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Facilitating Dialogues for an Understanding of Disability and Technology

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M.Sc. Thesis
June 2023

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Abstract

Designing for disability is a task designers and technologists are increasingly asked to do, whether it be for legal reasons or equitable design goals. Biases and assumptions, specifically the ones that make up ableism (embedded in methods used and the underlying ‘why’) often lead designers to fail at these goals. To facilitate designing for disability, a toolkit has been developed to allow designers and technologists to more easily understand how to design for disability by fostering a nuanced understanding of disability and the common pitfalls that current interventions fall into. The toolkit is underpinned by evaluating the existing State of the Art, collecting insights from disability studies literature as well as primary research activities like a survey, expert interviews and a personal observations reflection on how this work in done in practise. The toolkit is then evaluated and found to improve the level of critical insight people have on products developed to interface with disability by promoting more nuanced conversations. A framework for how to support designers and technologists on the task of designing for disability is also developed. This work can provide a structure and tool for designing more equitable tools, products and systems by providing a mapping of the problem (Ableism) and amplifying the perspectives, experiences and ways of knowing/doing of Disabled People.

Acknowledgement

Thank you to my family, friends and my community. Thank you to my parents and my brother for supporting me in all the ways they do. Thank you to Femke for acting as a sounding board supporting me both in and outside of this project. Thank you to all that have helped me by showing me all the ways we can be, rich in possibility and strength.

And to all those who have shared their stories, hope, dreams and fears, you give texture to the meaning of this work.

Thank you to Birna, Cristina, and Angelika for your input and guidance.

Terms

There are many specialised terms and turns of phrase that are used in this document that come from technology as a discipline, the field of disability studies, or the wider diversity, equity and inclusion discipline, they are defined below.

Access needs - Access needs are a way of describing what a person needs to access/use a tool or perform in a situation/environment, all people have access needs like adequate lighting to see at night or a comfortable temperature for a working environment.

Ableism - Ableism (discrimination in favour of non-disabled people and against disabled people) impacts technological imagination. Like sexism, racism, and other types of bigotry, ableism works in insidious ways: by shaping our expectations, it shapes how and what we design (given these expectations), and therefore, the infrastructure all around us. [1]

Disability Dongles - “Disability Dongles are contemporary fairy tales that appeal to the able imagination by presenting a heroic designer-protagonist whose prototype provides a techno-utopian (re)solution to the design problem.” [2]

Masking - masking is the performance of ”normal” behaviour with the goal of being viewed as being socially acceptable, to a neurotypical society.

Neuronormative - Focusing on, or privileging, the neurotypical above the neurodivergent.

Normative - Focusing on, or privileging, ”normal” over the wide range of human diversity.

Neurotypical - used to describe individuals with typical neurological development or functioning, i.e., people without ADHD, ASD, LDs, APD, or Intellectual disabilities.

Neuroatypical - the opposite of neurotypical, people with a non-traditional neurological development or functioning ie people with ADHD, ASD, LD, APD, or

Intellectual disabilities.

Neurodiversity - The term used to describe the diversity of neurological development or functioning that exists with in humans, both of neurological minority and the neurominority.

Assistive Technology - Assistive technology (AT) is any item, piece of equipment, software program, or product system that is used to increase, maintain, or improve the functional capabilities of persons with disabilities. [3]

Othering - Othering situates individuals or communities as outside of the “in” group, it is a political and social phenomenon and underpins many different prejudices like xenophobia, homophobia, racism, sexism, and ableism.

Racialised Communities - Frequently referred to as ’visible minorities’ the term ‘racialised communities’ encompasses all people that are non-Caucasian in race or non-white in colour. This term is used since minority places white persons as the majority regardless of statistics and visible as a marker of skin colour when the dynamics is more often from historical and cultural origins then skin tone. [4]

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Chapter 1

Introduction

The perspective and insights of disability are underutilised in the development of technology [5] [6]. Technology is frequently held up as a solution to the social, societal, and human problems of today, especially when talking about disability[1] However, there are currently few good tools to present and understand the intersection of ableism, disability and the technology that we build. Disabled people make up a significant percentage of the population and have been the catalysts for countless technologies that now shape our world. Disability effects every community, industry, and country on earth,"The number of people with disability are dramatically increasing. This is due to demographic trends and increases in chronic health conditions, among other causes," according to the WHO [7][2]. The number of disabled people ranges in estimates but the WHO states that there are over 1 billion disabled people globally [7]. There are 2 million disabled people within the Netherlands according to the Dutch Ministry of Health, well-being and sports [10], 31.1% of people are disabled according to The Academic Network of European Disability Experts (ANED) in the Netherlands [11] and 25.0% of the EU population is disabled according to the same source [11]. This makes disability a prevalent issue and concern in the spaces of technology, product, and service development.

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[1] In the forms of AT, medical intervention and technologies to address the care needs of disabled people.

