# Institutionalisation of Citizen Involvement in the Local Disability Councils



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Emilie S. Nielsen, 20191397 Marie Louise Løken, 20191388 Sebastian M. Andersen, 20165069

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Supervisor: Andreas Birkbak





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## Abstract

The purpose of this Master thesis has been to analyse how citizens with disabilities are represented and involved in matters of accessibility through the local disability councils. In the local disability councils, citizens with disabilities have been appointed to represent the interest and experiences of others living with a disability on issues regarding local disability policies in collaboration with municipal representatives. The focus is on how the disability representatives represent a variety of different disabilities as well as how this representation has an impact in the decision-making processes of the municipality. By applying qualitative methods like participatory observations and interviews we have conducted a total of four observations and 16 interviews in total. We have applied the organisational criteria of openness, intensity and quality for classifying dialogic procedures described by Callon et al. in their concept of hybrid forums, to analyse the possibilities and constraints of the collaboration in the local disability councils. We found that the controversy of the roles of the local disability councils is yet to be identified and are negotiated as they consider themselves to be both a municipal advisory council and a usercouncil. With outset in the framework of Callon et al. we found that by reconfiguring the local disability councils as a user-council there is potential to reintroduce research in the wild into the council, which have not been present due to the institutionalization of the local disability councils.



# Table of Content

Is It Accessible for Me?	
Introduction to the Field	7
What is a disability?	
Models of Disability	
Disability in Denmark	
Local Disability Council	
Informants and Members of the Council	
Framing the Thesis	
Hybrid Forum	
Classifying Dialogic Procedures	
Dialogue in the Local Disability Councils	
The Pursuit of Expertise	
Studies of Disability	
Anthropological Studies of Disability	
Disability Studies in STS	
A Techno-Anthropological Approach	
Entering the field	
Methodology	
Methods	
Exploring the Issue	
Narrowing the Issue	
Experiencing Disability	
Digital Approaches to Methods	
Ethical Considerations	
Analysing the Representativeness	
Perceptions of Disability and Expertise	
Openness	
Diversity of Groups	
Redefining Representation	
Intensity	
Earliness of Involvement	
Composition of the Collective	
Quality	
Speaking Your Mind	
Continuity of Voice	



Discussion	80
Mobilising Research in the Wild	
Reflection	90
Alternative Directions	
Conclusion	98
Reconfiguring the Local Disability Councils	



## Is It Accessible for Me?

Kristian and his friends have not seen each other in a while, and they decide to drop in for a beer at one of the local bars. He is excited to join his friends, but soon anxiety sets in. Kristian is a 27-year-old man who enjoys the occasional beer and social interactions with his friends when he is not busy with volunteer work. Kristian also has cerebral parese and finding a bar with proper wheelchair accessibility can be a challenge. "Considering that I live in a big and vibrant city, I use it way less than I would actually like, simply because it is troublesome" Kristian says. Whenever a friend suggests a new bar or café, Kristian must plan thoroughly ahead. The first thing he will have to do is get an impression of the outside accessibility. A main issue with the city is the old architectural style where entrances are often elevated from street level. If he does not know the place already, he will use Google Street View. "I am a big fan of Google Street View, because it can show me the front of the building and if it is accessible for me". Kristian knows that if he cannot gain access to the building, he will need to suggest a new place which he knows has wheelchair access. He states that he can be reluctant to suggest disability friendly alternatives, if his friends seem fond of a new venue. "Sometimes it is easier to find an excuse like 'I have to drive home' or something like that, but it does limit my social interaction".

The inspiration to research people with disabilities' experiences with accessibility came from a place of personal interest. One of the co-authors of this project, Emilie, had one day noticed the little bar on top of the pedestrian-crossing box, which had small knobs on it. Upon further investigation, she learned that they were designed to inform a visually impaired person of the number of traffic islands in an intersection. With this new attention to disability friendly design, Emilie began noticing more accessible designs. Stairs, curbs with knobs and guidelines and she soon noticed places where they were potentially missing. She became aware of how this could influence the accessibility for people with mobility issues and people with visual impairments. We discussed, in the group, these issues and began questioning whether the process of planning public urban environments involved people with disabilities.





*Picture 1: Pedestrian-crossing box with assistive bar for visually impaired citizens. Prepared by Authors.* 

In addition to Kristian's experience, a campaign from the Danish Disability Council [Danish: Det Centrale Handicapråd] (DCH) introduced seven different challenges that people with disabilities encounter in their everyday life. One of these issues was accessibility (Det Centrale Handicapråd 2019).

With the question of how citizens with disabilities are involved in city planning, we decided to research the underlying issues of accessibility and representation of disability in a local, political context.

Since 2006, all municipalities in Denmark have been required to have a Local Disability Council *[Danish: Lokale Handicapråd]* (LDC). The role of these councils is to advise on any



projects related to disability, herein accessibility. Members of the LDCs consist of municipal elected representatives along with citizen representatives of the disability community. The purpose of including citizens was to create a forum for exchange of experience where the municipality could obtain information on how to provide proper access for their citizens with disabilities (Kommunernes Landsforening 2018). In a survey done by the DCH, the Chairs of several LDCs were asked which political areas they thought were important to discuss and which areas were troublesome to achieve results in. One of the areas was accessibility, where 52,6 % of the respondents thought accessibility was one of the most important areas to discuss. Of the 52,6 %, 75 % had already brought the subject up for discussion. 19 % stated that accessibility was one of the most troublesome areas to achieve results (Det Centrale Handicapråd 2020, 4). Because of the collaboration that is facilitated between citizens and the municipality within the LDCs, we found the dialogical practices and procedures, that are enacted in the LDCs, to be interesting to apply as research objects.

Accessibility is evidently an issue related to other groups as well. We have on multiple occasions witnessed parents with strollers having to navigate around poorly parked bicycles, elderly citizens struggling to get downstairs with or without their walkers, children who cannot open doors if they are too heavy. For us to frame our research and narrow the scope we have decided to focus on disabilities, specifically relating to mobility and visual impairments. We apply the definition from the ACCESS project which defines mobility disabilities as impairments resulting in inability to use one or more extremities which can lead to difficulties in walking or grasping objects (Accessibility.com 2021). For visual impairments, we apply the definition provided by the Institute for Blind and Severe Visually Impaired [Danish: Institut for Blinde og Svagtseende], which defines it as impairment of vision that cannot be corrected using contact lenses or glasses (IBOS 2021).

Regarding the LDCs and the disability representatives, we were intrigued by the representational aspect. As none of the authors of this thesis have a mobility- or visual disability, the issue of accessibility is not something we have paid attention to before. So, without the bodily experience, can anyone represent citizens with disabilities, and is having one type of disability prerequisite enough to represent another? The concept of representation unfolds on several levels. A micro level of how an individual can represent other in-



dividuals as well as on the societal level of how the LDCs represents citizens with disability in political discussions. In our opinion, no matter how ample one might be at representing a group, the representation is useless if the representative is not involved in any discussions or negotiations. Yet again, while the involvement might be sufficient, the representation is still deficit if the experiences shared are not passed on to the rest of the municipality due to lack of procedures of information flow.

The Center for Equal Treatment of Disabled [Danish: *Center for Ligebehandling af Handicappede*] (CETD) conducted an evaluation of the LDCs' experiences and impact in 2008, two years after the establishment of the LDCs. The report stated that in most of the municipalities the councils were well-established. It also highlighted a connection between consensus of tasks, ambitions among the council members and the council's experience of being involved in decision-making processes (Center for Ligebehandling af Handicappede 2008, 10). Some of the challenges the councils faced in the early years were an unequal distribution of work. The general capability of impact was dependent on the Chair's ability to manage the council work. In the report, CETD stated that factors such as good collaboration and engagement are vital components (ibid., 11).

The report describes a series of challenges being:

- Issues of stabilizing the council itself, its internal collaborations, and workflows as well as the members' work effort and the acquaintance with the council in the municipality.
- 2. Some LDCs experience a lack of support from the municipalities and an inability to qualify their advice to the municipality. Many council members consider it challenging to act in the political environment between municipality budgets and a prioritization of the disability sector.
- 3. The challenges regarding informing the public of the council's work. To be involved in decision making processes, the councils need to be visible among the citizens, Politicians and management (ibid., 13).

To shape our research, we apply the concept of *hybrid forum* by Callon et al. (2011) to analyse the potential for *dialogic procedures* in the LDCs, and we explore the notion of representation through Collins (2004) concepts of *interactional*- and *contributory exper-*



*tise.* Our aim is to identify relevant issues and provide possible solutions related to accessibility and the work of the LDCs by applying an STS focus on how materialities and procedures are interrelated in shaping human experiences and relations.

We have formulated the following problem statement:

How are citizens with disabilities represented in discussions on accessibility in a public built environment via the LDC?

- How can citizens with disabilities be considered experts within the LDC?
- How does the collaboration between municipality and LDC facilitate dialogic procedures?
- What capacity for impact does the LDC have in the municipality?

Our thesis is driven by an interest in understanding how citizens with disabilities are involved in the municipalities' work with accessibility and how citizens with disabilities experience accessibility in the urban environment. With anecdotal experiences from individuals who had felt excluded and forgotten when the municipality embarked on new construction projects, we entered the field by talking to citizens with disabilities and arranged interviews with the local disability councils that advise the municipalities with first-hand experience on disabilities.

Our first chapter is an introduction to the field where we elaborate on the definition and use of the term disability. We review how disability has been perceived historically in different disciplines and introduce the organization of the LDCs and the members we have interviewed.

In the second chapter, *Framing the Thesis*, we elaborate on our theoretical framework of analysis and how we apply it in our thesis. The use of our theories stems from an interventionist desire to identify questions and possible solutions related to involvement in accessibility for citizens with disabilities.

In the third chapter, *Entering the Field*, we introduce the methods we have used to obtain the data for our theories, as well as our reflections on the use of the chosen methods, our



impact on the field, and the ethical considerations we have made regarding anonymity and protection of our informants' identities.

Following the chapters that introduce and conceptualize our thesis, we begin our analysis by applying a phenomenological oriented approach to examine the different understandings and experiences of disability. We investigate how the dichotomy between experiencing something for oneself and representing others' experiences affects the LDCs' members' ability to represent citizens with a disability. We analyse the procedures that facilitate collaborative and representational work by applying the three organizational criteria for dialogical procedure Callon et al.'s concept of hybrid forum.

We discuss our analysis and investigates through the concept of hybrid forum how different re-configurations of the LDCs can allow for further impact and representation.

Before concluding our thesis, we reflect on other theoretical approaches and how the application of these might have shaped the analysis in different directions. We also provide a brief reflection on how the problem-based learning approach applied at Aalborg University has influenced our thesis.

All these considerations, discussions, and reflections on our findings, come together in the answering of our problem formulation, where we conclude our questions.

Emilie S. Nielsen, Louise Løken Sebastian M. Andersen Techno-Anthropology Master Thesis





## Introduction to the Field

In this section we will introduce the field and elaborate on the issues. We begin by clarifying the definition of disability, impairment, and handicap and how the terms are applied in our ethnographic context. Furthermore, we will also provide the reader with statistics, or lack of set, on how many citizens in Denmark potentially could be affected by the issues with accessibility.

Having clarified the terminology and accounted for how many are potentially affected, we will provide the reader with a brief historical overview on how disabilities have been considered through the decades.

As our thesis is scoped around the LDCs we will lastly in the introduction to the field provide a formal explanation of their configuration and how they are constructed according to the legislation. We will further introduce our informants in the two LDCs we have investigated.



#### What is a disability?

It is common in the Danish language to describe physical- and mental impairments as a *handicap* (spelled alike in Danish and English) or that the person is *handicapped* (Kulick 2014). As to the definition of a handicap, Danish interest groups refer to either the United Nations (UN) or World Health Organisation (WHO) when coining the term.

"Persons with disabilities [red. Danish *handicap*] include those who have longterm physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others" (United Nations 2006; Danske Handicaporganisationer 2021a).

Likewise, WHO operates with a *relational understanding of disability* which implies that a disability is not residing in an individual, but is a barrier constructed by society (Dansk Handicap Forbund 2021).

A disability, or handicap, is a result of a reduction of function engaging with a societal barrier. However, the terms handicap or handicapped is commonly used in the Danish language to refer to a person, regardless of societal considerations. For example, the Danish Disability Organizations *[Danish: Danske Handicaporganisationer]* (DDO) further elaborates on the UN definition by explaining that "you have a handicap if you have a prolonged reduction of function which limits you in your everyday life" (Danske Handicaporganisationer 2021d). It is interesting to notice that while the organisation emphasises the societal relation to a handicap, they describe a handicap as something belonging to a person caused by their own bodies and limiting themselves.

The term disability is common in the rest of the world, whilst handicap is still widely used in Denmark (Kulick 2014). The word handicap in English stems from the late 1800s and could be used to describe people with economic, social and moral disadvantages (Okrent 2015). Handicap is coined by the Cambridge Dictionary as:

"not able to use part of your body or your mind because it has been damaged or does not work normally. This word is now considered offensive by many people,



who prefer to say someone is disabled or has a disability" (Cambridge Dictionary 2021b).

As for disability, Cambrigde defines it as "an illness, injury, or condition that makes it difficult for someone to do the things that other people do" (Cambridge Dictionary 2021a).

Based on the definitions from Cambrigde, a handicap is when your body or mind does not work 'normally' while a disability is when you do not have the same physical or mental ability to engage in activities to the same extent as other people. While handicap can appear offensive to the English native, it is not exclusively used as such. Ulrich (2016) describes a disability as a "reduction of function or the absence of a particular body part or organ" and a handicap as "viewed as a disadvantage resulting from a disability that limits or prevents fulfilment". She defines being handicapped as when society fails to meet the needs of the disabled, thereby providing the disabled with a handicap (Ulrich 2016).

*Handicappet* in Danish refers to both an impairment as well as the disadvantages in the engagement with society. In English, a disability is the disadvantage in the engagement with an inaccessible environment whereas impairment describes a reduction of function. Handicap in an English context can be both an oppressive way of describing a person's disadvantages or a way of describing the disadvantage that occurs in engagement with society.

Kristian turned his electrical wheelchair slightly to the left and looked at the pedestrian street with a side gaze. A breath of air came from the right and covered his eye with a bit of his hair. His assistant stood up as if by a reflex, removed the hair and sat down again. Kristian turned his wheelchair towards us and said "Even if I could move anywhere unhindered... I would still have cerebral parese. Perhaps some would call that an impairment. I would probably still refer to my condition itself as a disability".

In this thesis, we will use the word impairment when referring to the physical condition and disability when referring to a person with a disability in a societal context.



### Models of Disability

Different *models of disability* have been introduced and used to understand and investigate the situatedness and experience of disability. Jackson (2018) explores the issues with built environment accessibility and how an understanding of the different models of disability might inform an improvement (Jackson 2018, 1). The different models are the *charity, medical, social, relational* and *diversity* models, and illustrate different ways of perceiving disability and people with disability throughout history (ibid., 2).

The first model was the charity model of disability which is described as two-sided. It encompasses a notion of caretaking and protection, of the vulnerable *other* and of society. The charity model dates to the late 1800s and early 1900s, common practices were to segrate *deviant members* of society. The segregation resulted in a lack of public visibility of people with disabilities, elderly, mentally impaired and *defective* children (ibid., 3).

The medical model of disability builds on the medical practices of classifying levels of deficiency or deviance compared to a normative set. The tenet of the medical model is that a disability can be diagnosed, cured, or rehabilitated by modern medicine and/or medical technology. The treatment is provided by medical professionals and the aim of the medical model was correction of the impairment for the social good (ibid.).

With the medical and charity models of disability, the notion of disability has been embodied in the person dealing with reduction of functions. In the early 1960s, British researchers and disability activists, Finkelstein and Hunt, developed a new social theory which moved beyond the narrow medical view of disability. They concluded that "social exclusion of people with disability was an outcome of the materialist landscape of the industrial era' rendering them economically unviable" ibid., 4). Based on these thoughts, another British academic and disability activist, Oliver, developed the social model of disability in the early 1980s. Jackson describes the social model as "essentially, in moving disablement from an internal, individual pathology location to a primarily, external, societal environment" (ibid.). According to the social model, disability is the product of barriers within an oppressive and discriminating society, rather than a result of an impairment. The individual is no longer something needing to be cured or fixed, rather society must dismantle the barriers constructing a disability (ibid., 4-5).



Alongside the introduction of the social model, a Swedish social theorist, Nirje, formulated the principles of normalization. He emphasized the need for deinstitutionalization and recognition of the diversity of the human condition. To Nirje, disability and access to an ordinary life is not mutually exclusive. He especially focused on the inclusion of people with disability in the built environment, and his work represents the emerging idea of social inclusion for people with disabilities in the community (ibid., 5). In the 1990s-2000, led by Nordic scholars and activists following the interest in people-environment interaction, a new model was introduced. The (Nordic) Relational Model of Disability (RMD). The RMD revolves around three main tenets on disability as being a person-environment mismatch, contextual and relative (ibid.). The RMD is also the one which the DDO, UN and WHO has built their definition of disability upon.

The relational model indicates a symmetry between a disability and the obstacles posed by an accessible environment. We asked Anna from the DDO how she would define a disability, and she cited the UN definition on disability, coining it as relational and elaborated by listing four kinds of disabilities: Physical, sensorial, cognitive, and mental.

Three of our informants, Therese, Kristian, and Aslan answered the question of whether disability is solely relational, to which they all began by referring to the definition used by the UN and the DDO as a relational concept.

Therese is a 26-year-old girl who studies veterinary medicine and participates in wheelchair rugby. She was not familiar with the LDCs but agreed to meet us in her apartment so we could get an impression of how it was to be a self-dependent student with paralyzed legs. In Therese's apartment, everything including the kitchen, bathroom and terrace was especially designed for her condition. She moved around seemingly effortlessly as the space was fitted to her needs. So how about the disability, was it gone? Therese smiled slightly at this question. "I do not feel disabled, especially not here. But if someone asked me, if I had a disability, I would still say yes". As for Aslan, he too liked the thought of disability being a relational concept inhabiting the instances where society is not fit for him and his wheelchair. He is part of the organisation Danish Association of the Physically Disabled [*Danish: Dansk Handicap Forbund*], and when asked if Physically Disabled in the



name of the organisation would then only relate to instances where members experienced barriers, he laughed a little and said "No, I suppose not. Physically Disabled probably refers to the condition of the members". These statements supported our assumption that disability cannot only be considered relational to an inaccessible society but must also be perceived as internal.

While a relational model is commonly used in a Danish context, others have questioned the dichotomy between internalized and externalized disability as well. This brings us to the last model: the Diversity Model. The Diversity Model advocates for a perception of disability as a human variation and to focus on how society's systems operate with variations introduced by disability (Jackson 2018, 6). In relation to the built environment, this model dictates that accessibility is not achieved solely by antidescriminational regulation, but instead requires a *universal solution*, which acknowledges the diversity of disabilities. The founding fathers of the Diversity Model, Shriner and Scotch, criticizes part of the Social Model, and indirectly also the Relational Model, for being a civil right or 'minority group' approach (ibid). They question the socio-political definition that disability is imposed by the surrounding environment, which consequently should result in the removal of said disability if the barrier is removed. This creates a false dichotomy between ability/disability and instead there is a need for the pursuit of universalism because it serves people with disabilities more effectively than a minority group or civil rights approach (ibid). Universalism reflects the view that:

"disablement is a universal human phenomenon rather than a minority one [...] A universal approach to disability shifts the focus from 'special responses for special needs' (where such needs are competing with those of the general population), [...] to an approach that 'accepts difference and widens the range of normal' along an ability-disability continuum that can be applied to all humanity" (ibid.).

We understand and apply the model of diversity as a framework of perceiving disability. Not as a dichotomy between disability and ability, but as a spectrum or variety of different bodily capabilities. While solutions fit for all can approve the livelihood of people with disabilities, we also acknowledge the immense work a shift to universal solutions would



require. Rather than arguing for universal solutions, we apply the diversity model to argue that even with universal, accessible solutions the disability itself is still present and exists in multiple varieties.

