Sign Language (SASL) to the English text, and back again.

What should be noted when comparing these cases, is that those organising to further research on MD have been doing so longer than the actors in the Deaf co-design case. This shows in the effectiveness of AFM, and how Deaf co-design is in the beginning steps of implementing its videotelephony telephony on a regional basis in South Africa.

What is most interesting to note is the fact that AFM started everything on its own. There is no mention of co-production of knowledge or medicine in this case-study, whereas this *is* the case of co-design. Co-production and inclusive design are inherent to this. The gradation of co-production varies, with little influence of the Deaf community in the beginning and squaring out to a balance to the point they are at right now. What can be learned from the case of AFM is how to professionalise and commercialise a cause, but even greater is the lesson drawn to get society moving towards social inclusion of those excluded.

Comparing this case-study with the MD-case mentioned in chapter 3.3, a table summarizing and relating the two cases mentioned is depicted in Table 2, on p. 63.

Table 2 Comparison of Muscle dysmorphia-case to Deaf co-design within a technoscience context

	Muscle dysmorphia	*Deaf videotelephony*
Was there some form of organisation?	Through the organisation of family members of those with MD, as well as MD-patients: **AFM**	There are **multiple** international **Deaf organisations**, as well as national and regional communities in South Africa.
Was there lay-knowledge?	AFM has 'lay-knowledge', filling the niche of knowledge on MD and thereby becoming the experts.	Deaf communities know the problems that Deaf people face daily through **societal inequality**.
What is the role of large labs?	AFM dictated what research was to be conducted; **they were in the power position.**	Most notably in the beginning: **using the opinions and knowledge** of Deaf people **to further their design for these participants.**
What is the role of traditional academia?	**Traditional academia was not interested in this niche** as there was little to no funding available for it. There was little traditional expertise. Eventually started looking into MD as well, after AFM created notoriety and awareness to this research subject.	**Kick-starting the project of creating new telecommunication technologies** to aid Deaf people in communicating within a hearing world. Eventually creating a research method where Deaf people are co-designing with scholars to create videotelephony applications.
Did social structure change?	Those with MD were recognised as being more than their diagnosis. **Inequality towards MD-patients was reduced – they became full citizens.**	The Deaf community gained **power through their improvement in digital skills and literacy**. One community decided to stop collaborating with the scholars as they could do it on their own. **Societal structure was not altered.**
To what extent do the experiments, investigations, and insights shape views of 'nature' and human bodies	Generated a new perspective of those who have MD. They became people who had a genetic disposition, instead of merely suffering from MD.	Not mentioned
To what extent do these insights apprise technological innovation?	New ways of gene therapy, **creation of needs-based innovation**.	Through the involvement of Deaf people, their insights are shared with scholars who create technological innovation in tandem with this Deaf community.
Did relations change?	Those with MD are no longer excluded from society. They managed to take action and generate knowledge and attention, thereby shifting the power-relationship. **Inequality was lifted**.	From being dependent on the scholars due to low literacy and digital skills, the Deaf participants improved this skill-set through the aid of scholars, thereby becoming independent of said scholars. Relations changed until equality was more or less created between these two groups. **Societal inequality persists**.

This table shows that societal and economic inequality towards people with MD was lifted – through their actions in terms of research, funding for their cause and creating public awareness. Traditional academia was not a part of this movement, at least in the beginning. The creation of new technological tools and treatments is in line with Nussbaum's (2002) idea of human capabilities, and technological aid to these capabilities.

Reflecting on the work done in South Africa, there are similarities and differences to AFM. Traditional academia was and is a significant influence in the push to technological innovation for Deaf people. Societal structure has not yet been altered and inequality persists in South Africa, especially for Deaf people. A prominent commonality consists of Deaf people as well as lay-knowledge gaining in importance in current studies, creating technological aids to showcase their capabilities in society.

3.5 Summary

Inequality is damaging to individuals and society as a whole. The capabilities approach shows how technological development can create a more just society, wherein in non-normative bodies are treated equally. The case study of AFM and Co-design in South Africa shows how minorities with lay-knowledge can push technological development. In chapter 4, Deafness and inequality are discussed in the context of South Africa. Social and economic inequality is analysed to underscore the need for change. Co-designing new video telephony applications could advance Deaf people's situation, similarly how AFM's Téléthon helped further French citizens with MD's cause.

Chapter 4

Videotelephony and Deaf users

Introduction

The context concerning Deaf community-based co-design in South Africa is given through a literature study, as well as provided insight by Dr W. Tucker of University of Western Cape, and P. Chininthorn, in affiliation with BANG and TU Delft. The case study mentioned in chapter 3.4 will be the main focus of this research, as well as Chininthorn et al. (2016).

Though the research question guiding this thesis consists of how videotelephony changed due to Deaf co-design, we must first build upon the context of co-design. In other words: why are South African Deaf communities working on designing videotelephony. The answer lies in the social and economic inequality that Deaf people face in some gradation all over the world. Because the focal case study in this thesis is based in South Africa, the South African context must be presented in which this type of co-design of videotelephony came into being.

To do so, chapter 4.1 focusses on Deafness and inequality in South Africa, with specific attention on how the lack of facilities that support communication through South African sign language (SASL) generates this inequality for Deaf people. Furthermore, Deafness and poverty are analysed as this is one of the main catalysts for the technological need that created the case study of co-design of videotelephony with Deaf communities. Chapter 4.2 will focus on community-based co-design. Nussbaum's capability approach showed that technological support would enable societal participation for all. This framework is employed by the researchers working with Deaf people to ensure academic and lay-knowledge meet and create

together. Before that would happen, several phases happened. Using ANT as a way of interpretation, the four moments of translation are described after which the three phases of the community-based co-design approach went through are discussed. The role of Deaf communities and the results of their studies are presented.