#### Disability in Denmark

How many people does inaccessibility affect? We have asked this question multiple times, yet it is close to impossible to answer. In Denmark, there are no statistics for people with disabilities. Statistics used by organisations and articles are based on sample tests conducted by private organisations. Through our interviews, we have been informed by several informants that one of the reasons that statistics of disability is not a thing in Denmark is that disability is a subjective matter, hence there is no specific method of surveying how many are living with disabilities. In addition to this, one informant noted that the lack of statistics could also have its roots back to World War 2 where disability was frowned upon and having a disability was reason enough to be sentenced to death. While most of our informants agreed that the subjective component of a disability could be difficult to quantify, they did also argue that statistics on how many people are affected by a disability would be a helpful tool in arguments with Politicians, Architects, and other decision-makers.

With this in mind, we wish to make a feeble attempt to provide the reader with some idea as to how many people are living with a disability in Denmark. We tried to use the member count from the DDO, who has 340.000 members across 35 different disability organisations. However, as these members can be both people with disabilities, next of kin, or people supporting the organization, finding an exact number for how many are living with disabilities is not precise (Danske Handicaporganisationer 2021c). VIVE published a report in 2017 based on information gathered among 20.451 respondents (VIVE 2017, 17). The respondents were between the ages of 16 and 64. 9,9% of the respondents stated that they had an extensive physical disability. The questionnaire was based on the personal evaluation of the respondents, and it was not indicated what an extensive physical disability referred to. The population in Denmark of citizens between 16 and 64 years old was 3.612.116 in 2016 when the sample was done. Based on the 9,9% with extensive physical disability in the sample group, VIVE concludes that this is equal to 357.599 citizens in Denmark who are living with an extensive physical disability (ibid., 22). From the



member count in the DDO and the VIVE report there is a difference of 17.599 people, or a difference of 5,17 % in those numbers. The number is however potentially larger as the report does not include the older segment above 64 which is a segment prone to reduction of physical abilities due to age. We therefore have reason to believe that the number of people with extensive disabilities is higher than 350.000.

In this thesis we have worked with people using wheelchairs and people with visual impairments. As to how many are dependent on a wheelchair is an even trickier question. The statement that 30-50.000 citizens are wheelchair users is floating around the internet (Om erhverv 2016; Nye vinduer 2020; Fogde 2019). It is often used without reference and in the rare cases where a reference is noted, it is often either the DDO, Danish Agency for Higher Education and Science, or the report from VIVE, but in neither of these are any original sources or the statement itself mentioned. When it comes to visual impairment, the VIVE report stated that of those experiencing a severe disability, 3% have a sensory disability (VIVE 2020, 5). The sensory disabilities cover loss of sight, hearing, or speech (Aruma 2020), and according to a report from the Eye Association [*Danish: Øjenforening*] approximately 3,8% of the Danish citizens have a visual impairment with the majority being 65+ years old (Lohmann 2014).

#### Local Disability Council

As the counties were transformed into regions, the LDCs were established in every municipality in Denmark in 2006 (Center for Ligebehandling af Handicappede 2008, 8). The construction of the LDCs is dictated by the Ministry of Social Affairs through the latest statutory order no 1555 from November 2nd 2020 (Retsinformation 2020). In this, the LDCs are required to be consistent of six to fourteen members. Three to seven of these are to be representatives from the DDO, while there must be an equal number to this representing the municipality. The municipal representatives can be appointed from either the administrations, representatives from independent institutions, or private actors who execute relevant tasks within the municipality (ibid.). In the statutory order it is dictated that:



"The local disability council advises the municipal council on disability policy issues and communicates views between the citizens and the municipal council on local policy issues concerning people with disabilities." (ibid.).

While the statutory order dictates the constitution of the LDCs, the executive order, which was last updated on May 12th 2021 and formulated by the Ministry of Social Affairs, elaborates on the tasks and construction of the LDCs (ibid.). The executive order dictates that the disability representatives can be appointed from organizations outside of the DDO and the municipal council oversees inviting such representatives. The number of external representatives must not exceed the number of representatives appointed by the DDO (Retsinformation 2021). From the two municipalities we investigated, one of them had invited a member from outside of the DDO member organisations.

The tasks of the LDCs are not elaborated in the executive order aside from what is already stated in the statutory order. Rather, the executive order is focused on where the LDCs can draw inspiration from. One suggestion is to draw inspiration from other LDCs or the DCH. The only restriction to the work in the LDCs, is that they cannot discuss personal cases (ibid.).

Dictated by the statutory order and the executive order, it is the DDO who appoints the disability representatives. They act as an interest organization in disability policies and is an umbrella organization consisting of 35 different disability organizations. Along with appointing members to the LDCs, the local DDO departments are also actively seeking to establish a close relation through dialogue with the municipalities outside of the LDCs. They further seek to influence political decision-making regarding disability policies, and through the local DDO department, DDO seek to have a collaboration with the different disability organizations to ensure a diverse representation of the disabilities in the municipality (Danske Handicaporganisationer 2021b). On their website, the DDO has highlighted the importance of the established LDCs, and they argue that a strength of the councils is that people with disabilities can represent themselves, and other disabilities, in a political context. The DDO finds the LDCs a necessity to ensure citizen involvement in



disability policies. However, they also highlight the necessity of improving the competencies within the council to strengthen the impact of the consultations reports and heighten the strategic political awareness (ibid.).

In 2020 the DCH published a flyer titled *The Voices of the Disability Councils*. They made a survey among the Chairs of the LDCs who were asked about the local disability policies and the collaboration between their LDC and the municipality. 80 % of the LDCs' Chairs responded in which 86 % represented a municipality which had a disability policy. 70 % stated that having a disability policy had an impact on the rest of the work done in the municipality. In the survey the Chairs responded that 48 % experienced that the municipality set aside money for disability-related projects in the budget, whereas 39 % experienced the opposite. As for accessibility, 60 % of the Chairs responded saying the municipality provided good conditions for people with disabilities, whilst 9 % responded saying they experienced bad conditions for people with disabilities. (Det Centrale Handicapråd 2020, 1).

In this thesis we have investigated two municipalities with a population larger than 50.000 citizens (Videncentret Bolius 2021). The two municipalities were complimented for their work practices in the LDCs, and we were intrigued to investigate what was already considered good practice cases. With this, we will present our informants from the municipalities in the next subsection to provide the reader with a description of the field of study.

#### Informants and Members of the Council

Our informants are primarily members of the LDCs, being the disability representatives, Politicians and Officers. We have furthermore interviewed one citizen from each municipality, as well as project managers employed by the municipality and representatives from disability interest organisations.

During the exploratory discussions with the chief consultant from the DDO, we became aware that the two major groups dealing with accessibility issues were wheelchair users and people with visual impairment. To investigate the experience of accessibility, we have recruited four wheelchair users and two visually impaired. Most people with visual impairment encounter their disability later in life and the majority of wheelchair users



are either born with their impairment or face it by the age of 16 on average (VIVE 2017, 17). Two of our wheelchair users were above the age of 60 while the other two were in their twenties. Our informants with visual impairment were both in their 70's.

For a full list of all informants and interviews, please refer to annex 1.

Each of the LDCs we included in our research consisted of three Politicians, three to four Officers and six to seven disability representatives. We interviewed a Politician, an Officer and two disability representatives, in each of the LDCs to get insight in the practices and attitudes of all three groups.

Ida is a political member and has been part of the LDC for 10-12 years. In her political wing there was allocated two out of three seats in the LDC and when we asked her if there was a contested election for the seats, she said that it was very easy for her to get one. According to her, the LDC is not very "hyped", and she stated that other Politicians prefer to enter councils where there are more votes to pick up during elections. She also stated that she had an agenda with being part of the council. She herself is a next of kin to some-one with a disability, hence she was very aware of the importance of the work in the LDC. Her most important task is to have a close dialogue with the members of the LDC, and to be able to carry it into the political system. Because she is a member of the municipal council, she has other political tasks and connections to other councils. She therefore considers it her task to transfer the disability representatives' wishes, objections, experiences, and agreements from the LDC and back to her hinterland and the groups, committees, and councils she is part of.

The other Politician is Emma who has been part of the LDC for 8 years. In the municipality where she was elected there was only one seat in the LDC allocated to her political wing. She had to fight for the seat against a member of another political party, but she won the seat by forfeiting other "more desirable and profitable" seats in the municipality. To her, the social and disability area has become a special area of interest, where she has also worked with the municipality to set up a vulnerability council. She describes that she has a strong and basic sense of justice and wants to be "the voice of those who do not always"



have a voice themselves". Like the Politician in the other municipality, she considers herself to be the one who brings information back and forth between the LDC and other relevant councils and administrations.

Isabella is an Officer working for the department of City Planning and Housing and has been a member of the LDC for the last 5 years. Since she is independent of election results, she can be part of the LDC until she no longer wants to or upon agreement with another colleague. She was appointed by chance, though she felt a commitment to the LDC as she has a daughter who at one point used a wheelchair. She is not as active in the meetings that do not concern her own administration, as their topics can sometimes be very specific and technical, and she leaves the solutions and proposals to those of her colleagues from the other administrations. In addition to answering questions, coming up with solutions and discussing the LDC's proposals with her administration, she sometimes brings cases up in the LDC meetings herself. The other employees in the administration are aware of her being part of the LDC, and whenever a new build- or planning project enters her administration, she makes sure that the other Officers check in with the rest of the LDC before starting the project.

The second Officer, Victor, is Head of the department for Roads and Green Areas, and works with urban planning and infrastructure, among other things. He has been appointed to the council by the technical director who was a member prior to him. The technical director got tired of constantly having to pass his office, as the topics in the LDC meetings typically required Victor's core competencies. When he attends the LDC meetings, he admits that he is not the one to talk the most and does not speak if the conversation concerns the other administrations. However, he always likes to listen and provide technical assessments if it becomes relevant. To him the LDC is a great place for discussions. He believes they have a good dialogue, especially with Eric and Jacob as they are the disability representatives whose interest lies within accessibility. He is used to either Eric or Jacob approaching him directly whenever they have experienced an issue with accessibility. Likewise, he will also ask them directly if he has a question about the needs for people with disabilities.



The last group is the disability representatives. We interviewed two disability representatives in each municipality, both Chairs and two ordinary members, one having a disability himself while the other was next of kin to a person with a cognitive disability.

Eric is Chair and has been a member of the council since the establishment of their LDC, while Jacob has been a member for 10 years. All the disability representatives are responsible for different areas so that they all work with the area that interests them the most, e.g., Eric and Jacob are responsible for accessibility, while others are responsible for the social or employability area. Their job is to advise the municipality on all issues related to disability, but according to Eric, this is not always happening. He believes that they do not facilitate enough meetings in the LDC to manage all the work related to it. This has left Eric to read through all the committees' agendas every month, and comment on the points they in the LDC can do something about or have an opinion on through consultation reports. Both Eric and Jacob invite the Officers and Politicians on city hikes where they get equipped with either glasses to make them visually impaired like Eric or use a wheelchair like Jakob. This is Eric's and Jacob's way of transferring their experiences of living with a disability onto the Officers and Politicians. They have found that it helps them in the discussion on improving accessibility in the municipality.

In the other municipality we also interviewed the Chair and a disability representative of the LDC. The Chair, Ursula, has been part of the LDC for 6 years. Prior to a LDC meeting she usually hosts a meeting exclusively for the disability representatives where they discuss the points on the agenda for the formal LDC meeting. Ursula likes to show that the disability representatives are engaged in the policies in the municipality. To make sure their presence is noticed she spent a lot of time writing consultation reports to different projects. To engage even further, she holds annual meetings with the Officers from the social administration. According to her, she collaborates with him often as most of the disability policies are situated in his administration. The other disability representative, Oskar, is a next of kin to a person with a cognitive disability. Oskar has been part of the LDC for 12 years. According to Oskar, the job of the LDC is to represent citizens in the municipality. He elaborated on this saying there is an informal agreement amongst the disability representatives that, regardless of their own disability or formal background, they consider themselves as representatives of the citizens. In terms of being included in



the build projects in the municipality he thinks the Officers are good at including them in the beginning of the process but acknowledges that there is still a long way to go until sufficient involvement. Oskar is fond of the collaboration in the council. He feels that the Politicians and the Officers are engaged and feel accountable for the LDC. However, through the interviews Oskar would usually answer as him being a representative of a specific disability organization and not as a representative in the LDC. During the interview, his focus was directed at the specific disability organization and how the LDC was more of a forum where he could express the needs for people with cognitive disabilities. While Oskar does not represent a mobility or visual disability, we found it relevant to include him to examine his representational capacity as a non-disabled member.

Departing from our introduction to the field, we find it relevant to investigate the LDCs and how the representatives work collaboratively. Having provided the reader with an introduction to our informants we will move on to the next chapter, where we present our theoretical framework for this thesis.



Fechno-Anthropology Master Thesis





## Framing the Thesis

During this chapter, we wish to provide the reader with an explanation of our chosen theoretical framework, hybrid forum and the organisational criteria of classifying dialogic procedures presented by Callon et al. (2011). In this chapter, we will also provide the reader with our reflections on using hybrid forums. We will further introduce the concepts of contributory- and interactional expertise, explained by Collins (2004), as a supplement to the framework of hybrid forums. Lastly, we will provide the reader with a state of the art regarding disability research and disability studies in field of anthropology and STS studies.



## Hybrid Forum

Research has traditionally been conducted by scientists or experts and secluded research, referring to research done among, and limited to, scientific arenas and actants such as laboratories and scientists, risks losing its touch with the world in which the science resides. Without being in touch with the world, secluded research can face issues of implementation and relevance, in an ever-changing society which might not be interested in the results anymore (Callon et al. 2011, 94). The battle between science and the validity of lay knowledge is often discussed, and Callon et al. argues for the importance of linking science to the real world by relying on the participation and inclusion of laypersons. To create a symmetry between scientifically situated knowledge and lay-knowledge, he introduces the phrase *research in the wild*, emphasizing that "laypersons are full-fledged researchers in their own right" (Callon et al. 2011, 99).

He links research in the wild to his concept of hybrid forums which are spaces where negotiations between research in the wild and secluded research can take place. Hybrid forums stem from the approach of Actor-Network Theory (ANT), introduced in the 1980's by Callon, Latour, Akrich and Law which has later been applied to a range of different uses and modified since its introduction. One array of concern within the post-ANT approaches is that of issues of political character. Different approaches of post-ANT have become political by examining the conditions under which hybrid actors come together and new knowledge emerges (Michael 2016 2006, 116). Hybrid forums belong to this group of post-ANT approaches which are concerned with how otherwise marginalized or excluded actors can be incorporated (ibid.). For hybrid forums, the focus is on how "hybrid forums bring together specialists and laypersons, citizens and representatives" (Callon et al. 2011, 35). Hybrid forums differ from formal institutions as the latter already have established structures and ideas of power, science, technology, and democracy (Galis 2011, 834). Instead, hybrid forums are public, open spaces where diverse groups can discuss socio-technical controversies regarding the collective. They are hybrid because they consist of heterogeneous groups; groups which carry out research in the wild, institutional researchers, scientists, and other experts, who negotiate with each other (Callon et al. 2011, 18). Or as Amilien et al. (2019) describes it:



"It is a question of enabling different groups to partake in the dialogue process and share the public space, so that all voices and identities can be heard. Everyone, from experts to laypersons, can contribute with information and knowledge that will enrich the discussions, by expanding and improving current understanding and points of view, by revealing uncertainties and exploring constraints, by suggesting innovative solutions and regenerating the dialogue." (Amilien et al. 2019, 3153).

Hybrid forums cover a wide variety of existing procedures for dialogue; focus groups, public inquiries, consensus conferences etc. where controversies are at the core. One of the founding elements of hybrid forums is the existence of controversies, which Callon et al. describes as "enriching democracy" (Callon et al. 2011, 28). Controversies and confrontations are a central element to all public engagement methods that aim at facilitating a dynamic and positive engagement to reach mutual discoveries and comprehension. (Amilien et al. 2019, 3153). The important component of controversies in hybrid forums is that they entail a socio-technical dimension, where the social and the technical are understood to be interwoven (Callon et al. 2011, 28). In hybrid forums, participants are both active speakers and listeners, learning from each other, as they act together in constructing the local community. Amilien et al. points out that a key attribute to hybrid forums is that participants are not discussing "a world which is already made [red. but] a world in the making" (Amilien et al. 2019, 3153). In Callon et al.'s words, hybrid forums "are powerful apparatuses for exploring and learning about possible worlds" (Callon et al. 2011, 28).

Like the traditional ANT approach, the concept of hybrid forum is also concerned with a study of actants and how they relate to each other (Blok and Jensen 2011, 6, 23). As such it originates from, and subscribes to, a relational ontology in which what distinguishes subject from object is their mutual relations rather than their inherent substance (Wildman 2006, 1). Traditionally, the social sciences have made distinctions in the agency between human actors, the artefacts they produce, the animals and plants they surround them with as well as abstract human creations such as words, thoughts, practices, and skills. By encompassing the principle of generalized symmetry, and a material-semiotic



approach to practice, ANT gives equal agency to everything, a priori the distinctions. Actants are woven together in never ending heterogeneous networks of material-semiotic relations, where both human and non-human actors become actants, which are described and analysed using the same terms (Law 2003, 1-4).

#### **Classifying Dialogic Procedures**

Having applied hybrid forums as our framework for the analysis of LDCs, we reflect on the criticism posed by some social scientists on the approach of ANT, and how the concept of hybrid forums can contribute with new approaches, or risk reproducing existing issues. The notion of the symmetrical approach to both humans and non-humans, has posed the question among some social scientists of whether this symmetry implies that non-human actants have intentions and feelings (Galis 2011, 830). Rather than considering the actors as separate, ANT scholars propose that the analysis should follow the attribution of roles, hence following the exchanges of agency within a network. Agency depends on the object's role or position and agency can be transformed from one object to another. Humans might be endowed with logic, choice, experience, and intentions, but this would not be possible to enact without the existence of material-semiotic surroundings (ibid., 831). Galis explains that different bodily forms, abilities, and disabilities are not independent of architecture, but are mutually constitutive as "the generalised symmetry principle implies that disability is an effect of a process of associations in a network" (ibid., 831). Another criticism of ANT is the lack of focus on power dynamics. While the formation of networks entails practices and functions of minorities, ANT does not allow for a recording of potential discriminations and exclusions (ibid., 832). A key phrase in ANT is to *follow the actor*, an approach which does not outline any specific action or explains anything. It is radical empiricism in the sense that it discards all prior assumptions, and it implies a constant emerging empirical field (Winthereik 2019, 24). In response to how ANT can be used as a theoretical framework, Latour argues that by following the actants, researchers can explore the connections that result in why and how actions and relations emerge. The purpose is not to inform but to be informed. To Latour, critique is not a perspective that is added using theory, but rather a possible result of an analysis which follows the central actants' issues (Winthereik 2015, 6). Strathern has proposed an extensive critique of the network approach in which researchers follow the actants by stating that there are differences in the empirical and conceptual worlds and that



these notions of differences might not be shared by the informants (Winthereik 2019, 25). By following the actants, ANT inspired scholars are at risk of following the relations assumed to be relevant to the informant, rather than what lies beneath the relations.

It is curious to note that while Callon himself was part of introducing the approach of ANT, he, alongside his co-authors, offers specific concepts and tools for analysing the network. The concept of hybrid forums offers a variety of different tools to analyse different power positions, mainly those between established groups and emerging groups. For example, while ANT dissolves the distinction between a micro-macro level (Latour 1996, 371), Callon et al. reinforces the distinction by differentiating between different stages of translation which is situated in both micro and macro level and the research's situatedness in the world (Callon et al. 2011, 48). They further introduce the concept of dialogic procedures, which Callon et al. suggest is relevant to consider in terms of assessing the democratic capabilities of a hybrid forum (ibid., 158).

The criterion for classifying dialogic procedures consists of six criteria and related subcriteria, which are used to evaluate procedures that allow for dialogic democracy to develop and their ability to facilitate dialogue (ibid., 158). For our analysis, we will apply three of the six criteria for classifying dialogic procedures. The criteria are divided into two categories. Organisational criteria classify procedures in terms of their ability to contribute to an establishment of democratic confrontations as the procedures are considered more dialogic if they encourage exchanges and debates. The other category is the implementation criteria which are added to evaluate the implementation of dialogic procedures (ibid., 161). We find that an assessment of both categories of criteria is necessary to determine whether a hybrid forum has potentially successful dialogic procedures. However, we have decided to focus on how the LDC enables citizens with disabilities to participate in discussions on accessibility with the municipality, and we will therefore analyse the existing procedures, and assess whether they are present, and if so, how dialogic they are. Due to this focus on the practice of the procedures, rather than on their implementation, we only include the organizational criteria in our thesis. The organisational criteria are *intensity*, *openness*, and *quality*. Openness refers to an evaluation of the procedures permitting new groups to participate in discussions and the degree of diver-



sity. Through openness, both the representativity of the groups and their ability to participate in debates is assessed. Intensity is described as an assessment of the degree in which laypersons are allowed to collaborate with specialists, often determined by the earliness of the involvement of the laypersons. It is further assessed how the collective is composed regarding readiness to participate in negotiation on new collective ideas as opposed to remaining firm on individually composed ideas. Quality relates to the ability of the groups to remain authentic while also evaluating how far the collective can push the discussions in terms of their potential to last outside the hybrid forum (ibid., 158-160).