4.1 Deafness in South Africa

This analysis must begin by focussing on South African Sign Language (SASL), as it is because of a barrier in communication that inequality arises for those who are unable to hear. As stated in the introduction, there is a distinction between Deaf (capital 'd') entails the people that are a member of a minority group, sharing a language and culture different from the dominant group, which uses sign language as their first language. In contrast, Chininthorn et al. (2016, p. 1) states that *"Deaf with a small 'd' […] denotes a person with hearing loss"*. Those who are Deaf, and therefore use signed language for most of their interaction with the world, experience discrimination regarding the access of information in the majority hearing society (Heap & Morgans, 2006).

The South African National Council for the Deaf changed to the Deaf Federation of South Africa (DeafSA) (Jordaan & Chetty, 2013), resulting in profound changes in policy for those who are Deaf in South Africa. Examples are how a single sign language, the aforementioned SASL, was designed, created and adopted to substitute the multiple dialect variants, as well as the promotion of sign language. Deaf people expected that societal norms would change towards them, where they would be accorded equal dignity and reciprocal respect. Progress has, however, been slow.

Signed languages differ in structure when compared to spoken languages and can therefore not be translated word-for-word (Stokoe Jr, 2005). Translation is, in this case, always interpretation – miscommunication happens quickly, and, social barriers are intrinsically

formed. However, Deaf people can communicate through SASL. Studies have shown that if signed language is accessible to all, rich and poor, then Deaf people are equally as able as hearing people (Groce, 1985; Heap, 2003; Washabaugh, 1986).

Within public services and businesses there are substantial impediments to communication. Members of the Deaf community struggle daily for equal access in public sectors, e.g. education, water, health care, food, social security, and legal services (Heap & Morgans., 2006, p. 139). In terms of statistical values, DeafSA *"has estimated at least 70 per cent of Deaf people are unemployed, 40 per cent maintain subsistence levels lower than that of their hearing counterparts, and up to 68 per cent live in informal housing settlements"* (Heap & Morgans, 2006, p. 139)

The basis of inequality can be already be found in the educational context. Various South African places of education for Deaf people use different SASL dialects , even though SASL should unify the Deaf in South Africa. Several deaf schools discourage or do not even teach any sign language (Aarons, 1999). Chininthorn et al. (2016) states that SASL being a part of schools' curriculum, was not given approval for teaching at deaf schools until 2012[1]. Because of this, Deaf children who went to school before 2012 learned signed language from their peers (Aarons & Glaser, 2002). Dialects developed because of this, which were passed on throughout all the different parts of South Africa, spanning multiple generations (Aarons & Glaser, 2002). As long as these dialects exist, there is no uniform method of communicating with all South African Deaf people.

Moreover, it left a significant percentage of Deaf people bereft of education. Due to only fourteen per cent of teachers at Deaf schools being able to sign fluently, multiple subjects were untaught in SASL (du Bruyn, Southey, & Viljoen, 2008). These unnecessary barriers ensured

[1] Department of Basic Education Republic of South Africa. South African schools act, 1996 (Act No.84 of 1996): approval of the amendments to the regulations pertaining to the national curriculum statement grade R12. gov.za. 2014. URL: http://www.gov.za/sites/www.gov.za/files/38225_gon913.pdf

that Deaf school leavers have, on average, the same skill for reading and writing as nine and ten year olds (Aarons & Akach, 1998). Subsequently, 75 per cent of Deaf adults in South Africa are functional illiterates, and 70 per cent of the Deaf community has no job ("Nelson Mandela Bay. Deaf awareness brochure," 2012). Compared to the entirety of the nation, the disservice done to Deaf people becomes clear: South Africa's cumulative literacy rate was nearly 95 per cent in 2015 (Plecher, 2019). Because of this, there is great inequality between those who can hear and those who cannot, leading to those who cannot hear without a job, education and possibilities to advance.

South African parliament employs sign language, but the way words for the same concept are signed out differs per SASL interpreter. This means that if the interpreter speaks a different dialect than the recipient, there will be miscommunication. When faced with a crisis, miscommunication can create potentially harmful situations for those who are less-informed.

An option to negate miscommunication and inequality of access and opportunity can be found in SASL interpreters. However, these are not great in number. In 2004, only four interpreters were accredited by DeafSA. Between fifteen and twenty interpreters were active without any training or accreditation. The largest group consisted of children or parents with Deaf relatives, i.e. the grassroots interpreters who were scheduled for formal training. Those were all the interpreters available for a country with 57,7 million citizens, of which between 500.000 to 1.5 million citizens use SASL (Heap & Morgans, 2006). Table 3 summarises the ratio of interpreter to SASL users, as illustrated by Heap & Morgans (2006, p. 140).

Table 3 SASL interpreters in South Africa, by category, number and by the ratio of interpreters to SASL users (Heap & Morgans, 2006, p. 140)

Category	Number	Ratio of interpreters to SASL users 500 000 (low estimate)	Ratio of interpreters to SASL users 1.5 million (high estimate)
Professional based on accreditation by the South African Translators' Institute	4	1: 125 000	1: 375 000
Professional on the basis of SASL fluency, experience and competence	15-20	1: 33 333 for 15 1: 25 000 for 20	1: 100 000 for 15 1: 75 000 for 20
'Grassroots' interpreters Children of Deaf parents and teachers of the Deaf	40 selected but awaiting training that was due in 2004	1: 12 500	1: 37 500

By 2011, eighty-four SASL were registered by DeafSA (*Policy on the Provision and Regulation of South African Sign Language Interpreters*, 2011). This included forty-three untrained, thirty-one level 1 interpreters (completing 240 hours interpreter training), ten level 2 interpreters (having spent an additional 480 hours of interpreter training). What must be noted, is that SASL interpreters can request official accreditation without completion of formal training (*Policy on the Provision and Regulation of South African Sign Language Interpreters*, 2011). Because of the cost and limited availability, trained and accredited SASL interpreters are insufficiently able cater to the needs of Deaf South Africans adequately.

Relay interpreters are a different category, usually found in contexts in which the signer who can hear is unfamiliar with the SASL dialect that the Deaf person uses (Heap & Morgans, 2006; Morgan, 2001). In cases such as these, a third-party Deaf person familiar with both the dialect of the client as well as the interpreter will act as a relay interpreter. Interpreter services are costly, though, although negotiation of the fee is possible. At the time of writing 1 Rand converts to €0,0581. DeafSA specifies a cost of R120 per hour (€6,90) during standard office hours, and R150 per hour (€8,70) deviating from those standard hours. The minimum cost for interpretation service is R500 (€29,-) (Heap & Morgans, 2006, p. 140). In other words, *"one*

hour of interpreting in the middle of a week day morning for a clinic or doctor's appointment could cost R500 and more" (Heap and Morgans, 2006, p. 140).

To put this in perspective, it was only as of January 1st, 2019 that South Africa's national minimum wage went into effect. The legislation stipulates a *minimum* national rate of R20 per hour, or R500 per month, depending on the number of hours worked (Omarjee, 2019). This entails that, if a Deaf person were to work at the best possible minimum wage, they would have to spend their entire month's salary on affording an interpreter to get access to health care – a full month's work because their first language is not accessible for free.

Economic inequality

The question becomes whether for all Deaf people can afford these interpretation services. The 70% unemployment for uneducated people rate says no. To put the economic inequality into perspective, the following section interprets statistics regarding poverty. South Africa's official national poverty lines are divided into three categories, shown in Table 4 wherein the amount of Rand per person per month is also depicted (StatsSA, 2019).

Table 3 South Africa's official national poverty lines (2019)

Poverty line	Rand per person per month
Food poverty line	R561
Lower-bound poverty line	R810
Upper-bound poverty line	R1,227

The three categories, as defined by StatsSA (2019) are:

1. The food poverty line, referring *"to the amount of money that an individual will need to afford the minimum required daily energy intake"*;
2. The lower-bound poverty line, referring *" to the food poverty line plus the average amount derived from non-food items of households whose total expenditure is equal to the food poverty line"*; and
3. The upper-bound poverty line, referring *"to the food poverty line plus the average amount derived from non-food items of households whose food expenditure is equal to the food poverty line"*.

Around half of the population (55.5%) is living underneath the upper-bound poverty line, and around a quarter of the population (25.2%) is living underneath the food poverty line (*Household Affordability Index*, 2020).

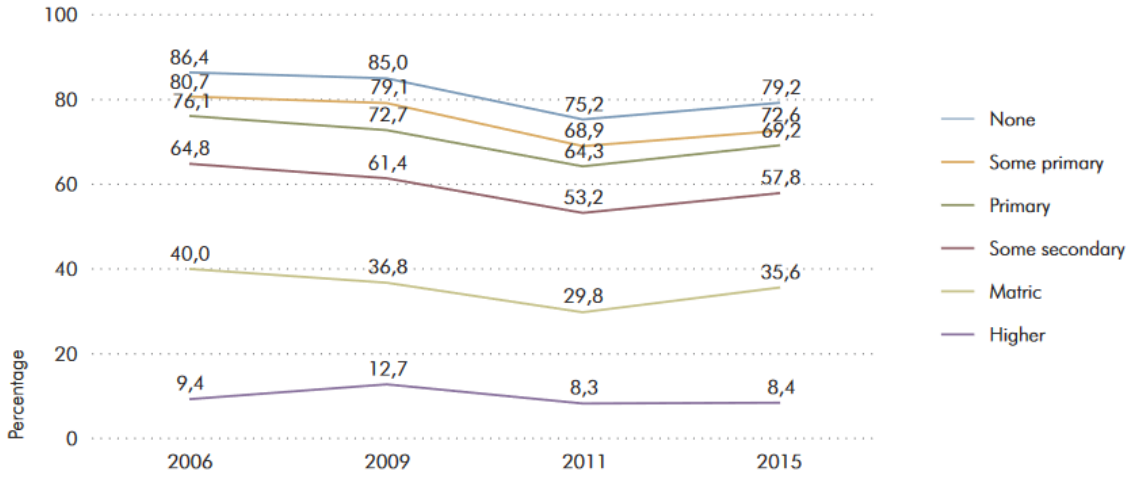

Figure 8 Poverty headcount by educational level attained for individuals aged 18 and older (UBPL) (2006, 2009, 2011 and 2015)

Figure 8 illustrates that nearly eighty per cent of uneducated South African adults lives in poverty (Lehohla, 2017, p. 15). There is a positive correlation between poverty and education, as demonstrated in Figure 8, which is essential to note as p. 57 revealed that 75% of Deaf people in South Africa did not receive many years of formal education and became functionally illiterate. According to Lehohla (2017), there is a correlation between the educational level of a person and the likelihood of employment within the formal work setting, as well as less proneness to falling under the poverty lines (Lehohla, 2017).

This societal and economic context is necessary to understand the need for technological intervention of some kind. The following section will spread out the analysis of how technological empowerment through co-design of videotelephony came into being for the South African Deaf community.