By introducing the term of dialogic procedures, as well as the terms secluded research, research in the wild, established groups etc, Callon et al. contest the traditional approach of ANT by enforcing a priori scope of the analysis. As for the criticism towards ANT's lack of attention towards power dynamics, we find that by focusing on how marginalised groups can enter the arena of research and influence politics through the lenses of the three criteria, hybrid forums offer an analytical scope which can also be used to study relations of power. For our analysis we have chosen to apply this scoping as we find it useful in assessing the involvement of disability representatives and the potential for impact on accessibility through the approach of LDCs.

#### Dialogue in the Local Disability Councils

The LDCs are constituted as part of the municipalities and are therefore institutionalised. Because of this, we do not find that the LDC are a full-fledged hybrid forum, but we do see similarities which we argue make them comparable to one. As shown with the models of disability, the topic of disability has been contested and negotiated through time, and it is relatively modern to consider accessibility as a societal issue rather than an issue related to individuals. This shift in attitude has brought along numerous controversies on how to design accessible cities which have currently been dominated by a tendency to accommodate abled bodies. There is also a rising awareness of different disabilities' needs opposing each other. People in wheelchairs for example need a lowered curb, but service dogs, used by people with visual impairment, only stop if there is a steep change in level between street and sidewalk. On the other hand, people with visual impairment are fond of strategically placed cobblestones, like the ones placed between the tiles of the



sidewalk, while these can be a real obstacle for a wheelchair user. Controversies have a key role in the constitution of hybrid forums, and controversies like the ones mentioned above are part of what is discussed within the LDC.

Hybrid forums are further described as open, public spaces. Whether the LDCs can be considered open will be contested as part of the analysis but based on their legislative description and their organisational relation to the municipality, we do not find it accurate to call them neither open nor public. The members rarely change and when they do it is as part of a formalized process of election by either the municipal council or the DDO. This also entails that the same group of members discuss a wide variety of topics, whereas in a hybrid forum the engagement from both the public and the institutions would change depending on the topic. However, since the overall topic of the LDC is disability related, one might argue it is not necessary to involve new actors at every meeting.

While the disability representatives engage as representatives of the public, or as Callon et al. puts it, laypersons, they contribute with experience-based knowledge and engage in discussions with the municipal representatives who represent the political, institutionalised opinions. We find that applying an analysis of the criteria for classifying dialogic procedures can inform the assessment of the collaboration between the disability representatives and the municipal representatives. Our aim is to analyse the collaboration within the LDC and the potential for the discussions to have an impact in the decision-making in topics related to public accessibility. Furthermore, while we have so far elaborated on our argument of the LDC as not being a hybrid forum, we find it relevant to investigate what organisational changes could be made to give the LDC the status of one, and what such changes would imply.

Research in the wild and secluded research are characterized by the type of knowledge they are based on. Callon et al. describes the distinction between *experientia* and *experimentum*, where experimentum is knowledge mastered through experimentation by the scientific research collective, and experientia refers to "common knowledge" or the experienced knowledge held by laypersons (Callon et al. 2011, 76). By not including laypersons, scientists risk focusing on the technical aspects and undermining the related social issues. Callon therefore argues that "laypersons can and must intervene in the course of



scientific research, joining their voices with those of the people we call specialists" (ibid., 70). Callon et al. applies the concept of research in the wild as an opposition to institutionalized research. Research in the wild is based on experientia, as it is the experienced knowledge of laypersons, and the concept research in the wild creates symmetry between scientific knowledge and lay-knowledge, where the knowledge of the laypersons is considered valuable to scientific research.

We do not find that the knowledge the disability representatives contribute with is research in the wild, because it would defeat the purpose of this kind of research being done outside institutional spaces. However, acknowledging that they are indeed contributing with experiences, we have aimed at coining this kind of expertise in other terms inspired by Collins.

#### The Pursuit of Expertise

Callon et al. notes in relation to representation and representativeness, that spokespersons of laypersons can represent by becoming credible and legitimate. Credibility is, according to Callon et al., achieved through participation in technical work, where the spokesperson can gain an understanding and technical vocabulary of the issue at hand. While credibility can position the spokesperson as an expert among experts, it is the notion of legitimacy that ensures their connection to the social movement they represent. Successful representation is, according to Callon et al., establishing the link between participating in the established research collective, while maintaining the link to the social movement (Callon et al. 2011, 84). Having argued that research in the wild is not currently present in the LDCs, due to the institutional situatedness, we want to explore the concept of representation through the notion of credibility and legitimacy departure from the experience-based knowledge of the disability representatives. We examine these by applying Collins et al.'s (2007) concepts of contributory- and interactional expertise (Collins and Evans 2007, 14). Both concepts build on the phenomenological experiences of the laypersons by differentiating between direct and indirect experiences. Having contributory expertise, Collins argues that a person becomes an expert when the person holds a competency within a specific task or field, which the person can execute subconsciously (ibid., 24-27). A contributory expertise is therefore a direct practical experience



with a subject. Likewise in our empirical data, citizens with disabilities have a contributory expertise with how it is to live with a specific disability, as they themselves experience it.

As for the question of how they can represent other types of disabilities, Collins' concept of interactional expertise becomes relevant. Interactional expertise is the competence to represent others' experiences without having practical experience with the subject itself. Collins proposes a critique of a traditional phenomenological approach stating that "We [e.g., traditional phenomenologists] tend to believe that only those who, as we might be inclined to put it, 'share the form of life' of the relevant activity would be able to understand it fully" (Collins 2004, 126). Rather than subscribing to a notion of expertise as result or direct experience with a subject, Collins argues that expertise can also be obtained through the experiences of others (ibid., 127) Collins uses an example of obtaining interactional expertise through the shared experiences of being blind and using a white cane. By spending enough time with a blind person, to the point of immersing into the life of the blind and learning how they live, Collins can represent these lives without ever having been blind or walking with a white cane himself (ibid., 127). We use Collins' concepts of expertise to analyse the representative capabilities of the disability representatives, by analysing how credibility and legitimacy can be obtained as part of the expertise.

With our application of hybrid forums and Collins' expertise, we wish to briefly reflect on the differences between a post-ANT and a phenomenological approach. The main difference is symmetry, which is the same type of explanations for successful and unsuccessful knowledge claims. Phenomenology does not share the ontological assumptions that give agency to non-human actors a priori their distinctions, as it is difficult to get access to the experience of objects (Verbeek 2011, 29-30). ANT and phenomenology both have intentionality, but in phenomenology, only humans can have intentions. How we understand the world, and what is in it, is entangled, and having true authentic access to reality is problematic. When we are in the world, our consciousness is directed towards something, which influences our perception of the world, referred to as intentionality (Jacobsen et al. 2020, 283-284). In combining a post-ANT approach with a phenomenological one, we acknowledge their fundamental ontological differences, and we are aware that applying post-phenomenology, rather than phenomenology, is more common in relation to ANT's



relational ontology. While post-phenomenology does not apply a symmetry between heterogeneous actants, it does relate to ANT in the sense that post-phenomenology is occupied with the relations a subject has to the world as mediated through a technology or an object. By doing so, more apparent lines can be drawn between the apparatus of the two approaches. In our analysis we find that it is relevant to study the competencies of expertise, which are obtained through experiences, as we are not focused on the experience as a relation. With attention to citizen involvement and hybrid forums, which constitute our theoretical framework, we will apply a phenomenological approach to investigate and analyse the experiences of disabilities, and how these experiences configure users as experts.

#### Studies of Disability

In terms of disability research in Denmark, Bengtsson and Bonflis (2013) from the Danish National Centre for Social Research and Metropol, argue that compared to countries like Norway and Sweden, Denmark has few entities of disability research (Bengtsson and Bonflis 2013, 14). In Norway and Sweden, research communities within disability studies have evolved with the aid of earmarked support from public research councils. There is a strong collaboration between academia at universities which is supplemented by national research institutions, unlike in Denmark, where disability research is far weaker at the universities (ibid.). Most of the research and assessment conducted in Denmark is by private consultancies hired by government departments to assess social, labour market and educational-related initiatives. Accessibility research in relation to disability studies was considered a new area of research in 2013, and Bengtsson and Bonfils consider it to inhabit the border between technical, science and social research (ibid., 30).

#### Anthropological Studies of Disability

The classic field of anthropology is concerned with culture and has as such contributed to knowledge about relativity, relevance, and the definition of meanings within cultures. The concept of culture has also been a cornerstone within the anthropological study of disability and the lens of culture has been applied in a variety of ways. To some anthropological scholars, disability may be considered a culture while others investigate how culture can be considered a disability. Cultural norms and values have also been analysed as influencing the conceptions of disability (Reid-Cunnigham 2009, 99). Within cultural



anthropology, the focus has particularly been on the notion of an outsider with an analysis of how different cultures perceive and identify *otherness*. Especially concepts like *stigma* and *deviance* have been essential within social and cultural anthropology and anthropological researchers have often applied the concept of liminality, which refers to transitions between social roles and statuses, to explain a stigma applied to people with a disability (ibid., 104, 107). A major anthropological contribution to the studies of disability has been the notion that disability is a social, biomedical, and cultural phenomenon, and can be studied as sociocultural experiences (ibid., 100). In most studies of disability within an anthropological framework, the degree of an impairment is rarely significant, but defined by "societal standards for normative bodies, behaviours, and role fulfilment" (ibid., 107).

Using Reid-Cunningham's historical overview of disability studies in anthropology, we briefly provide the reader with an introduction to some major influences within this field of research. One of the first studies of disability was done by Benedict who in 1934 published a study on how epilepsy was perceived cross-cultural, offering a cultural framework of disability which has been central within anthropological studies on disability (ibid., 102). Later in 1953, Mead argued that people with disabilities should be included within a realm of *normal*, which was significant at the time as it proposed the importance of including people with disabilities in anthropological enquiries to fully understand the complexity of humans (ibid., 102). A decade later, the disability rights movement was introduced in the United States and together with it an independent living model which broke with the institutionalisation of people with disability and brought attention to the rights of people with disabilities. The social conceptuality of disability within anthropology formed the social model of disability and Sociologist Goffman's (1963) concept of stigma supported the following phase of disability studies in anthropology by analysing how stigma is part of constituting disability as something different from the normal (ibid., 103). Up until the 1970s, anthropologists had used an etic approach which used culturally neutral terms provided by an outside observer to enable cross-cultural descriptions. However, the etic approach to disability studies was contested by Frank in 1984 who introduced the phenomenological perspective to the studies of disability. By using phenomenology to study disability, Frank applied an emic approach, which is specific to a culture and describes behaviour in the context of a social environment. With Frank's work came


a detailed description of the experiences of people with disability in the United States and it changed the existing paradigm of analysing disability in different, foreign cultures to an interest in more local instances and experiences of disabilities (ibid.). Some of the most prominent anthropological voices today within disability studies are Kasnitz and Shuttleworth. They advocate for the engagement of anthropology in disability studies and are especially concerned with promoting the legitimacy of disability studies conducted by researchers with disabilities (ibid., 104).

An example of the cultural approach can be found in the text *The interactions of disability* and impairment by Coleman-Fountain and McLaughlin (2013). They investigate why some differences in appearance and capacities of the body become significant in determining people's social position. They apply *symbolic interactionism*, which is a theoretical perspective of how repeated, meaningful face-to-face interactions among individuals are part of creating and maintaining a society (Carter et al. 2016, 931). Through symbolic interactionism, they aim at attending to the ways "in which subjective experiences of the body emerge in the interplay between physical and cultural interaction" (Coleman-Fountain et al. 2012, 134). Their focus is on the significance of social interactions and how these constitute the ways bodies are made sense of. While mainly operating on a micro level, assessing the everyday encounters, Coleman-Fountain and McLaughlin also explores how these interactions are intertwined with the macro level of power dynamics and discrimination. They apply Goffman's notion of stigma to investigate how a disability is part of constituting individuals as different or other from the constructed normal (ibid., 2012, 135). This investigation of the otherness of disability and interactionism as constituting a social role leads them to explore the institutionalisation of bodies and how disability is embedded in institutions and how different narratives can damage the perception of impairment and disability (ibid.).

The classic cultural and social anthropological approach is concerned with humans, cultural norms, and social roles. Common methods applied by classic anthropology involve detailed descriptions of people's experiences based on time intensive observation where the researcher aims at understanding the practices through a participation in them (Reid-Cunnigham 2009, 107).



While anthropology is occupied with human subjects, experiences and cultural influences, STS applies to a certain degree the same set of methods, but with an attention towards a socio-technical approach. Attention within this approach encompasses human as well as non-human actants, as technologies, tools, procedures etc. are part of influencing the social (Geels 2006, 1000).

#### **Disability Studies in STS**

Inspired by feministic STS, where dichotomies are constituted through interactions with technologies and symbols, Moser (2009) presented a new conceptual approach to disability studies. She is interested in exploring embodiment as a practice in relation to ongoing enactment, materialization, and process (Moser 2009, 84). This approach is inspired by the tradition and interest in science and technology studies to "explore the constructed nature of facts, object, embodiment and matter in scientific practices, as well as the role of facts, objects, technologies and materiality in the structuring of social life" (ibid., 85). She applies a semiotic approach that stresses the material heterogeneity and the fact that these are neither just social nor discursive, instead, they are situated in practices and within a wide set of relations. The approach also focuses on process rather than product and that order or construction is not something that is achieved once and for all, but that it is an ongoing process which is continually established. Finally, the material semiotic approach is attentive to the multiplicity and dynamic instance of practices, circumstances, and arrangements (ibid.,85-86). Moser refers to decomposition as the decomposition of practice. She describes it as "a body becomes an able body through the enabling material practices it is involved in. Equally, a body becomes a disabled body through the disabling material practices in which it is involved" (ibid., 88).

Along the lines of Moser, Galis (2011) applies the conceptual vocabulary of ANT to studies of disability. He argues that within disability studies, there has been a rising need for a theoretical vocabulary that can answer the question of how people become, and are made, disabled as well as who has the authority to determine what disability is, and how it is represented (Galis 2011, 825, 829). The use of ANT breaks with a previous epistemological idea of the hegemony of an individual subject as the sole generator of socio-material realities. Instead, the experience of disability can be considered as embedded in complex networks of socio-material relationships. By abandoning the subject as the unit



of analysis, which is a common approach in classic anthropology, the researcher can order disability as a simultaneous biological, sociomaterial and semiotic relation produced by heterogenous objects.

### A Techno-Anthropological Approach

Through a techno-anthropological approach, we argue that our research combines the framework of both STS and classic anthropology. In Techno-Anthropology, the aim is to understand and analyse the experiences of actants and bring forth the qualities and representations (Botin 2013, 88). The process of bringing forth encompasses an element of engagement and involvement, which also situates the researcher as part of what is studied. Within Techno-Anthropology is an underlying interest in transforming and influencing the field of topic and an attempt to improve or modify technological processes, design-solutions, and socio-technical collaborations (ibid.). As Techno-Anthropologists, we are therefore more than observers, as we are aware of, and concerned with, the dynamic and transformative forces that surround us.

With the techno-anthropological motivation to engage as actors of change, it becomes essential to evaluate and reflect on our normativity as our analysis is bound to be influenced by this. We believe that people with disabilities have a right to be included in society, and that appropriate measures must be invoked to ensure accessibility. With appropriate measures, we argue that participation in everyday activities should be accessible on equal terms with everyone else but do acknowledge that in some instances accessibility must be achieved through additional devices or alternative solutions. These solutions or devices must however not impose a degenerating feeling with the person. We argue that citizens with disabilities must be involved in cases that affect them in any way, and in approaching the field we have been influenced by an opinion that the current involvement was not sufficient.

We have introduced our theoretical framework of hybrid forums which we will apply to investigate how the members of the LDCs can represent people with disabilities in relation to build environment projects. By focusing on the symmetry between actants and the relations that configures the network of a hybrid forum, or in our case the LDC, we avoid blindly following the relations proposed by the actants and scaffold our analysis to what



is relevant to the analysis of the criteria of dialogic procedures. By including both human and non-human actants, we apply a relational ontology. As we are occupied with understanding the relations, based on the experiences of the LDCs' members, we have argued for the use of a phenomenological epistemology which concerns itself with the actions, experiences, and intentionality of the human actants. We have further introduced the approach to disability studies within classic anthropology as part of displaying how STS differs from classical Anthropology. Emilie S. Nielsen, Louise Løken Sebastian M. Andersen Techno-Anthropology Master Thesis





# Entering the field

In this chapter we introduce our methodological approach, which is occupied with studying experiences and social relations, to examine the LDCs' capacity to represent citizens with disabilities. The reader will be provided with a review of the qualitative methods we have applied in our fieldwork. Our empirical data consists of 16 interviews and 4 participant observations. This chapter will provide reflection on the methods applied, how we as researchers have been part of shaping the data collection and ethical considerations relating to the anonymity of our informants. Techno-Anthropology Master Thesis



# Methodology

We apply institutional ethnography as our methodological framework and aim at understanding the composition of the LDCs and how it influences the representation of a disability through an experience of living with a disability. Institutional ethnography proposes that in studying social relations, the research origins in the experiences of people rather than in a predefined theoretical framework (Smith 2006b, 2). This approach resides in a non-positivist or interpretivist methodology which considers phenomena and social relations as relative to each other and positions the researcher as part of the subject being studied (Carson et al. 2001, 16; Smith 2006a, 16-17). Institutional ethnography studies how social relations structure people's life and how these interactions are institutionalized, but without studying the institution or organisation itself. Our field of study is motivated by a curiosity and analytical need of understanding the experience of people with disabilities and the LDCs' capacity to represent this group. In addition to understanding the experiences of living with and representing a disability, our aim is also to contribute with ethnography which can generate action by proposing constructive suggestions to changes in the procedures of the LDC. Following the course of experience, our object of study has been the members' experience with representing people with disabilities, and how the LDC as an organisation utilizes this representation during actions of citizen involvement. To avoid an idealistic approach to change-making, where the generation of solutions is in focus, we apply critical proximity to guide our dive into the network of issues, and how they are developed and negotiated in a socio-technical setting.

Critical proximity is described by Birkbak et al. (2015) with inspiration from Latour and Haraway. The inspiration from Latour stems from a point that critique does not automatically imply a *critical distance*, i.e., Latour critiques branches of academia for keeping the issues at arm's length and analyses them from a point of view of generalization, rather than considering the actants own entanglement with the practices thus rendering distance impossible (Birkbak et al. 2015, 270-271). As for Haraway, critical proximity is influenced by her argument of *situated knowledge* which entails that knowledge is always situated in a context and must be considered as such. From the critical distance and situated knowledge Birkbak et al. suggests critical proximity as an approach to follow and identify the existing struggles (ibid., 267-268). Critical proximity is different from Latour's critical distance in the sense that it appreciates user involvement as a site where



critical engagement comes into play (ibid., 271). Critical proximity is concerned with the underlying issue and the way researchers engage with the object of study making them part of what is researched. Rather than taking an ideological stance, the approach of critical proximity is interested in decisions and negotiations which constitutes an issue. Identifying the on-going struggles is referred to as *issuefication* where rather than discussing whether an issue or solution is possible or not, it is occupied with how issues arise in socio-technical dynamics and what new possibilities it creates (ibid.).

With the scope of critical proximity, we considered our fieldwork to be part of a mutual relationship with our informants. We were aware that our informants might also be interested in our project and its results and therefore also invest themselves into it. They have been part of scoping our project and have engaged as allies for us to access the field of disability studies e.g., when Anna informed us about the role played by the LDC and Eric facilitated the contact with the other members.