4.2 Community-based co-design

The objective of this study is the examination of progressive development of new social relationships by way of the constitution of a technology community-based co-design. Community-based entails inclusion of the excluded in the design process, making it co-design. The phases towards Deaf telecommunication tools are grouped around the following:

1. The first phase is about creating a technology base, wherein participants were dependent on the researchers. Communication tools developed here were mostly text to speech, as the development of the internet and digital tools was still in its infant phase.
2. The second phase is a community action research, wherein the participants and researchers were more or less independent from one another. Videotelephony was one form of digital communication tools, though the uptake for this was not as the research team expected.
3. The third phase, which is the current state of research and design, is community-based co-design, wherein participants and researchers are equal. The digital video relay tool was created by both teams. The uptake by the Deaf community was high.

Each subsequent phase of the research and design process that would follow applied, developed and evolved their research method after research with the research team and the gatekeeper of the Deaf community.

Four moments of translation

Translation is a process permitting a network to be represented by one actant, e.g. a singular being or another network (Callon & Latour, 1981). Callon (1986) concretized the process of translation as four 'moments':

1. Problematization – defining the nature of the problem in a distinct situation by an actant and consequentially, establishing dependency;
2. Interessement – the solidifying of actants in the functions suggested for them in the actant's problem resolving-programme;
3. Enrolment – defining and interrelating the roles allocated to the actants in the point two;
4. Mobilization – establishing that purported spokespersons for appropriate collective entities are accurately representative for all that are part of the network.

These four phases will be presented in the following section wherein the work of Dr Tucker's research group BANG is analysed and traced. The beginning consists of two scholars who were working on their research: one focused on providing Deaf users with a device translating speech to text and the other focused on VoIP. Two decades worth of further development is what shall be analysed and discussed.

I. Problematization

The analysis starts at a 2001 conference at the University of Western Cape (UWC). In 1998, telecommunication provider Telkom held the monopoly in South Africa. During this time, Telkom started to give research funding to the universities across the country to their computer science and electrical engineering departments. Dr Tucker used that opportunity to get some funding, as Telkom wanted him to look into a broadband application, and – at the time – voice over internet protocol (VoIP). Researchers and stakeholders of the academic community assembled to examine the possibility of transforming the scene of telecommunications in South Africa. Dr Tucker was at the time working on VoIP, as well as instant messaging through software named Telpad to talk cheaply to his family overseas. Through chance, Dr Tucker sat across the table from Dr Glaser, who was working on speech-to-text converting technology for

the Deaf, and they realised that their research topics complemented each other well. A bunch of things came together.

"We realised, sitting across the table, that she is trying to get cheap access for Deaf people and I am trying to figure out how to use technology to get cheaper access. It started me on this thing where we can use technology to provide affordable and accessible communication for people that are cut off from the digital communications that you and I take for granted every day on the smartphone." – Dr Tucker, 2020

Once they realised how both research topics could be enhanced, the researchers wrote articles dedicated to the future project they wished to launch. Their question was simple: how can Deaf people improve their lives through the use of digital communication?

No clear answer was given straight away because, at that time, digital communication stood in its infant phase. No explanation is possible at this point in time in response to the ensuing essential question stated later in the research: what are the needs of Deaf people when it comes to digital communication? Other questions accompany the first. How can Deaf people gain access to digital communication? When do Deaf people feel the need for digital communication? What should the appearance of the digital tool be? The research group chose to do more than mere production of these issues. They defined the actants and their subsequent identities to organize themselves an requisite passage point within the relational network that was created.

Interdefinition of actants

The definitions of direct actors, as presented in numerous studies, is basic, similar to Callon (1984) his method of analysis. It also ensures precision regarding the analysis on how the actors relate and how they are involved with the issues that have arisen. Multiple social groups can be

identified throughout the two decades worth of research. These definitions are synthesised as follows:

a) Deaf Community: they live in South Africa, a place with limited access to interpreters for Deaf people. Deaf education is not that great, and a large portion of this group is functionally illiterate. Because of this, a significant part of the Deaf community finds themselves underneath the upper-bound poverty line. With SASL being their first language, the necessary access to a job, public institutions and organizations is limited. Being able to communicate with hearing people, as well as other Deaf people, is something that would help this group in breaking societal isolation. Gaining access to health care is something that Deaf people want, but are unable to do so without an expensive interpreter.
b) Academic peers: involved in seminars, colloquia and symposia or citing in various journals, their knowledge on Deaf communication, Deaf culture or the needs of Deaf people in South Africa is limited. They are unable to answer the question of how Deaf people can gain access to digital communication tools. They are interested in advancing the knowledge discussed and proposed.
c) Digital communication tools: a particular technology which is used to further contact between people worldwide. They have only been seen by the broader public as fully-tested and functional version, at the moment they were launched in society. The question asked by the research group assumes their form can be altered to suit the needs of the Deaf communities.

These three actants are the key-players within this case-study. University of Western Cape (UWC)'s research group on this topic disclose what they are and what they want. They declare themselves researchers who, inspired by the possibility of technological development, seek to

advance the position of Deaf people within a social and economic context. By propositioning this analysis, those involved with the UWC research group hope to make South African Deaf people's life more accessible, as well as boosting new development of telecommunication tools. A single question – how can Deaf people improve their lives through the use of digital communication? – is sufficient to include a set of actors through fixation of their respective identities and their interactions.

Defining obligatory passage points

The UWC research group does not restrict themselves to identifying actants. They showcase that it is in the actants own best interests by conceding to the suggested research project. Argumentatively this develops as follows:

- if digital communications tools want to be effective (regardless the mechanisms explaining the process)
- if their academic peers want to accelerate knowledge of the subject (disregarding their motivations)
- if the Deaf community wants to improve their social and economic standings (whatever the reasoning for it) they must:

1) give an answer to the question: how can Deaf people improve their lives through the use of digital communication and, 2) admit that their alliance for answering this question is beneficial for all.

II. Interessement

The theoretical aspect of problematization has now been spread out. On paper, in the accounts and scientific articles written by the UWC, the groups that were identified appear as having a

solid identity; according to Callon (1984) reality is, however, an ongoing process. The narrative at this point shows no demonstration yet of the relationships between the identified entities. All entities drawn in by the process of Problematization is able to comply with integrating into the initial plan or refuse altogether. As the phase of problematization demonstrates, the entities' formulation of identity and goals are composed and adapted only via action. 'Interessement' is, according to Callon (1984, p. 207), *"the group of actions by which an entity"* in this case, the UWC, *"attempts to impose and stabilize the identity of the other actors it defines through its problematization"*.

Various ways can be used for implementing the aforementioned actions. Interresement is, according to Callon (2007), one of such ways. To be interested is to be in between. The question becomes: between what? Our focus returns to the UWC. Through the phase of problematization, and similar to the case of Callon (1984), the UWC researchers join forces with the digital communication tools, the Deaf community, and academic colleagues to achieve a set goal. The development of digital communication tools showcases the general interessement mechanisms. The UWC is stimulated by the possibilities inherent to developing digital communication.

III. Enrolment

Callon (1984) reiterates that allies, or actual enrolment, are not per se the result of the process of interessement. The issue is to convert a question into a series of statements: Digital communication tools connect Deaf people to the (hearing) world; the Deaf people want to interact with everyone – hearing and Deaf people alike. By using a term such as 'enrolment', society is more than an entity consisting of roles and subsequent holders of the aforementioned roles (Callon, 2007). As Callon (1984, p. 211) states: Enrolment specifies *"the device by which a set of interrelated roles is defined and attributed to actors who accept them. Interessement*

achieves enrolment if it is successful. To describe enrolment is thus to describe the group of multilateral negotiations, trials of strength and tricks that accompany the interessements and enable them to succeed."

IV. Mobilisation

The fourth moment of translation regards the accuracy of spokespeople. In other words: *"Who speaks in the name of whom, and who represents whom"* (Callon, 2007, p. 13)?

The questions raised in these four phases of translation need to be given an answer in order to make the project successful. The following three phases depict the movement of actors within the research conducted in South Africa regarding the development of digital communication tools. It will showcase ongoing insight regarding representation and consequent usage of designed tools.

Phase one

The first results presented by the UWC research team were not accepted without negotiations. The proposition: 'Digital communication tools connect Deaf people to the (hearing) world' is a statement which the experiments accomplished in phase one eventually questioned. When the UWC started, their first communication development stemmed from wanting to bridge the communication between Deaf to hearing. According to P. Chininthorn, the UWC research team had more input than the Deaf community by suggesting the technology that the Deaf community can use.

> *"That has happened over time, where we were dependent on the Deaf community for the research topics; they were dependent on us for the skills." – Bill Tucker, 2020*

The UWC research group could take control of the design process, and the Deaf community was the design tester. Their only input was in the form of representatives from the Deaf community to test the design that the researchers created.

The digital communication tools that were created this way were not a success for the Deaf community. They could not always convert text to speech correctly. Furthermore, the tools for these communications was pricey at the time, and the majority of the Deaf members were uncomfortable texting because of their low functional literacy.

> *"Within the BANG research team, they realised because of having mostly researchers involved in the design development progress, the uptake from the Deaf community members was low on these communication tools." – P. Chininthorn, 2020*

No digital communication tool developed satisfied the needs of the Deaf people involved. With scientific peers, the transaction was simple: the discussion of the results illustrates an inclination to accept the idea of Deaf communication tools and perceived the development to be reasonable.

Phase two

Because of progressive insight, the UWC research group started to think about new research methods to start the design development progress, which became the second phase, through community action research. This period was from 2004 until 2007. During this phase, the UWC research group used a mix of action research together with the user-centred design. They had realised that Deaf people were less involved in the design development process. The question that arose was how to make their involvement possible, as they had low literacy and lacked digital skills. One choice they made was computer aid literacy. Digital skills, i.e. how to use the computer, were developed for Deaf members of this community, to explore the technological options available for their communication purposes.

The members of this community attended the workshops, courses or training. At the same time, other Deaf communities started using CamFrog as a tool for video communication. However, the Deaf community that BANG worked with did not trust these telecommunication technologies because people would misuse it and sometimes, pornography would pop-up on CamFrog (Blake et al., 2011). They did not want that to happen to their community. BANG was asked to develop a video conferencing communication tool explicitly designed for Deaf people so they could avoid those design flaws from the on-the-shelf, existing communication tools. Due to the advance in their digital skills, the Deaf community was able to steer the design process by asking what they sought. The goal was no longer to have 'Deaf to hearing' communication, but rather Deaf to Deaf because they want to strengthen their close-knit relationships to create a block to push back against societal norm and exclusion. Though the Deaf community asked them to design the tools for them, and at the same time, once they tried CamFrog, to communicate with Deaf organisations and used it to communicate with other Deaf communities in other areas or even internationally, they saw the benefit of it.

A relatively small number of Deaf participants spoke in the name of the others. However, the question regarding representation arose: are those few spokespeople enough to represent the more extensive, anonymous mass? A concept called controversy comes into play here; meaning *"all the manifestations by which the representativity of the spokesman is questioned, discussed, negotiated, rejected"*, and so forth (Callon, 2007, p. 72).