An important consideration is how we as researchers influence and represent the studied object. Part of the institutional ethnography approach is to recognize that we as researchers are situated in a historical context, and that our experiences, interpretation, and mediation will always be influenced by the social relations we engage in (Smith 2006b, 2). While our aim is to produce knowledge and present the reader with a description of a problem, we must be aware of our role in framing and formulating the issue at hand. Mantzoukas (2004) describes research findings as "in essence, a makeover of the researched world(s) that in a clear, powerful, and "truthful" manner is being (re)produced within the research text, thus providing greater, deeper, or more holistic knowledge" (Mantzoukas 2004, 994). The researcher must be aware of what and how they represent what is studied. To do so, researchers must ensure a consistency, reliability, and dependability between what is being studied and what is represented (ibid., 995). An approach to ensure a certain degree of representation is to bring forward the narrative descriptions made by the informants themselves (ibid.). We have in our research been occupied with what our informants expressed as the issue and their description of relations and situations. To avoid misinterpretation, we actively use quotations and references to conversations so that what is expressed is not misrepresented by our motivations but brought forward through investigations in the field.



However, Mantzoukas also poses criticism towards this approach, of researchers relying solely on quotations as legitimizing their representation (ibid.). He stresses the importance of reflectiveness about, not only the representation of the field, but also the influence the researcher is bound to cause solely due to their presence. It is essential that researchers consider their own epistemological and ontological assumption and how the lenses and frameworks are influencing the knowledge produced. Otherwise described by Mantzoukas as "the means and production of knowledge and the relationship that exists between the knower (inquirer) and the wouldbe knower (participant) [...] regulates to a great degree what eventually is represented by the research text." (ibid., 996). Considering ourselves as part of the non-positivist paradigm, which argues for a plural concept of truth and reality which is dependent on subjective viewpoints (ibid., 1000), we acknowledge that our position as researchers compromises subjectivity too which makes us an inevitable part of the studied object.

With this in mind, we will elaborate on our motivation and agenda and reflect on how these can influence our knowledge production and representation. While trying to identify the underlying issues with accessibility and representation of disability, we aim at conducting action generating ethnography with the purpose of not only identifying issues but producing possible solutions. From the interviews with the members of the LDCs we have sought to understand how they work collaboratively and display examples of productive collaboration and cases of issues with collaboration. To guarantee a certain quality of representation, we will throughout the thesis reflect on the production of data in our analysis and conclusion.

There are some fundamental differences between the social-constructivism approach of institutional ethnography and a post-ANT approach such as critical proximity, which needs to be addressed. With post-ANT the researcher is encouraged to follow the network, with no clear limitation as to how far out the actants should be followed. With social-constructivism, and especially institutional ethnography, the issues examined are limited to a defined institutional setting where the production of knowledge is situated (Gad and Jensen 2010, 71, 77). Furthermore, while institutional ethnography acknowledges the presence and influence of especially written texts, it is perceived as a means of establishing and participating in a relation rather than being an actant (Billo and Mountz



2015, 6). Acknowledging these differences, we will apply the situated scaffolding of institutional ethnography, along the similar scaffolding of hybrid forums, to argue for a limited research object being the actions related to the representative work of the LDCs. In terms of materials, we use the heterogenous concept of actants to investigate how consultation reports, wheelchairs, white canes etc. are part of constituting relations and experiences. Institutional ethnography and critical proximity share an emphasis on practices and an attention towards the elements of a complex network of relations constituting people's experiences, engagements, and actions. By combining the approach of institutional ethnography with critical proximity, we recognize the influence of our positioning and interpretation and aim at approaching the field as reflected as possible.

## Methods

For our data collections, we have used the qualitative methods of semi-structured and unstructured interviews. We have conducted moderate- and active participant observations with our informants in their neighbourhood and participated in a LDC related meeting. To support our qualitative data collection, we applied literature research on studies and cases of disability studies and disability analyses from an STS point of view. Along with our methodological approach of following the actants, we wish to illustrate how our choice of methods adjust with the progression of the fieldwork by presenting chronologically how our problem arose and got defined through different types of interviews. We further wish to reflect on the difference between physical and digital methods and how it has affected our data collection.

### Exploring the Issue

Knowing that we wanted to investigate disability and accessibility, but without having coined the issue yet, we began the process by exploring the topic of disability, accessibility, and public build. Through literature search and case reviews, we had gotten an overview of the historical context of disability and gained insights to the state of the art of a classic anthropological and STS approach to disability studies. These insights proved valuable during multiple interviews when our informants elaborated on disability as socially configured. During one of these conversations, we referred to previous perceptions of disability as an individual issue in the medical model, and this ignited an interesting dis-



cussion on how different areas of technical sciences still perceived disability as individually embedded. By understanding the historical context and previous practices in disability studies, we managed to elevate the discussions from an explanatory level to discussions and reflections on contemporary practices.

As we were still in the phase of scoping our projects, we contacted project managers in a municipality, who were part of a team where they engaged with citizens in the local planning of urban spaces and were responsible for redesigning current areas. Curious as to how citizens with disabilities were involved with the planning and design of urban spaces, we chose to conduct the interviews as unstructured. The use of unstructured interviews is helpful to researchers who have a basic understanding of a broader setting or experience. This type of interview allows the researcher to focus on the conversation and follow the informant's interests (Robert Wood Johnson Foundation 2016). So, while exploring the issue, we could facilitate the conversation depending on what we, or the informant, believed to be interesting and relevant for the issue of involvement. While the interview itself is unstructured, with no firm interview guide presented, it is important to note that an unstructured interview is still prepared with an agenda. Bernard (2018) describes it as the interviewer and the informant sitting down to have a conversation, with the informant knowing the purpose of the conversation and the topic which will be addressed throughout the interview. Thus, the unstructured part is due to lose control of the informants' responses (Bernard 2018, 164). The unstructured interview gave us the freedom to be able to change style and strategy on the go. Our goal for these interviews was to obtain an understanding of the disability- and urban planning context in Denmark, as we had found it troublesome to find any literature or research published in the last 10 years. From our first interviews we found that citizen involvement was a main method for designing the areas, but while they aimed at including a wide variety of neighbours, it depended mostly on the personal engagement of the citizens involved, and the project managers' experience was not, that people with disability was very well represented in that matter.

Intrigued by the notion that perhaps people with disability were poorly represented in the development of new build environments, we contacted Anna, chief consultant for ac-



cessibility in the DDO. She highlighted the LDCs and explained their organizational structure and their relation to the municipalities and the local DDO departments. While all municipalities are required by legislation to have a LDC, practice and collaboration within the LDCs could vary in all the municipalities.

Departing from a broad, undefined curiosity of how people with disabilities were involved in the process of urban planning and design, we narrowed the scope to focus on the involvement process as facilitated by the LDCs. What became important to us was not the technical components of how to build accessibility, but rather how the experience of disability is represented by the LDCs, in a collaboration between the technical and social.

#### Narrowing the Issue

Having conducted the unstructured interviews and moving closer to scoping our project, we contacted Chairs from LDCs in two different municipalities. As we presented ourselves in the email to them, we also presented our project as researching how the municipality was doing citizen involvement, especially regarding people with disabilities, with the focus on design and build of urban planning. The first who responded was Ursula who agreed to have an interview over the phone, where we talked about how she experienced the accessibility in her municipality and how she experienced citizens involvement in the municipality. What should have been a semi-structured interview became more structured, as she was crisp and to the point in her answers and left little room to ask followup questions. We realized we had not managed to build rapport during the interview with her, which was perhaps the reason that it seemed more structured than we first had planned for. Described by Spradley, establishing report can be considered as a harmonious relationship between the researcher and the informant. It is built based on trust between the two, and although rapport is not equal to friendship, it is still a way for both to feel secure in the interview setting (Spradley 1979, 44-55). Considering us not feeling we had built rapport with Ursula, we still got valuable information from her regarding her work as Chair in the LDC, and we had made an agreement that we could contact her if we had any further questions.



The second Chair we got in contact with was Eric. He would also like to talk with us but would prefer if we could manage the technicalities of the interviews. He had a visual impairment, so it was difficult for him to arrange the meeting with all the technical details, but he would be more than happy to talk to us otherwise. We set up the interview and provided him with detailed instructions on how to access Microsoft Teams. We planned to conduct this interview as semi-structured. Described by Bernard, the semi-structured interview is, unlike the unstructured, set up with a formal interview guide and not just an agenda. The interview guide adheres to a pre-defined topic, and the semi-structured, unlike the structured, leaves room to pursue leads from the informants by asking follow-up questions. The semi-structured interview is a method well suited for making comparative data collection (Bernard 2018, 164-165). The purpose of the interview with Eric was the same as with Ursula, with the only differences being the platform it was held on. We talked about how he was experiencing the accessibility in his municipality, and how he experienced being part of the LDC. Establishing rapport with Eric came quickly, and the interview and he was quite reflexive in his answers about the LDC and accessibility in the municipality. The interview led us in the direction of the collaboration between the members of the LDC and with the municipality in general. As we were already curious about how disability was being represented in the LDC we asked him if the other members in the LDC would be interested in talking to us. He replied that he would have to check in with them, and he would get back to us as soon as he had. Not long after, he returned to us with a list of the members of the LDC. He had already been in contact with them and informed them that we would write and ask for an interview.

With access to most of the LDC, not only disability representatives but also Officers and Politicians, we returned to Ursula and asked for a follow up interview with her. The second interview with her was conducted through Microsoft Teams, conducted as semistructured, and this time we managed to establish report, which was perhaps due to the format of the interview. At this time, we were more specific in what kind of information we were interested in and what conversations we were interested in pursuing, and we had beforehand asked her to allocate a specific timeframe, whereas for the phone interview, the framework of it was of a more practical, informative character. For this interview, we got a sense of report, and the interview became more of a conversation than a Q&A. From the interviews we gained insights on how the LDCs were constituted, and



which tasks they worked on during their meetings. Furthermore, we also gained insights in how the experiences with having disabilities became part of in-direct citizen involvement in the municipalities.

With our minds now set on the collaboration within the LDC, while still focused on the case of accessibility, we reached out to other members of the LDCs. In both municipalities we arranged interviews with the leading Officer of urban planning, another disability representative and one Politician. All the interviews were conducted as semi-structured where we focused on the work, and engagement in the LDCs. Furthermore, we asked about the representation of disability in the councils. Regarding the members appointed by the DDO we asked how they managed to represent disabilities in the meeting, while the Politicians and the Officers were asked how they represented disabilities in their other positions in the municipalities.

Inspired by a phenomenological epistemology, the purpose of the interviews was to gain access to the informant's experience of living with a disability and representing it in the LDCs. Since our project has required different knowledge from different informants, we have chosen different forms of interview, based on, and adapted to the informants.

During the interviews with Eric and Ursula, we invited them on a walk-and-talk in their municipalities, so we could experience how they navigated around town with a visual impairment.

#### **Experiencing Disability**

During an interview with Elisa from the Danish Association of the Physically Disabled [*Danish: Dansk Handicap Forbund*] she drew a hard line between knowing something and then experiencing it. She had on multiple occasions witnessed architects, Politicians and other decision-makers act as per usual without acknowledging the difficulties wheelchair users encounter. "I often tell people like you and them, people with no disability, that they should for the next 14 days be aware of all the places they could not gain access to, had they been in a wheelchair. Just try and reflect when you take a walk around the city. Think about what it would be like if you were blind or in a wheelchair."



Applying a common ethnographic method, we returned to the field using participant observation. Described by Spradley (1980), conducting observations requires the observer to be explicitly aware of one's surroundings (Spradley 1980, 55). Explicit awareness is to notice what goes on in the surrounding. He draws on a case of a vending machine, where no one would usually notice how and why they press the buttons. They do it without giving it much thought to how the machine acts accordingly or how the surrounding environment is situated. By explicit awareness Spradley argues that the researcher must take notice of the small details as part of the observation style (ibid.). Furthermore, Spradley argues for different levels of observation, which is determined by the degree of involvement from the researcher. These levels are described in a range of passive- and up to complete participant observation (ibid., 58-61). We began our fieldwork with a moderate participant observation approach. When conducting moderate participation, the researcher balances between an insider and outsider position (ibid., 60). The differences between inside- and outside is that with an inside perspective, the researcher aims at understanding the practices by experiencing them as a participant, engaging in the practice. With an outside perspective, the researcher pays attention to the surrounding factors and how the object of study engages with these. The insider/outsider dichotomy can be considered as the differences between participation and observation (ibid.). As participant observers, we paid attention to the infrastructure and became explicitly aware of the obstacles people with disabilities would encounter in the city. We began by exploring the problem of accessibility as outsiders by visiting Ræmise Parken, a recently rebuilt park on Amager and noticed all the accessible areas for a wheelchair user. As we became more aware of accessibility, we sought to gain the understanding of people who were experiencing these issues with accessibility.





*Picture 2: One of the entrances to Ræmise Parken. Prepared by Authors.* 

We arranged four walks in total, where we walked around town with a person with a disability. For all our walks we were focused on understanding how people with disabilities were engaging with their surroundings and to experience which obstacles they might encounter daily. For three of our walks, we used moderate participant observation. Walking alongside them, and asking questions whenever we met an obstacle, or something disability-friendly in the infrastructure. During these participant observations, we balanced between the position of an insider, while due to our abled bodies remaining outsiders. We became explicitly aware of phenomena such as guiding lines, the sound from a crosswalk, cobblestones etc. While aiming for a phenomenological experience of being visually impaired by following the guidelines, traffic light sound signals, we were also acting as guides for our visually impaired informants by stating the green or red-light

46 of 103



signals or preparing them for obstacles in the way. We compensated for the lack of bodily experience by asking questions regarding the experience of having a disability.

Spradley warns of the risk of an impression overload, if the researcher aims to both be a participant and an observer (Spradley 1980, 57). Being aware of this potential issue, we made sure to participate in teams of at least two so that one could focus on the insider experience while the other paid attention to that from the outside perspective. Aside from moderate participation we also used the method of active participation. In active participation, the researcher tries to do exactly like their informants. According to Spradley this is not only to gain acceptance from the community, but also to learn the cultural practices (ibid., 60-61). Therese had offered to lend us one of her wheelchairs so we could gain our own experiences with what it would be like to navigate around town in a wheelchair. Eric would have liked to offer us a pair of glasses which would blur our vision like his, and a white cane to walk with. However, with Covid-19, he thought it would be better to leave it at home for the day. From the active participation we sought to gain an understanding of what it felt like to navigate around town, which we applied as part of understanding the representation of disabilities in the LDCs.

Having conducted the interviews with the members of the LDCs in the two municipalities, and four walk-and-talks, we sought to analyse how disabilities are represented in the LDCs and how this representation becomes part of a larger system of citizen involvement when designing and planning urban spaces and build environments.

### Digital Approaches to Methods

Working with people who experience different kinds of disability enriched us with new experiences and considerations in terms of designing the interview with regards to the specific impairment. The literature on how to conduct interviews with people dealing with a disability is scarce, with most of it focusing on the ethical considerations and advantages of qualitative research (Pretto 2019; Llewellyn 1995; Hartley and Mohammad 2003) whereas only a few covers the practical components of interviewing or involving citizens with disability (Larsen 2015, 13; National Center on Disability and Journalism 2021). Literature related to interviews using online platforms were occupied with practicalities and technical aspects and had no consideration towards disability.



As our thesis has been conducted during the Covid-19 lockdown in Denmark, digital methods for data collection have been required to a certain extent. During our 8th semester at Techno-Anthropology, we worked together on a project solely relying on digital interview methods among our peers, so the use of Skype, Microsoft Teams and Zoom was familiar to us. However, having to adjust the use to the different abilities of our informants became an important component when arranging interviews. When inviting our informants with visual impairment, we described the process of accessing Teams and using camera and microphone extensively. Knowing that they used speech technology to read the emails, we were aware of making the instruction short and to the point to avoid any confusion. Another consideration was the lack of physical body language. Interviewing Eric and Ursula, we realized that they could not see us nod, shake our heads, smile or make other attentive gestures, so we began engaging more verbally with sounds such as "Mhmm", "Aha" "Okay" and explicit laughter to indicate we understood and listened to their answers. Observations during the interviews were influenced by their visual impairment in two interesting ways. For Ursula, she used her computer to access Teams and casted the video onto a larger screen, so she could see us. This resulted in her computer being next to her, and she refrained from turning on her webcam as "you would only be able to see my arm". With Eric on the other hand, due to his visual impairment he used an assistive speech technology to navigate a website during our interview. This provided us with information on his daily practice using assistive technologies and the importance of website accessibility for visually impaired people.

The digital interviews did however pose an issue regarding one LDC member who had a hearing impairment. When inviting her to the online interview, she responded that she would like to be excluded due to her disability. She wrote that she had previously had some horrible experiences with the online format, and she would rather if we could send her the questions in an email.

The use of online interviews allowed us to schedule meetings with little or no break in between as transportation time was not an issue, and our informants could access the interview without worrying about logistics. Especially in times affected by Covid-19, where social distance and home offices were the new black, the opportunity to arrange meetings behind the dining room desktop made the exploratory phase very efficient. We



also got the impression that people were more willing to meet for an in-person interview or a walk if we had met them during an online interview first.

## **Ethical Considerations**

During one of our interviews, the informant stopped mid-sentence to ask if any statements would be quoted. She was eager to share her opinions but had some reservations in relation to what her colleagues might think of them. There is a general tendency among informants to be more open and sharing personal opinions and attitudes towards their colleagues, employers, organizations, and business partners if they are anonymized (Saunders et al. 2015, 619) and prompted by this episode, we decided to apply anonymization in our thesis. Since our research is focused on practices and experiences regarding the two LDCs, rather than an evaluation, we decided that the municipalities be kept anonymous too and we will not differentiate between them nor the two LDCs in the thesis. This is done for two reasons. The research is a study of practices rather than a comparison between two cases. The practices in the two municipalities are similar and it is more relevant to focus on what works and what can be done differently generally. The second reason for not differentiating between the municipalities is due to the number of members in the LDCs. It is reasonable to believe that if a statement from a Politician is categorized to a specific LDC, even if it is anonymized, the colleagues in that LDC will be able to figure out the identity of said Politician based on other statements from members of the same LDC.

In addition to anonymizing our informants and the two municipalities we have chosen to pseudonize our informants and the gender portrayed in this thesis is not necessarily a portrayal of their actual gender. The decision to provide our informants with a randomized name is to be able to tell narrative stories about our informants. This relates to our approach of following the actants and describing the struggles as they occur, since the reader will be able to identify different struggles related to different actants.

Before each interview, we began by explaining our research project and our reason for talking to them to ensure that they were fully informed about the purpose of our project. We obtained informed consent from all our informants and asked them for their permission to record the conversation for our own use. We assured them that their participation



and statements throughout the assignment would not be traceable. We informed them that if we were to use their statements, we would contact them before publishing, so they had an opportunity to oppose or approve their own statements.

As such we have read through our assignment for possible clues that can be identified by possible readers with access to internal documents and insider knowledge. We are aware that those of our informants who have referred to each other and know with which of their colleagues we have talked to, will be able to recognize their own municipality and possible statements from their colleagues, especially if these statements are some they have expressed to their colleagues before. We have therefore made our informants aware that we offer to send our assignment to all the informants we talk to, and that there is therefore a chance that some of their statements multiple our informants. We have not anonymized our informants Therese, as she allowed us to use her name and pictures taken of her with Emilie from our walk. Kristian is not anonymous either as he too approved of his name being used in the thesis.

Personal information is covered by the Data Protection Act (Datatilsynet 2021a). This means, among other things, that our informants' information must be protected with appropriate technical and organizational measures (Datatilsynet 2021b). Since Microsoft Teams is covered by the Data Protection Act (Smith 2021a), we have kept our informants' personal information in a Team, along with our interview guides and notes.



Techno-Anthropology Master Thesis





# Analysing the Representativeness

This chapter marks the beginning of our analysis. We examine the representation on both a micro- and macro level by analysing the credibility and legitimacy of the disability representatives in the two LDCs, regarding their ability to represent different kinds and degrees of disability as well as their knowledge of the municipal procedures. Following this, we analyse representation on the macro level by assessing the capabilities of the disability representatives to apply their representational competencies and accommodate the needs of the citizens in a collaborative process with the municipal representatives. We apply the organisational criteria of openness, intensity, and quality for classifying dialogic procedures to analyse what possibilities and constraints the collaboration facilitates in terms of involving relevant disability groups and including them in the process of achieving accessibility.



# Perceptions of Disability and Expertise

To approach the phenomenon of disability through experience, we met with Therese who introduced us to her daily life as a wheelchair user, while allowing Emilie to experience it herself for two hours in a borrowed wheelchair.

We were impressed with how agile Therese was in her wheelchair. Entrances we would beforehand have thought were too tall was not always an issue for her. The problems were primarily with combinations of a step, a door opening outwards and the door frame. Some shops had installed a ramp, and while some of them worked as intended, others were either too steep or too narrow due to a railing. Therese said that some stores had invested in ramps, but you would have to get inside and request for it to be set up. Another example of failed accessibility was at a pharmacy. To make a ramp which blended in with the surrounding design, they had used cobblestones as the material. Louise afterwards said that looking at Emilie, it had been difficult for her not to burst into laughter. She described the expression on Emilie's face as "an urge to facepalm herself in utter disbelief of what ignorant person would have designed a ramp with cobblestones". Aside from the



*Picture 3: Emilie and the cobblestone ramp. Prepared by Authors.* 



steep curve of the ramp and the lack of traction due to the cobblestones, the worst scenario, Therese described, was that the front wheels of a wheelchair could sometimes get stuck in between the stones and when that happened, there was nothing she could do to prevent falling over and hit face first into the ground. To a walking person, curbs and steps are nothing but a separation of road and sidewalk or entrance door. For a wheelchair user, curbs and steps can determine whether you are able to cross the road at a certain place or enter a shop.

During our trip with Therese, we became aware of how important the bodily experience of a disability was, and how we with functional legs would never have the same experience as Therese, even though we too sat in a wheelchair. At several moments when driving around, Emilie noticed how she compensated for balance by stretching her legs or touching the ground. Even though she focused on remaining as passive as possible below the waistline, the balance establishing movements came as a subconsciously bodily reaction. She further noticed that, knowing she could break a fall by simply standing up also made her boulder than had she been paralysed. Another aspect was the increased load of mental energy used on being present in the ongoing conversation while constantly scouting ahead for obstacles and curbs. Therese described that she herself felt an enormous mental strain that she had become accustomed to and no longer noticed, but having it brought up by Emilie she recognized the feeling and how tiresome it could make her after a day outside. By including these two examples we wish to highlight how experiences differ due to bodily functions, tacit knowledge, and intentionality. Even though Emilie and Therese were placed in the same situations, their experiences were different because of how their bodies were used to act and react. When falling over, Emilie's intentionality was directed towards the fall and her ability to break the fall by using her legs and feet. Therese's intentionality however was directed towards the fall and not being able to stop it. However, by sharing the experiences, and experiencing them for the first time, Emilie was able to vocalise situations and actions which had become tacit knowledge to Therese. Knowledge which Emilie would not have thought to vocalise had she not experienced them herself. For Therese, the experience of having a disability is only pronounced when her intentionality is directed at the phenomenon of disability e.g., when people refer to her wheelchair or the environment as inaccessible.



Another example of different experiences and perceptions of disability is with Kristian. His helper said that at a particular meeting, he was faced by his own presumptions about other disabilities, though he was used to different people and disabilities as part of his work as a disability helper. During an online meeting where he participated as Kristian's helper, a girl, who also had cerebral parese like Kristian, but at a more progressive stage participated. She had, due to the illness, lost her ability to communicate verbally. Kristian's helper did not assume that she was going to participate much in the meeting and, slightly embarrassed, he added "I perhaps perceived her as being challenged mentally as well, and boy was I wrong!". The girl communicated using communication technology, and she proved herself to be both smart and humorous, making them all laugh at multiple occasions. Kristian remembered the episode too and agreed with his helper. He too had not thought much of her at the beginning and was surprised by her participation. He stated that:

"People tend to forget that even within disabilities, the range of disabilities is so wide. I am often confronted by other illnesses, phases of illnesses or types of disabilities, than my own, and I recognize this presumption that happens when faced with something unknown. I feel lucky to work in an environment where I meet so many different people and disabilities, because it is part of removing my presumptions."

We understand disability as being both an embodied experience due to an impairment *and* as relational when inaccessibility forces an intentionality towards the external barriers. The examples from our conversations with Therese and Kristian shows that the experience of a disability is highly individual, and the experiences can be perceived as common knowledge by the experiencer. Exactly this approach of common knowledge has been coined by Callon et al. as a type of experience-based knowledge which is held by laypersons and can allow them to engage in scientific and political discussions (Callon et al. 2011, 76). We will in the following section elaborate further on the approach of phenomenology and how personal experiences can elevate individuals from laypersons to experts.



If everything is an individual experience, then how can the representatives of the LDC guarantee an impact which accommodates a wide variety of disabilities?

Having argued for the importance of experience-based knowledge to represent citizens with disabilities, we will in this part analyse our empirical data to see how interactional expertise is a competency held by the members of the LDC. Furthermore, we will assess if people holding interactional expertise can represent a wide variety of disabilities and the need for accessibility. In the first example, we would like to turn to the disability representatives and their different disabilities.

We have previously described that there are 35 different disability organizations, with three to seven members appointed by the DDO. This excludes 28-33 disability organizations from being physically represented in the LDC. So how do they ensure representation of the excluded varieties of disabilities? In our first interview with Ursula, we asked her how she made sure the other disability organizations were represented, and she replied with "if I don't do that, then I am not doing my job as Chair properly." As we asked Eric the same question he said:

"If I do not know the answer myself, I will ask the [relevant] disability organization about the particular matter. I mean... I do not really know anything about diabetes, so I would rather ask someone who does. But at some point, I of course learn what they would answer, and then I just answer without asking them."

Eric's mission to learn as much as he can about other disabilities, becomes an example of how he applies an interactional expertise to represent the interests of others. Like Eric stated, he knew nothing about diabetes or the experiences of living with it, but through his communication with the disability organization he has gained knowledge of what it would be like to live with it, hence he can answer questions from the municipality regarding it. Eric's interactional expertise is required of him and the other members to function in the LDC as a disability representative. They hold a mix of contributory expertise regarding their own disabilities, but as of other types of disabilities and varieties within their own, they will have to use the competencies of interactional expertise to be able to translate the needs from other people with disabilities. Based on this example, we argue that Eric applies a method of gaining interactional expertise through conversations with relevant interest organizations. Techno-Anthropology Master Thesis





*Picture 4: Emilie uses an assistive text-to-speech technology to hear the text. Prepared by Authors.* 

Our second example is with Eric and the municipal representatives. When we met with him, he started off by apologizing for not bringing a pair of glasses to blur our sight and a white cane so we could have the same experiences as him. He elaborated saying that whenever a new person would join the municipal office for accessibility, they would usually go on a walk with him and Jacob, and either be placed in a wheelchair, or with the glasses and a white cane so they could experience having a disability. Victor, the chief Officer from the administration of infrastructure, laughed a little when he elaborated on these *city hikes*, as he preferred to call them. He added that when going on these city hikes, the people who would be assigned a temporary disability would be assisted by either Eric or Jacob, to make sure they did not hurt themselves. Victor saw the irony in that the ones



with a disability would be the ones to make sure that the Officers would not get injured from their temporary disabilities. To Eric and Jacob, this is a way of sharing the experience of living with a disability with people who do not have one. The Officers are provided with an opportunity to use their new knowledge of having a disability to understand the need for, and ensure, accessibility in the built environment. This also affected their attention towards the importance of accessibility. Several of our informants from the municipality had experienced issues of accessibility as a relative to a person with a disability. They stated that the issue of accessibility was not a priority to them beforehand, more like a thing on a to-do list that could be paid attention to if time allowed it. After their personal experience with either the walk with Eric and Jacob or the experiences of their relatives, the issue of accessibility had become more important and personal to them. We argue that experiencing the challenges of having a disability has changed their intentionality and attention towards inaccessibility. From these experiences the Officers and Politicians are invited into the realm of practical experience with a disability offering them a temporary glimpse of contributory expertise, which they can use to support their interactional expertise.

While the municipal representatives gain an interactional expertise, so do the disability representatives in relation to the municipal practices of planning new urban environments. We were invited to participate in a meeting between Ursula and two municipal representatives, where we experienced a tendency to also discuss the formulations and procedures of the municipality in relation to a policy paper on employment and disability. Ursula engaged in this meeting as both a disability representative, but also as a, what we would call, a feedback partner. We got the impression that she had a thorough insight into the practices and who to contact within the municipality. The language at the meeting was influenced by technical terms and phrases, which Ursula was aware of, and translated to us whenever we looked mildly confused.

Collins uses the example of language and the ability of speaking a different language. If a person has the practical experience and capability of speaking a language fluently, this will make him or her a contributory expert. However, Collins raises the question of whether the distinction between interactional and contributory expertise the practical experience is then simply regardless of the amount of experience with it (Collins 2004,



140). For the sake of our analysis, we wish to further investigate this question by applying our own empirical data.

A common situation where the use of interactional expertise is applied in the LDCs is in relation to the representation of cognitive disabilities. Due to issues of e.g., concentration, cognitive abilities or language processing, the representatives of cognitive disabilities are often relatives and not people experiencing the disability themselves. It is therefore relevant to discuss the possibilities, limitations, and boundaries of contributory- and interactional expertise.

If we compare the practical experience of having a physical disability and being in a wheelchair with the language example proposed by Collins, we could argue that Emilie has obtained contributory expertise from her practical experience of being in a wheelchair. Louise on the other hand would hold the competency of interactional expertise as she was not situated in the wheelchair but was introduced verbally to the issues and experiences of Emilie and Therese. However, as elaborated during our explanation of the phenomenological differences of intentionality when falling while situated in the wheelchair, the bodily conditions of Emilie and Therese affected their intentionality and experiences differently. While Emilie has achieved a greater understanding of being in a wheelchair and the issues of accessibility, she does not have the tacit knowledge like Therese.

As for the position of Louise, she gained the competencies of interactional expertise by experiencing the life of a wheelchair user through Emilie and Therese. We became aware however, that experiences such as slant pavements and the mental strain of looking for accessibility was so embodied by Therese, that she did not think of vocalising them. In relation to this, Collins argues that no matter how much a person learns from a contributory expert, there will always be some knowledge that gets lost in the process (Collins 2004, 136-137). A limitation of interactional expertise can therefore be the lack of information of tacit knowledge experiences that the experiencer fails to convey and the interactional expert misses. Collins further argues that to obtain proper interactional expertise, one must spend an immense amount of time with the experiencer to understand the facets of the practical experience (ibid., 136).



We argue that the members of the LDCs can be considered experts, by using the competency of interactional expertise to gain insights from people with other types of disabilities. This argument is based on Collins' concepts of contributory and interactional expertise and will be applied in relation to the representative role of the LDC's members. Furthermore, we argue that the Politicians, Officers, and disability representatives can also gain an interactional expertise through their collaboration with the disability representatives. Considering the number of cases and interactions the disability representatives have with other varieties of disabilities, they can obtain the unspoken facets of a practice. Through the collaboration in the LDCs, where the disability representatives are involved in formulating consultation reports and negotiating with the municipal representatives, we find that they obtain a technical vocabulary and an understanding of the procedures in the municipality which makes them credible. Through both their interactional- and contributory expertise, the disability representatives remain linked to the social world of the citizens with disability. By having personal experiences with disability and expertise in other disabilities, we find that they become legitimate.

Having argued for the competencies of contributory and interactional expertise and proposed possible limitations, we wish to continue the analysis by investigating how the procedures surrounding the LDCs facilitates representation and diversity among the members.

We have examined the experience of disability and how the dichotomy between experiencing something for oneself, and representing others' experience, influences the LDCs and its members' ability to represent citizens with a disability in the municipality. By using the competencies of contributory- and interactional expertise we found that it is possible to represent other people's experiences. With outset in this analysis of the representational component of the disability representatives, we will move on to the analysis of how the procedures and practices of the LDCs allow for this representation to be present and applied in the collaboration with regards to the criteria of openness, intensity, and quality.



# Openness

Callon et al. explains openness as a criterion that enables us to identify and distinguish between the procedures that restrict, or enlarge, the access to dialogue (Callon et al. 2011, 159). With openness, we can analyse to what extent new groups are invited to express their views, exchange their points of view, and negotiate both the production of new knowledge and the composition of the collective, by examining two sub-criteria:

- 1. "The degree of diversity of groups consulted and degree of their independence vis-á-vis established action groups.
- 2. The degree of control of representation of spokespersons of groups involved in debate" (ibid., 160)

Based on the criterion of openness, we analyse the question of what opportunities the citizens must enter the discussions, dialogues, or controversies within the LDCs, as well as how diverse the groups within are allowed to be.

The degrees of diversity and control are found by investigating the procedures and practices that surround them. Who is allowed to join the council, and what groups are invited to enter the dialogue? How independent are the groups allowed to be, and are the members able to represent the groups involved in the disability debates? In the case of the LDCs, the local government reform from 2007, and its accompanying executive order on the mandatory establishment of the LDCs, anchors all the tasks and rules for the performance of their procedures. The executive order determines what the LDCs are to do, what they can do, and what they are not allowed to do, including how they are to organize themselves and who is allowed to participate (Retsinformation 2021). In addition to this, the DDO and the National Association of Local Authorities *[Danish: Kommunernes Landsforening]* (NALA), have published a handbook, *The Good Practice* (2018), which describes the advisable performances of the tasks in the LDCs. Both the executive order and the handbook describes the means of dialogue and impact of the LDCs, such as appointing members, composition of the council, meetings, agendas, consultation reports and user involvement.



## Diversity of Groups

Starting with the first sub-criterion we would like to determine the degree of diversity and autonomy of the mobilised groups in the LDCs. How strong or weak their procedures are, depends on their ability to consider, the diversity of the groups invited, and the independence and self-determination of each group (Callon et al. 2011, 160).

In the executive order we find the descriptions of how the councils are to be composed, by whom, as well as the rules for participation. All LDCs must be composed of three to seven members appointed by the municipal council, and three to seven members appointed by the DDO. Whether or not local disability organizations outside the DDO, may be represented in the LDCs, are for the municipal council to decide. If they decide so, the new member takes a seat from the DDO, as the total number of disability representatives must not exceed the seven seats prescribed by the executive order. The number of members appointed among the disability representatives must be equal to the number of members appointed by the municipal council (Retsinformation 2021). In addition to appointments among themselves, the municipal council also decides what other members are to be nominated (ibid.). This means that all employees in the municipality, private or public, who the municipal council finds relevant for their work within the disability area, can become a member of the council. The executive order allows the municipal council to invite members from different social groups, if the number does not exceed seven members.

In one of the municipalities, the DDO has appointed seven disability representatives while the municipal council has appointed three Politicians, who represent their different political parties, and four officials as representatives from the different municipal administrations. In the other municipality, the LDC is composed of six disability representatives. Five are appointed by the DDO, and one is appointed by the municipal council since the organization the member is associated with, is not a part of the DDO. Like in the LDC, the municipal council has appointed three Politicians as council members and three Officers from different departments of the municipality.

Both LDCs are composed in the same way and during conversations with the members of the LDCs, the different types of members were grouped into the categories of Politicians,



Officers, and disability representatives: Politicians, are part of the municipal council, Officers from different administrations in the municipality, and disability representatives with different disabilities. We have chosen to adhere to these categories of members; however, we find it relevant to investigate the nuances of sub-groups. We perceive Politicians and Officers as two separate social groups, though still part of the municipal representatives' category, based on their titles and work tasks, and argue that the disability representatives as a social group, consist of different subgroups based on their different disabilities. They share having a disability, but the difference in their disabilities means that they also belong to other social groups such as wheelchair users or visually impaired. Although the procedures allow the municipal council to nominate all the different social groups, they find relevant for their work within the disability area, both municipalities have chosen to distribute their seats within the organisation of the municipality, thus weakening the diversity of the groups consulted. Even though the different Officers represent a diversity in their different skills and competencies, they still constitute the same social group. As such, it is the municipal council's perception of which groups they find relevant for the work with disability, that determines the strength of the degree of diversity of the groups consulted. At both LDCs, the disability representatives report that they, together with the DDO, try to nominate members with different disabilities, to strengthen the representation of citizens with different disabilities. Even though we find a diversity in the different disabilities the members represent, the disability representatives informed us that they have a hard time distributing the seats, due to a low rate of volunteering, and a difficulty in recruiting new, and especially young, members.

We find that the procedures allow for a strong degree of diversity within the groups consulted, but it is currently weakened by the municipal council's decision to distribute all their seats to representatives within the organisation of the municipality itself, and the disability representatives' issues with distributing the seats among their members. Although the DDO and the municipal council get an equal number of members to appoint, the executive order delegates the municipal council the right to interfere in the number of members the DDO can appoint. The municipal council can decide whether local disability organizations outside the DDO, should be represented in the council as part of the three to seven members the DDO gets to appoint, if the members appointed do not exceed



the number appointed by the DDO. Thus, the municipal council has an opportunity to appoint ten members in total, while the DDO only gets to appoint four. The municipal council, as the institutionalised established group, has the power to select laypersons, which contradicts Callon et al.'s point of symmetry between the established group and laypersons, since the position of the laypersons is not per se independent from the municipality.

#### **Redefining Representation**

With the second criterion in mind, we will analyse how strong or weak the procedures of the LDC are. The analysis will be based on the procedures' ability to allow for redefinitions of roles in terms of how they are represented (Callon et al. 2011, 160).

The executive order states that the LDCs must be composed in a way, where the members represent different disability groups and different sectors in the municipality, including both adults and children with disabilities. The disability representatives have divided different topics among themselves, based on the different administrations' area of responsibility including public build, health, and employability, based on the personal interest of the disability representatives. The representatives described that they tend to represent areas where their disability is especially relevant, such as with accessibility and wheelchair users. They do however acknowledge that issues and disabilities are not so strictly grouped, and they must be able to represent other disabilities than their own. The disability representatives informed us that they have done this many times and gradually learned how to represent the different disabilities that are not present in their council or area of responsibility. As such, the representation of different disabilities does not present at the council, is something they learn to represent through interactional expertise, in cooperation with citizens and disability organizations. As for the sub-criterion, what is relevant to consider is whether the procedures allow them to re-emerge as representatives of other disabilities than the ones they were appointed to represent because of changing needs.

The disability representatives themselves argue that they are sufficient at representing the citizens with disabilities, especially in one of the municipalities where the number of such citizens are rather limited, and they therefore have an adequate overview of issues and controversies. However, some of the Politicians and Officers have stated that they



think the disability representatives tend to allocate more energy on tasks and projects that are relevant to their personal disability or area of interest. We find that what is at stake here is a lack of alignment of how the disability representatives are expected to represent. Depending on the different cases, the disability representatives aim at re-configuring their representative role and the needs they bring forth. However, according to the municipal representatives, there is a need for stabilization of who and what is represented to secure equal exposure of all disabilities. Based on the perspective of Callon et al. and hybrid forum we argue, that to secure openness in terms of representation, the procedures are at the risk of being anti-dialogic if the institution, being the municipality, dictates what kind of representatives are allowed to configure their representation, the procedure can, according to the criterion, be deemed strong. However, we would like to analyse some of the pitfalls of the current, lack of, procedures for debating the representativeness.

The disability representatives themselves point to an issue of how to deal with volunteers in terms of criticism and ensuring proper representation. During a conversation Ursula mentioned that not all the representatives were great at understanding the issues at stake, and they tended to focus on their own, personal problems. We asked what procedures they used to handle such instances, and she responded, with a smile, that "they are all volunteers, and we cannot criticize people who volunteer". Jakob had experienced the same tendency among one of the representatives in the LDC he was part of, and their solution had been to informally exclude that specific member from most discussions making the member's participation mainly symbolic. We were curious as to why there were no procedures allowing them to displace such members. The only existing procedures relating to the dismissal of volunteers, dictates that the disability representatives must be citizens of the municipality, in which the LDC is constituted. They are up for election every four years in accordance with the municipal council elections (Retsinformation 2021). However, in both LDCs, several of the disability representatives have been members for extended periods of time, some of them since the establishment of the LDC back in 2006. Eric and Ursula stated that while the seats are supposed to be up for election, they experience very little interest from other DDO members to participate in the council.



A new member must be deployed before a current member can resign and there is therefore rarely turnover among the disability representatives.