This is because, as with the characterization of interessement and enrolment, only specific actants are involved, whether these be Deaf participants, scientific colleagues, or digital communication tools. To continue, representation of these few must be accurate for the mass. During phase two, the UWC research team realised that this is not the case. A transformation regarding their research method started, wherein the roles of each social group were discussed.

> *"You do not communicate within yourself 100%. You need to communicate with others. BANG learned that it is not about the design attributes of the technologies that would make people adopt it to their daily use, but it is the societal norm." – P. Chininthorn, 2020*

BANG started to reflect on their societal output and the research methods they applied. They discussed what they could do to improve it more, as the Deaf community still rejected the communication tools that had been developed. The UWC research group went from a researcher, top-down type of design process towards a grassroots, bottom-up approach in phase three. The Deaf community needed to be involved more assertively; they should be included in all stages of research.

Phase three

Both researchers and Deaf participants are defined as co-designers. The project proceeded according to the requirements of Deaf participants, with a reflection on learning how to do it themselves. The Deaf co-designers started to evolve the research method from only action research to an exploration of the context. This meant identifying the problems that the tools need to help solve, identifying the ideas for a solution as well as coming up with further solutions together with the researcher co-designers.

The researcher co-designers would proceed with selecting the ideas for a solution to make a testable communication tool. After testing, the communication tool can be redesigned in what else needs to improve, and it would be tested again. The research iterates in a cyclical procedure. All social groups are equal in this process. However, the researchers have more control in design development; they still make the end-decisions regarding this.

During this phase, the needs and solutions change again because this is the era of the mobile phone. This does not automatically mean a smartphone. Instead, it was the feature phone that was most often used, referring to the phones with physical buttons to push. Blackberry was popular because of the free chat app. The social value these phones held was high, as the Deaf people wanted to be connected.

Several of them who could afford Blackberries would use Blackberries because of the chat app, that they could chat with their Deaf peers. Those who used feature phones they used SMS. Some Deaf people are wealthy, and they could afford to get an implant or a smartphone, and they could afford the high-cost broadband that you and I are using now. Most people could not afford any phone though, so what happened was that they shared the phone.

"If I wanted to contact A and she said that she is sharing a phone with B, I would have to write to B as B does not live far from A. B would

> *come and tell A. A phone is a personal thing, right? Like your toothbrush. You have pictures there that might be private for you, but you share it. If they could afford, they would try to buy the phone that would provide them with free contact with each other." – P.* Chininthorn, *2020*

During phase three, there was no free internet at the onset. Deaf people had to buy a data bundle for the phone. As time went on, there was progress: from sharing feature phones to owning feature phones, Blackberries, and smartphones. Before Chininthorn left South Africa in 2017, around 90% of her participants used smartphones. 43 out of 45 participants in her study had access to mobile phones. However, it does not mean that all 43 participants had a mobile phone. Some were sharing phones too. It was still there, and they are now sharing smartphones.

This context is essential to note to gain perspective of the research trajectory. Smartphones with full screens were not affordable, yet the entire group felt they had to think ahead. Everybody recommended that we should target smartphones with a large screen, as this ties to the communication requirement that they know there is a shortage of SASL interpreters in the country. The question remained how videotelephony can alleviate this problem.

This research focussed on pharmacy communication; however, it could apply to every communication instance. The Deaf participants wanted to reconnect with their hearing family members and any hearing person that they need help from, like health professionals or a social worker who can help them with legal advice. The case-study that is analysed further is that of SignSupport: an application for smartphones wherein video is the main feature. As Dr Tucker said: "They *need* video. It turned out that they can use text, but they are not literate in text. They are literate in sign language."

> *"You might ask: they were illiterate, how could they chat? If I texted you, I would write 'you' as only the 'u' character or in the way that they were able to understand each other. It is not 100% right, but they could understand and pick up from each other. I used to have a message from Deaf people, but it was difficult to understand as a hearing person." – P. Chininthorn, 2020*

Communication is vital for efficient co-designing. Even though they took on the role of co-designers, some signing explanations were involved in explaining what their ideas were. In any data collection, professional interpreters were hired through the recommendation of the Deaf community. As the dialects in SASL (p. 61) meant that if *any* SASL-interpreter was hired to interpret during the data collection, it might not work. The interpreter might use signs that Deaf people in that community would not be familiar with. Language barriers still existed, exemplifying the complexity of this problem. As Chininthorn states: "*For example, the word 'risk factor'; there is no sign for risk factor. A risk factor is not even a cause. They had to contextualize and sign it in a sentence to convey the message."*

The uptake of the Deaf community was higher in phase three. This was due to two reason: first, they used a community-based approach, and second, the goal from the onset was about empowerment. The UWC research group was not working to further their research career but to help, support and empower minority groups. There is an apparent gain for these groups. Chininthorn stated that: *"This is referred to as the adaptation of communication tools in their daily lives."* That is what lead the uptake for the Deaf community because they were continuously involved in the process. Chininthorn: *"They felt like they owned it."*

During this stage, the original Deaf community involved stopped their cooperation. After twenty years of involvement with this research-process, they questioned why there was nothing practical available for them. *Chininthorn: "This community depended on us, as in us: the research team, and there is the phase that says: we know something. We can co-depend on each other. Moreover, now, they are in the phase: we are better off without you. Because we know how to deal with it."* Through gaining digital skills and raising their level of literacy, as well as social activism to better their situation, they became a passive stakeholder. Another Deaf community stepped in as co-designers, to create a videotelephony application for the health care context.