At one of the LDCs they have established a procedure that enables them to enter a collaboration with the municipality's different social groups, by producing knowledge outside the classic procedures. By inviting Politicians, decision-makers, and other social groups, to a walk through the city with various artifacts that impairs their vision or halters their mobility, they enable the participants to gain empathy and an understanding of the obstacles and barriers experienced by their citizens with disabilities. Thus, creating new knowledge with, and for, the participants, which enables them to gain interactional expertise. We are told that it is mostly Politicians, and Officers from other departments who are out and about, so even though the potential for diversity in the participating groups is great, for now the procedure only mobilizes the same three groups that already exist in the LDC: Politicians, Officers, and disability representatives. These procedures enable the municipal representatives, to a certain degree, to represent the needs of disability among their colleagues outside of the LDC. We find this aspect interesting because it shows that there are procedures within the LDC that allow for the municipal representatives to re-configure their role of municipal representatives and enable them to also engage as representing disabilities outside the council.

Callon et al. is with the second sub-criterion occupied with the extent of how groups have access and power to modify their identities and, depending on the experiences and knowledge shared, modify their expectations (Callon et al. 2011, 159). Based on our analysis, we argue that there is room for re-configuration of identities depending on emerging knowledge, however the sub-criterion is weak in the sense that the procedures it is supposed to assess is close to non-existing. We find that there is a need to negotiate and formulate procedures of how the representation is enacted in the LDCs, and how the members can properly deal with issues of representation related to the capabilities of the volunteers. Subscribing to our conceptual framework of hybrid forums, we further argue that such procedures must be established in a collaboration between the disability representatives and the municipal representatives, to avoid rigid procedures determined by a position secluded from the social world.



As for the criteria of openness, we conclude that while none of the LDCs are diverse, due to the limited social groups appointed by the municipal council, the legislation allows for the potential of a strong degree of diversity, as it enables members from different social groups to compose the council. If the criterion of openness is to be stronger, there is a need for an increase in the mobilization of social groups for dialogue, and more social groups as members. While having potential for a strong degree of openness, the executive order also reenforces the imbalance of power distribution as it positions the municipal council as the decisive entity in who is allowed to engage in the LDC, and just slightly favouring the citizens' contribution in terms of requiring most disability representative seats to be allocated by the DDO.

We argue that the degree of openness is characterised by the institutionalisation of the LDCs, where the municipality is granted a power position in determining the general composition of the council. It is furthermore, and perhaps paradoxically, also influenced by a lack of proper procedures in terms of allowing the representatives to extend or change their representation depending on the subjects discussed.

Having analysed the criterion of openness, we continue by investigating how the LDCs' members are involved in the processes of planning accessibility in public build and how the collaboration between the groups is configured.

## Intensity

Another of Callon's criteria for classifying dialogic procedures is that of intensity. Intensity is described as how procedures enable laypersons to engage in the knowledge production (Callon et al. 2011, 158). He divides the criterion of intensity into two sub-criteria:

- 1. "Degree of earliness of involvement of laypersons in exploration of possible worlds
- 2. Degree of intensity of concern for composition of collective" (ibid., 160).

He elaborates on these points by stating, that in regard to knowledge production, the simplest way to analyse the intensity of the collaboration between secluded research and



research in the wild is to measure how early laypersons are involved in the research process (ibid., 158). He argues that different procedures allow for different entry points, which can be as early as formulating the problem, or by the end of the process when conclusions have already been made and are implemented (ibid., 158-159). For our analysis, we start by focusing on sub-criterion one, the earliness of the involvement.

### Earliness of Involvement

From our interviews we have been informed by Isabella, Jacob, Ursula, Ida, and Eric, that in their opinion, project managers are not consistent in involving the disability representatives early enough. They have on multiple occasions experienced that the disability representatives are not involved before the project proposal is almost finalized, which prevents the implementation of changes recommended by the disability representatives.

Ursula, Eric, Isabella, Ida, and Emma expressed that they often experienced a tendency to either forget or under prioritize their LDCs and the involvement was therefore often too late, in their opinion. Ursula, Isabella, and Emma all mentioned an example of a large renovation project of a housing area nearby. Ursula had, together with another disability representative, been invited to the early stages of the planning process and had contributed with suggestions and feedback. The suggestions, planning and drawing was then handed over to the architects and construction company who finished the design and formulated, in collaboration with municipal project managers, a project proposal. When the project proposal was presented in the LDCs months later, Ursula was horrified to see that they had taken almost none of their notes into account and they had designed, in her opinion, some "absolutely ridiculous solutions". She described some of the issues relating especially to the outdoor area where a focus in the original project proposal had been to make it available for a wide variety of different citizens with disabilities, who were supposed to use it.

"It was originally supposed to be a green area with grass and benches. We really liked that idea and were eager to provide feedback on it. However, when we saw the design again, they [the architects] had changed it completely. We knew that they wanted to incorporate exercise installations, but the way they did it was hopeless. They had tried to make a natural ramp down from the exercise platform


to a rainwater drain, but the sides leading down to the drain were unmarked and with no identification of a change of level. If a person with visual impairment were to walk to the ramp from the side, they would fall right down. And if a person in a wheelchair was a little inattentive, or visual impaired too, they would roll right down and probably fall over. And then for the nice, relaxing area. Instead of grass it is filled with gravel, and they had designed the sides of the hole as benches. Great. Anyone who has been in a wheelchair knows how impossible it is to move anywhere in gravel, and how are they supposed to enjoy the sun with their relatives and friends if all the seats are placed high above the ground and only accessible by stairs?"

Ursula was angry that they had not involved the disability representatives in the process, and when the final project proposal was delivered to the municipality it was, according to the project managers, too late to make any changes. Ursula elaborated by saying that the municipality and the construction company perceived the renovation as fully planned and it would be too expensive for them to change it at this point. Isabella and Emma were unhappy with the outcome too. They both believed this to be a perfect example of the importance of using the LDC as a resource and involving them more in especially build projects where the cost of changing something is always increasing closer to finishing the project.

Ursula finds it silly that the consultation report formulated by the LDC is submitted to the municipal council at the same time as the committee's project proposal. In her opinion, it would make sense for the committee to incorporate the advice provided in the consultation report into the project proposal. She explains that she sometimes suspects that, when the municipal council is presented with two materials, one of them being the consultation report and the other being the final project proposal, the Politicians have tended to approve the proposal while not really considering the consultation report. The LDC has a legislative right to provide consultation reports, and for Ursula, this is her primary tool of engaging in projects. Ursula stated that she often writes a consultation report primarily for the sake of presenting the committees and municipal council with one so that its presence can remind them of involving the LDC.



Aside from the use of consultation reports, the disability representatives can also approach relevant Officers directly. Eric had an example with a staircase at the main square of their municipality. Due to a lack of white lines on the stairs, people with visual impairments perceived the stair as ground levelled and risked falling. Rather than going through the procedure of formulating a consultation report, Eric communicated directly with the Officer responsible for public spaces in the municipality.



*Picture 5: Stairs with with yellow marks to indicate top and bottom. Prepared by Author.* 



From the examples above we have identified two approaches of involvement in build projects being:

- 1. Reactive involvement. The disability representatives are involved through a formal process of formulating and responding to the specification of requirements.
- 2. Proactive involvement. The disability representatives engage directly with an Officer or Politician.

With the approach of reactive involvement, the involvement of the disability representatives is initiated by a predefined project which they can respond to, primarily through text, using consultation reports. While the disability representatives are occasionally involved in identifying an issue or a need within accessibility, the primary involvement occurs after an issue has been identified. For reactive involvement, we argue that their possibility for creating impact is reduced as their involvement is mainly confined by a predefined problem and project.

With proactive involvement, the disability representatives engage directly with project managers, Officers and Politicians. The disability representatives are part of defining issues of accessibility, and as such a more prominent part of defining the outcome, as they have already been part of framing the issue.

The DDO states in *The Good Practice*, that the municipality should include the LDCs early in the decision-making processes to avoid inconvenient solutions, which would have to be adapted later on to citizens with disability (Danske Handicaporganisationer and Kommunernes Landsforening 2018b, 6). Based on *The Good Practice* and statements from multiple members of the LDCs, we argue that the LDCs' members are aware of the importance of early involvement. However, as for whether they meet the requirement of sub-criterion one, it is difficult to provide a conclusion to. Isabella, Ida, Emma, and Victor all stressed the importance of early involvement. Emma elaborated saying that citizen involvement is still something quite new in the dictionary of the municipality, but everything points at a greater shift towards an increased awareness of the importance of involvement. She believed that this increased focus would also benefit the LDC, as more and



more Officers, committee project managers and Politicians opened their eyes to the usefulness of the LDC. Ursula, Eric, and Jacob also insisted on an increase in involvement, and they often spend time researching new projects and initiatives they could reach out to, without waiting for a formal invitation from the project manager, or the phase of formulating a consultation report.

We argue that there is an increase in proactive, early involvement and that the Officers and Politicians have become more aware of the importance of involving the LDC early. However, we have also heard multiple examples of late involvement or where the only involvement was the formulation of a consultation report. We therefore assess that subcriterion one is partially strong, but that there is plenty of room for increased involvement.

Continuing from this analysis, we move forward with an assessment of the second subcriterion. We especially find it relevant to investigate what approach the LDCs use when sharing knowledge, and how architects, construction workers etc. are included in this.

#### Composition of the Collective

The second sub-criterion of intensity is the concern for composition of collective. Callon et al. describes that the composition of a collective is part of determining whether research can be considered secluded or collaborative, and research leaning towards collaboration is closer to fulfilling the criteria for dialogic procedures (Callon et al. 2011, 159). Callon et al. mentions three different attempts of composing diverse groups ranging from least collaborative to most. The first attempt is when smaller groups are invited to voice their opinion. The second attempt is to arrange early exchange of experience between minorities and established groups to reach consensus. The third attempt is to promote negotiations which can create a new collective (ibid.).

As argued, regarding the sub-criterion on earliness, the timeliness of involvement can differ depending on the different cases. We have identified two approaches of involvement being proactive and reactive, and we continue to analyse the composition of the collective based on these two approaches.



During reactive involvement, the LDCs can voice their opinions on a project, and the project managers decide whether they want to utilize the recommendations or not. The composition during reactive involvement, where the main tool for involvement is the consultation report, is therefore like Callon et al.'s description of the first attempt where small groups is invited to voice their opinion. Even in cases where there has been an early involvement, the composition still risks being a voicing of opinion. An example is the renovation case presented in the previous section. In this specific case, the degree of earliness was initially an early involvement in the design of a project proposal, where the LDC could exchange experiences with the project managers. However, as the project proposal was changed without involvement of the LDC, the collaboration between the LDC and the project managers, architects and construction company were reduced to a voicing of opinion through a consultation report.

As for a proactive involvement approach, the disability representatives exchange their experiences during a verbal conversation with a relevant Politician, Officer, or project manager. Ursula described how one of their disability representatives was very experienced in the use of telecoils. Together, they wrote a proposal in a consultation report of making telecoils an obligatory device in public buildings, but they were met with a reluctant reaction from the Politicians. The disability representative decided to take matters into their own hands and approached the relevant Politicians directly and described the issues related to hearing loss. The Politician was invited to experience, using a hearing device, what difference the telecoil could make. In the wake of this, the Politician became invested in promoting the importance of telecoils, and the disability representative is now approached by Politicians and Officers whenever a question of telecoil occurs. We argue that in this case an approach of proactive involvement results in a composition of a collective where experiences are exchanged, almost to a degree of constituting the disability representative and the Politician as a new collective.

Another aspect we found interesting in relation to the composition of a collective, based on the example of the renovation described above, is the absence of the technical aspect. Callon et al. describe that hybrid forums are not concerned with the technical details exclusively but engage with controversies where the technical and social are intertwined



(Callon et al. 2011, 25). The LDCs are currently composed mainly of disability representatives contributing with contributory and interactional expertise within the experiences of having a disability. However, the issue in the case of the renovation was not directly related to the disability representatives, the Officers or Politicians, but rather the architects, construction company and municipal project managers. Ursula and Isabella both mentioned examples of mistakes made by bricklayers when renovating public squares. Even if the original brickwork was designed and conducted using guidelines for people with visual disabilities, Ursula had experienced an area where, after the renovation, the brick-workers had randomly paved the square and the guidelines did not make sense anymore. Isabella too used this example and elaborated, that there is generally a lack of competencies of disability accessibility among craftsmen and entrepreneurs. Though an accessible solution had been implemented in the original design, the companies responsible for the renovation did not always have insights into why the patterns on the bricks were laid as such originally, and this lack of awareness had on multiple occasions resulted in obstructed guidelines. Isabella explained that the purpose of the LDC is not to consult on technical matters as it should rely on experiences. For the technical aspect they have external accessibility consultants who could be hired onto a project by either the municipality or the architect company. The LDC was, however, still important according to Isabella as the accessibility consultants knew about the technical details of the building regulations but they did not necessarily have first-hand experience with having a disability. Yet Eric had expressed that the disability representatives would sometimes receive calls from the construction company asking about the requirements for steepness of a ramp or where to place the visual guidelines in accordance with the building regulations. By formally excluding the technical aspects from the LDCs, we argue that there is a gap between the technical and social aspects, which results in experiences and implementations being detached from the technical requirements, or not suited for the citizens.

We argue that the criterion of intensity is partially strong. The municipality is increasingly aware of the importance of early involvement, and the LDCs are actively engaging in the early stages of project proposals to ensure that their recommendations can be considered. The use of consultation reports has its flaws in the current procedure of submitting it alongside a final project proposal. The current procedure poses a risk of the recommendations arriving too late or that it might be more cost-beneficial for the project



managers not to include proposed changes. As for the collaborative work on projects, the consultation report also reproduces an approach of voicing opinions, rather than engaging in dialogue. Through a proactive involvement approach, the disability representatives invite Politicians and Officers to participate in experience exchange, however this exchange is limited to the personnel within the municipality and is at risk of excluding the technical aspects of accessibility. We argue that there is potential for a strong intensity as the LDCs are currently working towards early involvement and an increased dialogic collaboration, but there is an issue regarding the gap between the technical and social components.

### Quality

For the last section in this chapter, we would like to discuss Callon et al.'s third criteria for classifying dialogic procedures. Quality is a criterion which takes form in the discussions and collaboration between research in the wild and the secluded research. Like with openness and intensity, quality is concerned with the relation between laypersons and specialists. Callon et al. describes that the criterion of quality is concerned with the ability of actants to speak unrestaint, and a question of whether the knowledge gained from the discussions and collaborations is used, or if the knowledge gets lost afterwards (Callon et al. 2011, 160).

Quality is divided into two sub-criteria, *seriousness-* and *continuity of voice*:

- 1. "Are the protagonists able to deploy their arguments and claims, as well as answer objections, with the requisite acuteness and relevance?
- 2. Are the interventions and discussions spasmodic or can they last?" (ibid.)

Starting with the first sub-criterion we would like to discuss the members' potential to speak from the seriousness of voices, meaning whether the members can speak unrestrained. With the second sub-criterion, we will focus on the dialogic process in the LDCs meetings, and how the knowledge is communicated externally. Techno-Anthropology Master Thesis



#### Speaking Your Mind

Whenever a new project proposal is presented to the LDC, they are responsible for assessing it, and providing a consultation report if it is deemed necessary. As Chair for the LDC, Ursula oversees formulating the consultation report, based on agreements and comments brought up by the rest of the members. The common phrasing in the reports is "the disability representatives believe..." or "the disability representatives recommend that...". What we found interesting was the exclusive focus on the disability representatives, whereas the Officers and Politicians were not visible, neither by statements such as "the Officers/Politicians recommend" nor through a collective referral of the LDC. Instead, the phrasing is based on opinions from the disability representatives, which seemingly did not present the entire LDC. According to The Good Practice, it is an option, in case of disagreement, for the members of a LDC to explain their opinions individually in the consultation report, and in extraordinary cases members can also ask to be excluded from a specific project in the report (Kommunernes Landsforening and Danske Handicaporganisationer 2018, 13). 'The Good Practice' also states that such an exclusion or one-sided statement process should not become a norm, and in the handbook, it is illustrated as a bad example if it is solely the opinions of the disability representatives that is referred to in the consultation report (ibid.).

We inquired them about their annual LDC report and asked Isabella, Ursula, and Emma why they based the consultation report solely on statements from the disability representatives and were informed that they had two reasons for doing so. One reason is based on the risk of potential consequences, if the Politicians make a statement that their political party does not agree with, while the other reason is based on their positioning of the disability representatives, as being spokespersons for people with disabilities. Both Isabella and Emma argue that the voice of the LDC appears stronger if it comes directly from the disability representatives and their experiences with disabilities, rather than from the LDC. Due to this dichotomy between the members, we find that the Officers and Politicians become disassociated with, and within, the consultation reports.

When the consultation report is ready to be submitted, it is signed by Ursula as the Chair of the LDC. Since she is also a disability representative herself, the consultation report contains opinions and statements as presented by the disability representatives and is



signed by one too. This gave us an initial impression of the consultation report being solely based on discussions between the disability representatives themselves. From conversations with Officers and Politicians, we have learned that their contribution to the conversation differs both depending on them personally, and on the cases. Emma liked to be very vocal in expressing her opinion, to a degree where she had received a comment by a previous political member who stated that she engaged too much. Emma disagreed with this, as she saw it as her task to contribute with the political aspects and support the suggestions provided by the disability representatives. Yet her opinions are not disclosed in any consultation report, because she too felt like it would affect the autonomy and credibility of the disability representatives. She mentioned that she had sometimes experienced, during the discussion of a topic, some disability representatives not feeling comfortable presenting their opinion if they felt it did not fit the consensus. Instead, they approached her afterwards and presented their ideas, because they knew she would agree with it due to her vocalizing her political stance during the meeting, and often pass on the suggestions to her party.

A similar tendency among the disability representatives is also described by Eric. There had been some bad experiences with previous representatives from the municipality who, according to Eric, did not fully grasp the concept of the LDC and had even questioned the necessity of it. Fortunately, he now felt that they had a good collaboration with the current members and stated that he and the other disability representatives have spent a long time building good relationships with the other representatives. He elaborated on this by saying that they were aware of not asking for more than what was necessary for proper accessibility. Victor recognised this too, and he liked that Eric and Jacob always asked for practical solutions rather than a radical change in the organization. Ursula described the same approach in her LDC. She too was focused on having a good relationship with the municipal representatives, as she felt it was part of the foundation for their LDC to function properly and work result oriented. Both Ursula and Eric stated that if they stopped working collaboratively, the meetings could potentially turn into an hour of bickering, which would in no way create any results for better accessibility in the municipalities.

Regarding the seriousness of voices, the members' possibility of deploying arguments and claims is two folded. Considering the Politicians, there are internal discussions as to



how much the Politicians should interfere in the discussion with political reasoning. Even when the Politicians or Officers participate in the discussion, the consultation report will almost exclusively either present the opinion of the disability representatives or dilute a common consensus as a statement by the disability representatives. This results in a lack of transparency, and while Politicians and Officers might be able to deploy arguments or answer objections, like Emma stated she does, it is not made relevant or credited in the consultation report. The other aspect is concerned with the collaborative role and implied restraint, inhabited by the disability representatives. During conversations with Ursula and Eric, they both expressed that if the disability representatives became more persistent or demanding, they feared that the constructive relation with the Politicians and Officers would be ruined. This meant that they would sometimes restrain themselves from expressing their opinions, as Emma also noticed in the example above, or demanding more comprehensive changes within accessibility.

For the first sub-criterion, the members of the LDCs are to a certain degree able to present their arguments and claims, as well as answer objections. However, they experience a paradoxical dilemma between a mutual overbearing. The Officers and Politicians do not want to be cited for opinions that might not align with their peers, and they also want to avoid diluting the voices of the disability representatives, so the opinions of the disability representatives are the only ones represented. While the Officers and Politicians refrain from being quoted in the consultation report, the disability representatives do not feel they can be as ambitious in their work and recommendations, as it might influence the collaboration with the Politicians and Officers. We argue that the sub-criterion, seriousness of voice, is weakened in the collaboration, due to lack of representation among the Politicians and Officers, and the lack of authenticity among the disability representatives.

#### Continuity of Voice

Based on the need for having a good relationship, we would like to turn to the next subcriterion, continuity of voice. With this sub-criterion we will analyse if the discussions are spasmodic, or if they have potential to last.