Design features were discussed and tested (Chininthorn, Glaser, Tucker, & Diehl, 2016) and a videocall-application named SignSupport was created. When a Deaf person uses the SignSupport app to find out more about diabetes and want to ask questions, they could tap within the app to send a message to a call centre which in essence says: hey, I want to get more information. The person at the call centre might suggest that the Deaf person needs to talk to someone at the clinic, and they create a video conversation inside a browser. If, for example, it is for diabetes and the site is hosted by Diabetes SA (A South African NGO), the price will be zero-rated through negotiations with telecom providers that concluded with them zero-rating the traffic.

This means that Deaf people can have a video conversation within this context in sign language and *not have to pay*. This was a vital aspect of the project: it has to be done affordably since, as p. 64 illustrated, most Deaf people are poor. The communities on the ground have realised that potential. Service providers, even the government, have realised that this work can be useful. Deaf people need to have access to a service that can relay the information from the textual and voice language into sign language and back, and that is what this whole project is all about.

4.3 Summary

The conceptual instrument created in chapter 3, namely Nussbaum's capability approach and the analysis of societal and economic inequality and its relation to inclusive design, was employed in this chapter. Through this lens, as well as a Callonian ANT-perspective and SCOT, an analysis was possible to grasp the technological possibilities of videotelephony communication for Deaf users.

"Translation is a process before it is a result" (Callon, 2007, p. 75). This is the reason why research conducted these past twenty years has appeared in three separate phases, which in reality are not as distinct as they were depicted. The design process moved through a series of processes, reflections and discussions. Each of the phases does mark an evolution in the negotiations resulting in the selection of appropriate spokespeople, saying what the digital communication tools need, and are not disavowed: the problematization was transformed into mobilization.

Conclusion

Who in 1783, at the beginning of the story of videotelephony, could have predicted that videotelephony would become more than a 'fantastical' story where people could see each other and synchronously talk as well? Who could have thought that videotelephony would come into being in such a multitude of formats; that it would change the world on a global, but also an individual scale. The development of videotelephony throughout history shows that multiple versions of the same concept were created before the 'standard' setting of two or more webcams and microphones became the norm. The way to connect and communicate with others changed the most for Deaf people.

The research question of this thesis was as follows: *How did the involvement of Deaf people change the design of videotelephony*? One answer is found in the chronology of videotelephony in chapter two, wherein a Deaf American made sure that development of videotelephony would continue and at the same time remain affordable for the Deaf people living in his country. The design of videotelephony itself was, in this stage, not much altered from what was known. Even more so, in the initial phases of inventing videotelephony, there was a distinct line between producer and user. Deaf people were part of a broader public who were given the option of videotelephony – if one had the means to buy, install and maintain the technology.

A more interesting answer to this question is found in the analysis given in chapter four. The involvement of Deaf participants towards the development of videotelephony did not come into being immediately. Instead, the continuous reflection of their research methods ensured that the UWC's research team concluded that they had to empower Deaf participants not through the tools produced for them, but rather through creating an equal space for all involved

in the design process of these digital tools. The inclusive design ensured that Deaf people's opinion was heard and their knowledge was used to create a tool specifically *for* them, but also *with* them. Through community-based co-design, a platform of shared knowledge was created – a platform where researchers and Deaf people were equal.

Going from a tool that translated speech to text, to a videotelephony tool that the Deaf participants requested but did not use, the research of Dr Tucker and P. Chininthorn demonstrates that when Deaf participants are given the skills, general knowhow and equal standing, this form of community-based co-design can lead to fruitful technical solutions. SignSupport was the result of this form of design. It illustrates how designing with Deaf people ensures increased uptake of the tool. Simplified ways of contacting others ensured that the South African Deaf community can now contact health care professionals through videotelephony in their language. However, as Dr Tucker said, this format applies to nearly all imaginable contexts from banks to schools to police stations.

The first sub-question regarded the blending of academic and lay-knowledge. This case study demonstrates different types of knowledge being pooled, and those involved learning from the other. Social inequality meant that Deaf people were functional illiterates, but they knew about the Deaf community and culture, which the researchers did not. The researchers, in turn, had more knowledge regarding digital and design processes. By merging their knowledge, their product was robust and well-rounded.

The second sub-question pertained to co-design aiding Deaf people. Other than the apparent eventual product, co-designing created learning opportunities for Deaf people. Moreover, they were able to get handholds to empower themselves as they gained access to opportunities that they otherwise would not have. As Dr Tucker stated: the end goal is for the Deaf people to become independent of us.

The third sub-question was: what can be learned about the exclusion or discrimination of Deaf people within society through analysing the process of co-design of videotelephony with a Deaf community. The case study of Chininthorn et al. (2016) illustrates that the exclusion of Deaf people within South Africa is apparent in their continuous daily life. The work conducted to create SignSupport was, as Chininthorn herself said, the baby step that can be used as a blueprint for other situations. The shortage of SASL interpreters mentioned in chapter 4.1 regarding Deafness and inequality, as well as the poor economic conditions most Deaf people are in, meant that Deaf people have no option to make themselves heard in day to day life. Exclusion and discrimination can happen because Deaf people are oftentimes unable to rally against this.

This ties into the fourth sub-question regarding the obstacles that Deaf people face in day to day life because others cannot communicate with them and vice versa. Chininthorn et al. (2016) focussed on the pharmaceutical context, wherein Deaf people were unable to ask questions regarding their medication. Dr Tucker stated that the same technology could be applied by call centres for banks, governmental agencies, educational institutes, shops, courts, and police stations. All the places that a Deaf person should be able to gain information make a complaint or need help to improve their life.