What is interesting in relation to the relationship between Officers, Politicians and disability representatives is that while Eric, Jacob and Ursula described the collaboration as



well-functioning due to their conformity, Isabella, Ida, and Emma had a different opinion. They missed a more ambitious and perhaps even aggressive approach from the disability representatives. Isabella felt like they were too easy on the Politicians, and she encouraged more political lobbyism performed by the disability representatives, to invoke greater political changes in the disability policies rather than just provide recommendations in relation to project proposals. In her opinion, the consultation report was not a sufficient tool in ensuring changes, and she felt like Ursula spent too much time on submitting them, time that could be spent 'cornering' relevant Politicians. Ida stated that a more aggressive approach could ensure more permanent changes when assessing devices for accessibility, and she believed the need for a stronger mobilization should be initiated by the disability representatives as they already had strong connections to the DDO. Furthermore, she added that in addition to a stronger and more ambitious mobilization, the municipality also had to be more responsive towards grassroot organisations in general, as the municipal council had a tendency of shutting them down or settling the discussion with inadequate compromises. What is expressed by Ida, Isabella, and Emma, we interpret as an uncertainty of the impact of the work done in the LDCs. It relates to another perspective of the renovation case described in the section degree of earliness. Even though Ursula and another disability representative had been part of the early stages of the planning process, their contributions had been discarded by the municipality project managers and architects. Their recommendations were not implemented, and their work became spasmodic. To Isabella, this is an example of the limitations of the current organisation of the LDCs. If the municipality is not required to incorporate the changes proposed by the LDC, there is always a risk of the solutions being spasmodic and disregarded.

One issue of the solutions' potential to last, is the current organisation of the LDCs and the municipalities right to disregard recommendations proposed in the consultation reports. Another issue is related to the exchange of experience to the municipalities actants outside the LDCs.

Ida and Emma explained that whenever a meeting with the LDC had finished, they would apply any new insights from the meetings to similar situations. Ida considered herself to be a mediator between the discussions in the LDC, the administration for Employment and Social Affairs and the political party she represents. We asked her if she knew how



the other administrations, or the other political parties received information about the discussions in the LDC. Hesitant to reply, she said that she was unsure how the information was distributed in the other political parties and administrations. She assumed that either the Officers or the two other Politicians would also mediate the discussion from the LDC. She stated that there were no formal procedures of distributing the insights from the LDC, and that a great pitfall was probably the municipality's tendency to operate a little too much in silos of political orientation and areas of administration.

As for the Officers, we asked Isabella what the procedures were for her, whenever she had attended a LDC meeting. She would usually return to the administration either with the questions from the LDC members, or follow-up on specific tasks. The employees in the administration were aware that Isabella is part of the LDC, and she would always be quick to remind the other Officers to include the LDC in the project planning.

We argue that the continuity of voice is currently dependent on the distributive work of the Politicians and Officers. Almost all our informants described that the success and potential for impact of the LDCs, was highly dependent on personal engagement from the members. This is especially important in ensuring lasting solutions outside the confined room of the LDCs. While Eric mentioned the issue of implementing solutions and exchanging experiences due to the lack of collaboration with the previous municipal representatives, he experienced a greater impact when new members took the task of distributing the insights seriously. We therefore argue that the second sub-criterion has a potential to be strong. The current procedures of consultation reports that can be disregarded without consequences, which weakens the potential impact of the solutions. The distribution of insights is, due to the municipal silos, highly dependent on the personal engagement of the Politicians and Officers, as there is no formal procedure of securing the distribution of knowledge, which can affect the continuity.

In conclusion, the criterion of quality has a potential to be strong but is weakened by a lack of transparency in the consultation reports and the overbearing collaboration between the members. By prioritizing a good relation, the seriousness of voices does not live up to its full potential, and there is a need to implement formal procedures of the distribution of insights to ensure the continuity regardless of personal engagement of the members. Emilie S. Nielsen, Louise Løken Sebastian M. Andersen

Techno-Anthropology Master Thesis



# Discussion

We have analysed the competencies of expertise among the members of the LDCs and related them to Callon et al.'s representational concepts of credibility and legitimacy. With an outset in representation, we have analysed the procedures in and around the LDCs that allows for dialogue and thus affects the representation in terms of advocating for interests and causing impact of accessibility in public build. We begin our discussion by briefly considering how other approaches of representativeness and experience-based knowledge can inform the subject of representation. We then move on to discussing our findings in the assessment of the three criteria with attention to representation as also happening and being dependent on the collaborative procedures. By evaluating the criteria, we can assess whether the disability representatives are able to stay credible and legitimate, and how the link to the social world of the citizens with disability can be maintained through a re-configuration of the LDCs inspired by a concept of hybrid forum.



### Mobilising Research in the Wild

Agreeing that disability is to be understood as a complex, dynamic and relational phenomenon, as it is treated by material-semiotic scholars, we are also interested in investigating the actual experience of having a disability. Rather than asking what influences disability, we seek to know how it influences. Our reason for this approach is our focus on the representational capacity of the LDCs and its members. Subscribing to the notion that disability and ability is not a dichotomy but a continuum, it would evidently mean that different disabilities, or degrees of the same disability, are experienced differently. Martiny (2015) presents a new model of disability which he describes as the phenomenological model of disability (Martiny 2015, 553). The model is not occupied with physical explanations or social prescriptions when understanding disability but relies on firstperson experiences of living with a disability (ibid., 554). Martiny states that earlier attempts to use a phenomenological approach in health studies have often been occupied with an objectification of the disability and a 'I cannot' approach (ibid.).

We argue that a phenomenological approach inspired by Martiny's model can be used to investigate the experiences of both the internal and external components of a disability. However, the phenomenological model is not concerned with the physical- or social relations that is part of configuring a disability. It focuses on the intentionality of the experiencer, but as earlier described by Therese, even when she does not feel or experience her disability, she still subconsciously considers herself as having a disability. Describing this experience from the diversity model, we argue that Therese's experience is an example of the diversity of disabilities which is placed on a spectrum rather than a dichotomy between disabled/abled. Based on physical or social factors, Therese can feel more or less disabled, and we therefore argue that the external components are important to consider as well and that this can be done through a phenomenological approach.

While we have not applied the phenomenological model in our analysis, we find it interesting to consider the phenomenological attention towards intentionality and the idea that intentionality is embodied and subconscious. We have presented the critique by Collins towards a phenomenological idea of experience limited to the individual, where Col-



lins argues that interactional expertise is still founded in experience as it is based on second-hand experience. However, with the example of Therese, we argue that achieving expertise as interactional, there is a risk of overseeing the subconscious actions and ideas, even if one is to participate in prolonged activities over extended time. So, while we find that the disability representatives are qualified to represent other kinds of disabilities, we also want to stress that such representation is limited to what can be seen, experienced, and explained. There will be facets of the experiences that the representatives cannot grasp or mediate.

Moving on from representation on an individual level, to representing a group through the collaborations with a collective, as is the case with the LDCs, we will once again turn to Callon et al. Within a hybrid forum, Callon et al. specifies two major divisions between specialists and laypersons and the division that distances citizens from their representatives (Callon et al. 2011, 35). Having discussed the potential distances between citizens and the representatives through the analysis and discussion of experience-based knowledge and representativeness, we move on to the discussion of the criteria. A pitfall of hybrid forums is if the laypersons do not feel represented or involved through their representatives or due to the processes of involvement (ibid., 36). We discuss our analysis with the purpose of investigating how the collaboration between the municipalities and their LDCs can involve citizens in public accessibility projects.

We have analysed the LDCs using Callon et al.'s three criteria for dialogic procedures in the organization of a hybrid forum, with the purpose of assessing what capacity for dialogue there is in the collaboration between citizens with disabilities and the municipality.

The legislation broadly describes the different kinds of members that must be included but allows room for the DDO to appoint representatives among their member organisations. We have argued that issues of diversity among the disability representatives stem from the DDOs' difficulties with recruiting volunteers, rather than from restraining organizational limitations imposed by the municipalities or the LDCs themselves. While the legislative procedures of participating in the LDCs are rather flexible, we find it relevant to briefly discuss the consequences of voluntarism in relation to them. Many of the disability representatives describe that being part of the LDCs is very time-consuming, and as



most of them are active members of other disability organisations as well, they consider their disability-related engagements as a full-time occupation. The disability representatives do not mind the time-consuming aspect of it. While some of them state that it can sometimes be a little too overwhelming, it is nice for them to have an activity, as most of them are retired. A major issue for the disability organisations and the LDCs is to attract younger members, and a reason for this could be that the system of the LDCs is now conformed to members who have a secondary, permanent income and extensive time available. The reason for the voluntary status of the LDCs is because the current members united in negotiating it as such. For them, it does not make sense to receive payment which will have to be deducted from their social transfer. Young people with disability might be in search for a full-time employment, like Therese, or occupied with other organisational activities, like Kristian, and we find it reasonable to assume that for them the lack of payment, and the time required, would demotivate them to participate.

This is interesting in relation to hybrid forums, as Callon et al. appears to criticize the tradition of states and institutions for favouring secluded or established research, and by so alienating or excluding laypersons. They are focused on the different procedures that might devalidate the role of laypersons, or demotivate them from engaging in public debates, almost to a degree where we find that Callon et al. is on a mission to emancipate research in the wild. In our case with the LDCs, we found that the disability representatives have been an active part of shaping the recruitment and expectations of what it means to be a disability representative, and thus it is from the point of view of the laypersons that diversity, especially in relation to age, is challenged. In this sense, it is not institutionalization as a procedure that weakens the degree of openness, but rather the practices in the local municipalities.

An issue of institutionalization in relation to recruitment could be discussed in relation to the criterion of intensity. In the analysis of the criterion of intensity, we identified two types of involvement which we define as proactive and reactive involvement. Proactive involvement was characterized by early involvement where the disability representatives initiated contact with responsible Officers and project managers to influence a project in progress or change existing accessibility issues. With reactive involvement, the disability representatives engaged through written responses to already planned projects



through consultation reports. Like both approaches, is that while the LDCs have a right to provide consultation, the municipalities are not obligated to incorporate any advice.

We are supportive of the ambition of including lay-knowledge in public debates, and we have in our research found that the oppression and exclusion of laypersons are not necessarily done by public institutions or established knowledge groups. There are procedures, such as the consultation reports, or the lack of a right to enforce decisions which unable the LDCs to have proper and direct influence on the decision-making process.

While Callon et al. focuses on institutional and established boundaries of including laypersons, we find that it is at risk of overseeing obstacles of mobilization and involvement among the laypersons themselves. We argue that ensuring representativeness in terms of diverse disabilities and especially representation of age among the disability representatives, should be enforced among the disability organizations who can be said to represent the lay-knowledge. As was the case with the renovation of a housing area, and though they submitted a consultation report, the LDC got detached from the decisionmaking process until presented with the results. In the case with Eric and the guiding lines on the public stairs, while he did not have the capacity to decide whether it should be changed, or how, he experienced that the responsible Officer was attentive in involving him throughout the process with follow up questions. While we argued for a stronger degree of intensity in the cases of proactive involvement, a recurring theme in both approaches is the lack of co-decisions. According to its members, the LDC could provide recommendations and had a right to submit consultation reports, but they had no authority in the decision-making process. While Callon et al. considers the exchange of experience as relevant content for a hybrid forum, they state that the ambitious hybrid forum encourages established groups and laypersons to engage as partners where laypersons are part of negotiating outcomes (Callon et al. 2011, 160).

During our walk with Eric, he compared his LDC with two others. He stated that he had heard from his DDO colleagues who functioned as disability representatives in those LDCs, that the Politicians and Officers did not prioritize working with the disability representatives, and only worked according to what the legislation dictated. We got the im-



pression from Eric, that while the disability representatives provided consultation reports, these were not really regarded by the Politicians or Officers. Based on the tendency of the disability representatives to prioritize the good relation to the municipal representatives, and the example with lack of collaboration in other LDCs, we find that the municipal representatives currently have a great amount of power in dictating the collaboration, as they become gatekeepers in mediating the meetings.

In terms of recruitment of new disability representatives, we find it relevant to consider that this lack of participation in the decision-making process can also discourage future members, as it is difficult to grasp what impact the LDCs has. While the practice of the LDCs does not allow room for any decision-making capabilities, we did not find anything in the executive order which prohibits the LDCs from being part of negotiating the final solutions and participating in the decision-making.

When we entered the field, we questioned what the purpose of the LDCs was, and every time we thought that we understood their purpose, we were introduced to new statements on the role of the LDCs. We decided to pursue this confusion and found a discrepancy between whether the LDCs should act as citizen representatives, or solely as an advisory council. In a report by the DDO and NALA, they differentiate between user representatives, as citizens with a disability who use specific devices, and disability representatives who are the DDO appointed representatives, within the LDCs. The LDCs are described as constituted as part of the municipal council and not as a user council. In user councils, citizens are mobilized to be involved in processes of design and planning of new public areas. The purpose of the LDCs, according to the report, is to provide recommendations on the final project proposal and assess the user involvement in the process. It is not sufficient to involve the disability representatives on behalf of citizens (Danske Handicaporganisationer and KL 2019). Several municipal representatives expressed that they wish to see more ambitious work led by the disability representatives, especially in relation to involvement in the projects. We find that a lot of the different opinions to how the LDCs should act, are rooted in opposing views of what the purpose of the LDCs is.

The disability representatives appear to currently inhabit both the role of user representatives and LDC members. A specific example is the case described by Ursula where the



Road, Park and Environment Committee invited a variety of relevant citizen groups, including Ursula and another member of their LDC, to participate in an exchange of ideas. Their participation in this preliminary meeting was as user representatives from each of their member organisations in the DDO, which Ursula is also the local Chair of. After attending the meeting, Ursula asked if any members of the LDC would like to engage in the process of developing the requirement specification as user representative in collaboration with the committee. The collaboration between the representative and the committee is then situated outside the LDC and the representative only involves the rest of the LDC's disability representatives if there are any disability-specific questions he or she cannot answer.

A statement by Ida supported this intertwinedness when she referred to the importance of involving the citizens, which was also those in the LDC. She further elaborated that she thought the LDC was a suited forum for involvement. Jacob however seemed to disagree with the viewpoint that the disability representatives should engage as user representatives. He stated that the LDC is supposed to provide general advice on accessibility topics relevant to various disabilities, whereas if the municipality wanted advice on specific disabilities, they should contact the disability organisations. The greater critique proposed by several of the municipal representatives, was the lack of political engagement conducted by the disability representatives. Isabella stated that she would like the disability representatives to be less conformist and more ambitious, and Emma encouraged the disability representatives to engage more in the political arena and "cut through" there. She saw it as a disadvantage that the disability representatives aimed at being neutral and apolitical and it would suit them to do some political lobbying. When we asked the disability representatives if they thought they should be more politically engaged, they all replied that the purpose of the LDC was not to engage politically, but to provide recommendations. We find this statement paradoxical as it proposes an idealistic separation between their recommendations and the political arena, they were to be implemented in. One of our arguments of applying hybrid forums was that we recognize the issues discussed in the LDCs as controversies, and characteristically of these is that they are always interwoven in the socio-technical. Since the organisation in an LDC is situated within the political arena of a municipality, we find it unrealistic that any recommendations can be



made completely apolitical. We understand that the foundation for the disability representatives' recommendations are experience, and not politics, but argue that politics cannot be disconnected from the recommendations. Instead, in relation to the framework of the hybrid forum, we find it relevant to discuss how the LDCs can engage politically, and what consequences this entails on the configuration of the forum.

Ida points to the DDO in allocating a responsibility of promoting disability policies within the municipality. While she has beforehand arranged collaborations between different councils to ensure greater collective impact, she fears that such collaboration might be discredited if they are accused of being politically motivated or initiated. For her, it is important that the LDC remains apolitical so the interest of the citizens with disabilities can be pursued, rather than a political interest. She does however argue that interest organisations such as the DDO need to be better in engaging politically and paving the way for new initiatives. In the same sentence, she underlined that the political environment needs to be more welcoming towards grassroot movements, as there is a political tendency to shut them down early in the process. The movement is therefore two folded according to her. The disability organisations need to be better in engaging politically and the Politicians "need to be better at embracing the call for collaboration". While Isabella would like the disability representatives to be more political, she also refers to the DDO and the other disability organisations as having an important role by engaging in political lobbying, which can allow for more ambitious suggestions during the meetings in the LDCs.

The issue of the LDCs is that it is currently being applied as both a user council and institutionalized as part of the municipality. According to Callon et al. the institutionalization reduces the hybrid forum into a "tool of legitimation" (Callon et al. 2001, 154) where the hybrid forum becomes a place where the decision makers consult with user representatives. Despite the opportunity for the user representatives to present their cases, the institutionalization prevents them from being a part in the final decision making. The point of institutionalizing a hybrid forum is, according to Callon et al., for minority groups to be seen and not heard e.g., "getting people to speak in order to silence them more effectively" (ibid., 154-155). This critique proposed by Callon et al. is like the critique articulated by especially the municipal representatives of the LDCs. It is, as a side note, interesting that



the members most opposed to the limiting effects of institutionalisation, are the municipal representatives.

Currently, the LDCs do not have any decision capabilities in the municipalities, and although the municipalities are required to involve the LDCs regarding disability policies, they are not required to follow the advice of the LDCs. Drawing on cases of laypersons mobilising, we would like to exemplify how research in the wild can arise and engage politically in a collaboration with other groups.

Since 1983 Tuborg has collaborated with Muskelsvindfonden [*Translated: The Cerebral Parese Foundation*] in arranging Grøn Koncert. During this collaboration Muskelsvindfonden has provided volunteers to work during the concerts, and the profit from the concerts is allocated to research regarding cerebral parese (Grøn Koncert 2021). On their website they describe their ambition of being activists in their work to break preconceptions of living with a disability. This includes getting their members to be outspoken about living with a disability, but also to engage in political awareness (Muskelsvindfonden 2021).

Another case is Johnny Ancher, a citizen using a wheelchair, who was frustrated with how the municipality did not prioritize vulnerable social groups. Based on his experiences he decided to run for municipal election this fall. He has decided to run on a local list and not as part of a political party as he was focused on the prioritization of vulnerable groups and wanted that focus to be independent from the political orientation of the Politicians who were already part of the city council (Hugger 2021). By using these two examples of Grøn Koncert and John Archer, we provide the reader with an idea of how research in the wild is conducted in a context of disability, without the limitations of politically structured organisations.

We have argued that due to the institutionalization, the role of the disability representatives and their contribution cannot be characterized as research in the wild in the sense Callon et al. applies it to a hybrid forum. The disability representatives hold the competencies of interactional and contributory expertise which, like research in the wild, is based on experiences. The lacking degree of the organizational criteria indicates a lack of dialogic procedures which denotes the LDCs as hybrid forums and configures them as



institutionalized and established groups with rigid power distribution allocated to their municipalities.

To be reconfigured as a hybrid forum, there is a need for a mobilisation of the laypersons and a separation of the LDCs from the municipality. They can still function as councils that contribute with recommendations, but through research in the wild conducted within the disability organisations, more ambitious requirements for involvement can be made. Imagine that the LDCs became a forum where the disability representatives were detached from the institution of the municipality and engaged early and proactive as users in collaboration with the municipal representatives with the right to negotiate in decision-making processes. Then the LDCs could be considered as hybrid forums where established groups and research in the wild collaborate. The use of hybrid forums as a theoretical frame in the analysis of the LDCs, provides us with the tools necessary for assessing the possibility of involvement in public discussions, on accessibility with attention to the limitations of institutionalised lay-knowledge and participation in decisionmaking. Emilie S. Nielsen, Louise Løken Sebastian M. Andersen Techno-Anthropology Master Thesis



## Reflection

Having presented our analysis and discussed our results, we further want to provide the reader with some theoretical reflections on the use of hybrid forums and how different theoretical approaches might have shaped the analysis of our empirical data. We remain within the empirical case of disability and accessibility as negotiated in the LDCs, and investigate alternative analyses based on feministic STS, decomposition and recomposition, and participatory design.

During this chapter we will also reflect on how this thesis has been formed by our group work, as one of the core values of Aalborg University is Problem-Based Learning. We will reflect on how we work as individuals and how our professional- and personal identities have played into the group work.



### Alternative Directions

As for hybrid forums we found that it provided us with a clear set of analytical tools which traditional ANT is often criticized for lacking. Departing from the three criteria that classifies dialogic procedures, we have investigated different types of representation and systematically assessed the possible impact that the LDCs can have in both representation and the decision-making process of accessibility in a municipality. We acknowledge that hybrid forums contain more extensive analytical tools than just the three criteria for assessing the degree of dialogic procedures, and for future endeavours it could be relevant to analyse the three levels of translation (Callon et al. 2011, 48-70), to analyse in which phases of the different translations' issues of dialogue and involvement of laypersons might occur. Another relevant approach could be to assess another set of criteria proposed by Callon et al. While we have focused on the organizational criteria, the focus could also have been one the three implementation criteria, which evaluates the implementation of procedures that secures dialogues in the confrontations and debates (ibid., 161). By combining the organizational and the implementation criteria, it is possible to determine whether the procedures in a hybrid forum can foster dialogic democracy (ibid., 163). While such an assessment is relevant, our main objective was to determine whether the organizational aspect of the LDC enabled citizens with disabilities to influence the degree of accessibility in the built environment. While we argue that a thorough assessment of the LDC would have to include the implementation criteria as well, we find that for our framing, the organizational criteria is sufficient.

A different approach could have been that of feminist STS, which encompasses an attitude that differences between people should not result in inequality or oppression. While the feminist approach insists on questioning gender and race and their explicit and implicit influence on power relations (Gad and Markussen 2007, 157), we argue that when discussing differences that make a difference, disabilities could be analysed as such. Especially given the focus on exactly the otherness of disability researched extensively in classic anthropology. By applying feminist STS, we could have analysed how the political dimension of knowledge production is influenced by oppressing or emancipating power struggles (ibid., 160). For example, we briefly mentioned Eric's remembrance of a previous political LDC member who did not understand the importance of having a LDC.



Using a feminist STS approached, we could have pursued this example, and analysed how normative values among decision-makers in the municipality risks oppress citizens with disabilities. Another interest of feminist STS is to analyse how power differences are established through seemingly ordinary technologies or symbols, which promotes certain interactions (Jensen et al. 2007, 11). During the Covid-19 lockdown, the LDC meetings have been cancelled or held online. A deaf member described how she avoided online meetings, as she had had several negative experiences with this format. The use of online meetings thus becomes a potential oppressing practise if appropriate measures are not implemented. Consultation reports and requirement specifications too, have had an alienating or distancing effect on the discussions in the LDC and could therefore also be analysed as technologies that promote certain interactions.

Another approach we could have applied is Moser's perception of a body as emerging, learning and developing through practices, as opposed to a naturally given order of functions and competencies (Moser 2009, 88). This approach is somewhat critical to the classical anthropological tendency of othering of the body, and Moser describes the pitfall of many social and cultural approaches as perceiving the body as a stable reality which is perceived next to, or beneath, the social and cultural formations (ibid., 84). Instead, Moser argues that disability studies should look towards feminist- and social studies of science, technology, and medicine (ibid., 85). To avoid the dichotomy between body and context, Moser introduces two new terms, which she described as "empirically more open and less medicalized", being *decomposition* and *recomposition* (ibid., 84). With these terms, she aims at "staying true to the body and its role in the shaping of life" (ibid.). Her approach is that of a material semiotic one which investigates the nature of the body empirically as enacting and as an ongoing open process of mattering which enacts without supposing an ahistorical, naturally given and bounded individual body (ibid., 85). We recognized this notion of decomposition and recomposition in both Therese's and Kristian's description of their life with a disability. Therese's accident happened in the Netherlands during an internship in a stable. A horse kicked her with its front leg, and Therese spent the next six months in the hospital in Denmark. She explained that "suddenly, I got kicked out of my studies, my boyfriend left me, I lost my apartment because I could not enter it, and I had to readjust completely with this new situation." Today, Therese has bought a new, accessible apartment, re-entered university and



participates in wheelchair rugby. As for Kristian he explained that the progression of the cerebral parese forced him to adjust and adapt along the way.

"I know a lot of people who say, 'when I cannot eat on my own anymore, they might as well just pull the plug on me!' I felt the same at some point too. When it then happened, I was not quite done living and it became a challenge of adjusting to this new condition. I am fine with it now".

By applying the terms of decomposition and recomposition of bodies, we could have analysed the different phases that Therese and Kristian went through and what role the municipality has on this changing experience. Therese mentioned that she had on multiple occasions experienced an ongoing fight with the municipality to receive the necessary help, and during these processes she would feel even more disabled than before. Imagining another direction of our research, it would be interesting to investigate the relation between the municipality and the citizens with disability and analyse what procedures and interactions are part of recomposing or decomposing the citizens. The notion of decomposition and recomposition could also be applied to further argue for the importance of proper representation, especially in relation to age. If a disability is experienced differently throughout time and can be influenced by the engagement with different activities such as wheelchairs, telephones, study, work etc, it is important for disability representatives to be able to relate and convey the importance of these. Several of the disability representatives stated that they were perhaps out of sync with all the new technologies invented for people with disabilities. Eric specifically vocalised his impression with young, visually impaired people who utilized their phones in ways he had never thought possible.

Rather than analysing the LDCs as hybrid forums, we could have perceived them as design forums and assessed their degree of participation in the design of accessible solutions, applying the approach of participatory design. With participatory design, users are included as co-designers to anticipate, or envision, the use before actual use and to situate the design in the lifeworld of the users (Ehn 2008, 92). According to Ehn (2008), a design project can be divided into consecutive stages of *analysis, design, construction,* and *implementation* (ibid., 93). The approach of participatory design can be influenced by a variety of different factors such as a top-down perspective which hinders adaptation, hierarchical structures, and the rigidity of specification etc. To avoid limitations in the



different stages, the questions of participatory design is how human and non-humans can be aligned around a shared object of concern, how representatives are enrolled and how the design can be made public (ibid.). To a certain degree, these questions are like the concerns proposed by hybrid forums, but the approach is fundamentally different. While hybrid forums are concerned with whether laypersons are involved in dialogic procedures, participatory design is concerned with <u>how</u> laypersons are involved thus providing a more practical approach with a series of tools that can be implemented to achieve involvement. By applying participatory design instead of hybrid forum, our analysis could have investigated what tools were applied in the LDCs to promote participation and assess their successfulness in involving the disability representatives. We could have further experimented with different tools such as *boundary objects* and design-games (ibid., 94), and provided suggestions as to how the LDCs could promote participation in the design of accessible solutions. Such an approach could have been interesting, especially with considerations to how such design processes should be designed themselves to conform to the needs of people with disability as most of the current design games require at least sight. By applying participatory design, which was our initial thought, it encompasses a normative understanding that the LDCs are forums for design and that an issue of involvement is the participatory methods applied. During our empirical data collection and the following analysis, we found that the issue was not as much related to the design process of accessibility, but a question of what the LDCs should contribute with and to what extent they should be engaging actively. Due to this realization, we found it more relevant to assess what procedures were present for allowing for involvement and representation.

### **Reflections on Group Work**

At Aalborg University, academic inquiries are based on the mode of PBL which is an approach that situates academic practices in authentic problems and promotes group work among the students (Askehave et al. 2015, 3-4). Group work or team collaboration is something most students will encounter in their professional life after university, and when working with other group members," you have a responsibility for your entire group and vice versa" (Aalborg Universitet 2021). Due to these expectations of a successful group work, AAU have also provided a range of different tools to assist students in communication, creating codes of conduct, match their expectations and



handle eventual conflicts (ibid.). Group collaboration has been a major factor in the production of our thesis, and we find it relevant to elaborate on obstacles and considerations.

Prior to this thesis, we have all collaborated on at least one project during the Master's course and we were familiar with our different approaches to project work. Sebastian is theoretically sharp and good with words. Louise is fast at understanding organisational structures and her networking skills are unmatched, and Emilie has a great coordinative mind and skills to convert her thoughts into writing. Having been through previous projects, we had already had the discussions of how to constructively provide criticism and what we expect of ourselves and the others. We had gained a level of loyalty and familiarity that enabled us to discuss issues openly and provide professional criticism which we all understand is directed towards the project and not the person. However, what is relevant to consider here is what happens when life throws a curveball, and the current understandings and agreements must be revised and re-negotiated.

What we describe here is probably the snowball effect of how one member's situation can affect the others. During our 10th semester, Sebastian has experienced massive outside intervention requiring him to divide his focus between family needs and his participation in the project as well as a forthcoming ankle operation scheduled the day before the thesis deadline. Due to his ankle, he has also been required to increase his dosis of pain medicine to a level making him incapable of participating in the project for a certain amount of time after taking his medicine. This partial time-out of Sebastian has left Louise and Emilie with an increased amount of work in terms of writing the thesis. What we wish to highlight with these examples are:

- The potential issue of excessive forbearance
- Love and loyalty as both a force and an impediment

With an excessive forbearing for Sebastian's situation, Louise and Emilie compensated for Sebastian's absence, by producing more text and conducting most of the empirical data collection. Louise has high expectations and can be quite harsh on herself if she, in her opinion, fails to meet them. Louise is great at understanding the theories and their connection to the empirical data collected, but it is difficult for her to formulate it in writing. The increased textual work resulted in more comments and edits from Emilie



became a two-edged sword. Emilie felt a mental overload when opening her computer knowing that not only would she have to write her own part, but she also had to go through the work of the other's. Louise felt the same discouragement with producing text, as it would not be as good as she wanted it to be. For Emilie, this process of editing Louise's text became an issue of loyalty and professionalism. Whenever making an edit, she knew that it would hurt Louise's self-esteem. Love and loyalty became both a force and an impediment. The love for each other contributed to an overbearing with Sebastian and the mental strain of having to criticize each other's text. Love and loyalty are however also our greatest force. While we might be tired and frustrated of group work, we love our group members, and this mutual respect and love for each other enables the difficult conversations on how to handle the issues.

With Sebastian's situation, there was a difficult balance of providing enough space for him to focus on the issues surrounding him while also holding him accountable for his part of the workload. We realised our former way of collaboration no longer worked and decided to discuss this during a meeting. What was important for us was to frame this meeting, not as an intervention against Sebastian, but as a forum to discuss how we as a group could organise the group work to support him in the best way possible. The agreement was a more structured approach to Sebastian's tasks, where Emilie would precisely formulate the content of the task and a deadline would be agreed upon. Sebastian also stressed that though life certainly gave him lemons now, it was important that Louise and Emilie were honest about any issues as he knew they would be grounded in his contribution to the project and not him as a person. As for the issue between Louise and Emilie, Louise expressed her issues of self-esteem and made it clear that Emilie should never refrain from editing and criticizing due to an overbearing for Louise. She too knew that any edits were grounded in the text and not directed towards her.

These conversations led to an explicit understanding of the distinction between loyalty and professionalism. While having a responsibility towards the entire group, we also had a responsibility towards ourselves. We were able to openly discuss issues such as editing, hand-in and oral exam from a common understanding that while we all wanted to support each other, it was also okay for all of us to make our own performance a priority and discuss how these two components could best be made a symbiosis.



The purpose of this section has been to elaborate on the group mechanics behind the project and explain how the approach of PBL has given us further insight to collaborative work and equipped us with communicative and personal tools to handle issues in future teams.

Emilie S. Nielsen, Louise Løken Sebastian M. Andersen Techno-Anthropology Master Thesis



# Conclusion

With focus on accessibility, we have applied the LDCs as our object of study. With roots in Techno-Anthropology, we are action-oriented with the aim of contributing to change-making. In acknowledging that we as researchers engaged with our own normativity and that our frame of analysis was one of many different angles, we reflected on our positioning and the representation we contributed with using critical proximity. Our empirical data was based on ethnographic, qualitative data collection among two LDCs and other municipality and disability related informants.



### Reconfiguring the Local Disability Councils

With outset in our empirical data, we were interested in analysing representation on the micro and macro level in terms of a spokesperson's ability to represent a group, and how the collaborative procedures in the LDC allow for the representation to be transmitted to the municipality. To frame our analysis, we applied the concept of hybrid forum introduced by Callon et al. and applied the organisational criteria for classifying dialogic procedures as well as the concepts of credibility and legitimacy to characterise the reliability of representation. We argued that the current configuration of the LDCs are not hybrid forums, as hybrid forums are open, public spaces where established groups and laypersons can engage in discussions and combine the technical aspects of a controversy with the social world the controversy resides in. The LDCs are situated as part of the municipalities and the procedures and practices are thus configured as part of the institutionalisation with predetermined ideas of hierarchy, power, and decision-making capabilities. Having argued that the LDCs cannot be considered hybrid forums, we still found it relevant to analyse the component of research in the wild which Callon et al. frames as experience-based research or knowledge. We used Collins concepts of interactional- and contributory expertise to analyse how the disability- and municipal representatives could gain expert competencies based on their own experience with disability and others thus obtaining legitimacy. Likewise, we applied interactional expertise to argue that through conversations and collaboration with the municipality representatives, the disability representatives gain insight into practices and a technical vocabulary thus making them credible.

Before the analysis of how citizens with disabilities could be considered experts within the LDCs and thus represent the needs of other citizens in relation to issues of accessibility, we elaborated on the phenomena of disability through a notion of experience by reviewing our own participating in everyday activities with Therese and Kristian. The purpose of doing so was for us to understand the differences between knowing of a disability and experiencing it ourselves, thus familiarizing ourselves with the pitfalls of representing phenomena outside our own bodily experience. We argued that while most notions of disability refer to the relational model of disability where disability occurs in the engagement with an inaccessible society, disability is also residing in the individual due to



the impairment. This bodily, internal component of disability is part of shaping the experience and intentions that prompts the body and mind to act in certain ways. We got to experience the subconscious reactions of orientation towards lowered curbs or the overcompensation of one arm if there was a slant in the pavement. What was relevant to us was the point that these subconscious actions had been unspoken of during conversations and only brought up because we vocalised them. We therefore found that in order to represent citizens with disability, the representatives must have access to the implicit, unconscious reactions.

Due to their personal experience with their own disability, we argued that the disability representatives have competencies of contributory expertise. During meetings and knowledge exchange with disability organisations and other citizens with disabilities, they can gain competencies of interactional expertise making them capable of representing other varieties of disabilities. With these expertises situated in the experience and needs of citizens with disabilities, the disability representatives can situate issues discussed in the LDCs in the social world of the citizens, thus making them legitimate. The municipal representatives to gain competencies of interactional expertise through the engagement with the disability representatives and vice versa, in terms of expertise to engage in politics and technical discussions. The disability representatives thus become experts in disabilities through their own experiences and through prolonged engagement with other people and the insight into their experience. We found that while the disability representatives are experienced in representing disabilities, a major pitfall in their representation is related to representing different age groups. The representatives themselves are mainly above the age of 70 and have described a gap between the technologies and opportunities that young people apply today.

With the analysis of the representational aspects on a micro level, we moved on to how representation is maintained as part of the involvement of the disability representatives in the collaborative procedures in the LDCs. Through the analysis of the criterion of openness, we found that the legislative procedures that determine who can participate in the LDCs are flexible and embrace a degree of diversity. The executive order does not specify specific actants but allows for the municipal council and the DDO to include relevant



groups from loosely defined categories of established groups of municipal representatives, companies, and disability-related laypersons. However, by making the municipal council partly responsible for the inclusion of actants, we see that the practice of including diverse groups is limited as both LDCs were represented by the same municipal-related groups of Politicians and Officers.

As for intensity, the members of the LDCs described that the procedures did not thoroughly dictate when the municipality is required to involve the members in the planning of public build, and the earliness of involvement was dependent on the municipality's project Officers and the proactive engagement of the disability representatives. The only institutionalised and standardized procedure of involvement was the submission of consultation reports which was submitted to the municipal councils by the LDCs at the same time as the final project proposal. As for decision-making capabilities, the consultation report is solely recognized as recommendations, and the LDCs does not have any authority in the decision-making process. The LDCs are used primarily to achieve knowledge about needs in terms of accessibility and the members are not considered partners in the process of project planning. Some disability representatives have applied an approach of what we refer to as proactive engagement, where they actively engage with relevant Officers, Politicians and project managers and contribute with on-going advice throughout a project. This practice is however not a formalized procedure of the LDCs, and we argue that it is a result of the disability representative's urge to be involved.

In terms of quality, the discussions between the members and the different opinions is not transparent in the consultation report, as the written statements are signed by the disability representatives in both LDCs, rendering the Officers and Politicians more or less invisible. This is due to a consideration among the Politicians and Officers, that they want the citizens, represented by the disability representatives, to be the visible voice of the LDCs. On the other hand, the Politicians and Officers are also hesitant in going public with opinions that might contradict with the opinions of their political parties or committees. The issue of the lack of decisive power recognised during both the criteria of openness and intensity is present here as well since the lack of authority results in potential issues of influencing the work of the municipality. There are no formal procedures of how information should be passed on, aside from the consultation report, which members

101 of 103



among both the disability- and municipality representatives find inadequate. The flow of information is dependent on the engagement and interest of the Politicians and Officers, and the representation of the citizens is passed on from the disability representatives to the Officers and Politicians in terms of broader representation in the municipality. Several of the members, especially among the municipal representatives, are dissatisfied with the involvement and lack of decision-making capabilities of the LDCs, and they urge the disability representatives to engage more politically and act more confrontational. The disability representatives on the other hand argue that they are deliberately calm and constructive in their approach, as they have experienced a greater tendency of will-ingness among the municipal representatives to collaborate, if they themselves refrain from demanding too much.

For the capacity for impact that the LDCs have in the municipality, we argued that the impact is depending on different notions of how the LDCs should work. We find that there is a discrepancy between what the members of the LDCs envision as the task of the council. We relate this discrepancy to the concept of hybrid forums, as the configuration of the LDCs is determined by whether they can become one or not. Some of the members argued that their LDC was supposed to remain organized as a municipal constituted council, with the purpose of assessing procedures of involvement, rather than engaging as users in a planning process. Within this movement, the argument is that the LDCs should continue to rely on consultation reports and provide recommendations. The members subscribing to this approach promoted a change in the current procedures so that the consultation reports are used as part of the process planning, rather than being formulated parallel to the proposal, thereby making them more relevant. Other members argue for a re-configuration of their LDCs into more of a user council driven by representatives from interest organisations who engage politically to influence the disability policies of the municipality and through lobbyism promote the power of the LDCs. Now, the council is situated between these two roles, which devalidates their influence of both an advisory, municipal constituted council and of citizen involvement through a user council. The issues elaborated on in the introduction, which were identified in 2007, are still present and we find that a re-configuration and alignment of expectation of the LDCs is necessary to overcome these issues. We found that the representation is problematic due to the loosely described procedures which enables the municipality to enforce practices which do not facilitate



proper involvement of the LDCs or allow for the LDCs to have proper impact in the decision-making in relation to accessibility. In terms of our analytical framework of hybrid forums, we found the mobilization of a user-driven council promoted through lobbyism conducted by the interest organisations interesting, as this change of procedure could configure the LDCs as hybrid forums. With the use of other examples of movements driven by research in the wild, we argued that if the LDCs were to be user-driven and detached from the institutionalisation of the municipality, the representation of citizens with disability could have more impact.

With this thesis, we have identified a controversy regarding the work of the LDCs, where expectations of their function are currently negotiated and contested by their members. We have aimed at analysing the representational component of the LDCs and how the procedures facilitate involvement and representation of citizens with disabilities. Our aim with this thesis was to emphasise the devalidating components of the institutionalisation of the LDCs and to provide interest groups with material to engage in a political mobilization that can increase the impact of the LDCs.





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Annex 1

Occupation and name	Purpose	Method	Platform	Week no.
<b>Municipal project managers:</b> Olivia Bella Ingrid Irma	Exploratory	Unstructured- interview	Microsoft Teams	6, 10, 11
DDO: Anna	Exploratory	Semi-structured interview	Microsoft Teams	9
<b>LDC Chair:</b> Ursula	Exploratory	Semi-structured interview	Phone	10
The Danish Association of the Physically Disabled: Aslan Elisa	Exploratory	Semi-structured interview	Zoom	10

<b>Citizen:</b> Kristian	General experience with accessibility	Semi-structured interview	Microsoft Teams	10
<b>LDC Chair:</b> Eric	Understanding of organization and collaboration in LDC	Unstructured- interview	Microsoft Teams	12
<b>Citizen:</b> Therese Kristian	Experience of accessibility	Active/participant observation	Walk-and-talk	12, 14
<b>LDC Chair</b> Ursula	Understanding of organization and collaboration in LDC	Semi-structured interview	Microsoft Teams	14
<b>LDC members:</b> Jacob (disability rep.) Victor (Officer) Ida (Politician)	Understanding of organization and collaboration in LDC	Semi-structured interview	Microsoft Teams, Skype	15, 16

<b>LDC members:</b> Isabella (Officer) Emma (Politician) Oskar	Understanding of organization and collaboration in LDC	Semi-structured Structured interview	Microsoft Teams	15, 17
<b>LDC Chair:</b> Eric Ursula	Experience of accessibility	Active-participant observations	Walk-and-talk	15, 16