The fifth sub-question pertains to how co-design of videotelephony for Deaf people can aid society towards becoming more inclusive towards Deaf people. The first way of creating a more inclusive society is by acknowledging that societal standards are at the moment, excluding certain groups. Through academic research, notoriety is given to struggles of minorities. I am writing about this, 13.623km from Cape Town, because there was research conducted regarding this topic. Visibility of Deaf people is another issue to create an inclusive space within society for them. Political members, educators, or other forms of public figures can speak up about this; or even better, be a part of the Deaf community themselves. As crucial a step as signing a bill

pertaining the rights of Deaf people is, which not many countries haven done yet (as mentioned in the introduction), a bottom-up approach empowering local Deaf communities in skill and knowledge is even more critical. Through developing communication tools that give access to Deaf people, the everyday life of Deaf people can be improved already.

So, returning to the primary question asked in this thesis: how *did* the design of video conferencing change due to the involvement of Deaf people? All the typical aspects are needed. A video camera is necessary, a microphone not as much. A stable internet connection is essential, as well as a certain level of video quality. Ease of use has a different meaning for Deaf users compared to hearing ones, so the interface to connect or even asynchronously talk through videos messages is the main alteration. The most important aspect is that these videotelephony tools should be free to access for all Deaf people. Having access to hearing people cut off unless a price is paid creates vast social and economic inequality, as chapter three has demonstrated.

When analysing what can be said about the position of Deaf people through their participation and active help in co-designing videotelephony, the focus shifts towards the grander societal context. By changing this perspective, it becomes apparent that in South Africa, Deaf people are much excluded from essential services to empower themselves, or even to enhance their own lives. Communication is key to participation and inclusion in society. The threshold to improve their situation has needlessly been raised through the lack of facilities for People who are Deaf to communicate with hearing people.

Blake et al.'s (2011) study regarding co-designing their communication tools demonstrates that when Deaf people gain knowledge and skills to take matters into their own hands, they will do so. When the results of fifteen to twenty years of design did not satisfy the needs of the Deaf community, they paused their collaboration with the UWC research team. In doing so, they have indirectly stated that they can work to improve and empower themselves

without the aid of another actor. Another Deaf community is now working with the UWC research team, where the goal has become the empowerment of Deaf people through raising their digital skills. The question that will need to be answered in the future is whether or not it is probable, once the community is accepted as co-designers, that researchers might not even have the last word in design.

Concluding, the question that started the journey of this thesis was: how did design of videotelephony change through the influence of Deaf people? Reversing this question says: how did the influence of Deaf people change through designing videotelephony? The answer is found in a more equal society.

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Appendix

Codebook

Code	Name	Description	Example	# Quotes in total
Group: Design				
D1	Design requirement	Design requirements as formulated by Deaf participants	He practiced the community-based co-design research and then together with the Deaf community they said, we needed the communication to be bridged between Deaf patients and health care professionals who are hearing, because we need access to health information.	7
D2	Development of technology	How technology was developed	The SignSupport-website shows you where we got. The Zenzeleni website will show you where we are. And with Zenzeleni, two or three years ago we started spinning off companies that are owned by communities. And now we're learning how to do that with SignSupport.	2
D3	Inclusive design	Aspects of inclusive design	The SignSupport-website shows you where we got. The Zenzeleni website will show you where we are. And with Zenzeleni, two or three years ago we started spinning off companies that are owned by communities. And now we're learning how to do that with SignSupport.	8

D4	Reason for adoption of technology	Why users adopt technology	The SignSupport-website shows you where we got. The Zenzeleni website will show you where we are. And with Zenzeleni, two or three years ago we started spinning off companies that are owned by communities. And now we're learning how to do that with SignSupport.	2
Group: Equality				
E1	Empowerment	Empowerment of minority groups, specificially the Deaf community	The community depended on us, as in us: the research team. And then there's the phase that say: we know something. We can co-depend on each other. And now, they're in the phase: we're better off without you. Because we know how to deal with it.	8
E2	Role of actant	How the actant plays a role in the research	But that's a phenomenon, right? Although they paused their active participation, but they wanted to be informed so we keep them as a stakeholder: whom to be informed.	4
E3	Sign language	Aspects of sign language	We are talking mainly about Deaf who use sign language in daily communication but that also comes with a lot of struggles that they have to face when communicating with others in the society because not everyone knows sign language.	16

E4	Social value technology	How technology plays a social role in users' life	For example, if I wanted to contact A and she said that she's sharing a phone with B, so please write to B and B doesn't live far from me so B would come and tell me.	6
E5	Socio-economic argument	Socio-economic aspects within inclusive design/design with Deaf people	If I would just tell you about mobile phone use, I could see that every time that I went back I saw that they own more smartphones.	4
Group: Research				
R1	Funding	Funding of the research	multiple funders, and whether they have any influence in the decision-making, from my perspective: none.	2
R2	Goal of research	Goals of the research	I'm saying: we take the existing language and we build another layer on top of it, so that they can do the same things but in their own language and that's how I see all of this stuff moving forwards.	7
R3	Origin of research	How the research regarding inclusive design with Deaf people came into being	It started me on this thing where we can use technology to provide afforadable and accessible communication for people that are cut off from the digital communciations that you and I take for granted every day on the smartphone.	2
R4	Phase 1	First phase in the research. No influence from Deaf participants.	the researchers had more involvement in the development of communication tools. They had several tools. It started one by one and then the representative of the Deaf community were the testers.	4

R5	Phase 2	Second phase in the research. Some influence from Deaf participants.	In phase two, they asked BANG to develop a communication tool for them to have video conferencing. Designed specifically for Deaf people so they could avoid those design flaws from the on-the-shelf, existing communication tools	4
R6	Phase 3	Third phase in the research. Equal influence from Deaf participants and researchers	Yes, they couldn't build it but they could convey to us, they could explain to us what they needed, what their needs were, what they thought could happen on a mobile phone, or a laptop or a tablet.	3