[2] These observations are from before the covid-19 pandemic which many are now considering to be a mass disabling event [8] With 1 in 10 covid infections resulting in Long-covid [9], disabling condition that still needs more understanding

The perspective that disability presents has shaped many of the technologies that we now rely on. TTY/TDD[3] the precursor to SMS pushed it and the use of short forms in to civilian use by deaf/HOH communities, the first usable spoken interfaces (TTS) to the push for more efficient audio storage (LPS) come from blind/low vision communities [12]. The ramps we now roll delivery robots up and down on rely on curb-cuts pioneered by wheelchair users and fought for by the disability community[4]. In short technology and disability are **intrinsically intertwined** and shape each others possibility. However, this is not often taken into account in how some design technology, and as tech moves faster, disabled people are too often left behind [1] [13] [5].

If disability and technology are so prevalent and intertwined in our modern world, why are there still systematic in what gets built? This will be explored through an analysis of the state of the art (chapter 3) and of the literature (chapter **??**) in both technology studies as well as disability studies. This analysis will bring us to the conclusion that there ableism is encoded into the tools we use when making technology, specifically tools of discussion and framing. To address the issues presented by these tools; a new toolkit will be constructed. It will take the lessons learned, the state-of-the-art and the literature review as well as a variety of research activities that aim to pinpoint the patterns and reoccurring shortcomings that impact what designers and technologists build.

This will help us answer the main research question:

How to inform designers and technologists about disability and problems with accessibility?

This process results in the creation of a toolkit which is then assessed for its effectiveness in addressing issues that were identified in earlier stages of research. A framework is produced which may guide other endeavours in facilitating nuanced understandings of disability in a variety of contexts.The project attempts to intervene at an early stage and on a personal level about the question of how to design for disability. This is in order to address the task at the early

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[3] Teletyper and Telecommunications for the Deaf

[4] Thru events such as the 504 Sit-in and Activists like Ed Roberts

stages of the design process and undo some of the common mistakes that happen. In other words the Epistemic Violence that is ableism in technology has made disability " ... a type of knowing and lived experience that is systematically subverted." [14] and I aim to address this in some way. This approach is influenced by how I came to this problem space, my positionality and the methods and ethos of CripHCI.

1.1 Positionality

I feel it is important to talk about my perspective and approach to the research I have conducted. In part to be explicit about where I am coming from but also to ground the perspective I take in this thesis. I come to this topic as a white disabled woman. I have both disabilities and I am Neurodivergent. I have had some of these from birth and others have manifested later in life. I have privileges that many do not, my disabilities are non-visible (or easily hidden), and I use socially accepted assistive technology. I come to this work seeing disability as a natural part of my being, not good, not bad, just that it is, and technology, analogue, digital and biological, as a tool to help me do what I need and want to do.

As a researcher I employ and value lived experience as a tool. I have had the privilege of having operated in disability first spaces and have had the opportunity to learn first hand how access and accessibility shape spaces, dialogues and the power dynamics existing within conversations about and around disability with an honesty that is often reserved for spaces where the majority is of a minority. I believe that disability, and my interactions with it, have shaped how I understand my own and our shared humanity. I do not mean this from an "inspirational" perspective but from a human resilience and diversity perspective. These experiences shape how I view and understand the data I am collecting in this thesis and research. In some factors this may limit my objectivity but it also gives me access to spaces, perspectives and insights that I would not access, otherwise. This does present limitations however I do aim to take the care and time it will take to do this right, to be methodologically sound, ethical and just.

In this document I will refer to “this work”. By this I mean the work of making the world more liveable for disabled people. This work is on so many fronts: addressing ableism, addressing the cultural, technical, medical and logistical needs of disabled people. Making it easier for others to care about and for disabled people, making it easier for disabled people to shape their own lives. Making it easier to respect the autonomy of disabled people, to amplify Disabled voices (however they may communicate). To safely be Disabled. That is the work; this work is being done by so many people every day, both disabled and non-disabled people[5]. And I am deeply thankful to all that do the work.

1.2 Space of enquiry

My use of positionality and experience fit with in the domain of CripHCI [6]. “Crip HCI recognises the researcher as situated, and thus articulated within, the sociotechnical meta-contexts of society, scholarship, research, and design inquiry and practice.” [16] By holding often disregarded knowledge as expert we can see from a different space and angle. Crip Technoscience places disabled people as makers and producers of knowledge and key in making a world that is better, more just and a place where all can thrive. Crip HCI is uses that understanding and prospective and applies it to the tasks that HCI is asked to intervene on. Since technology and its development intersects (or is forced to intersect) with disabled people. In the words of Forlano “I believe it is my responsibility as a researcher to pay careful attention to these experiences because disabled people have long been experimental subjects for technologies that are later deployed in the general population.” [17].CripHCI asks for “A practice of articulation within disabled community, disabled space, and disabled consciousness is an essential and ongoing process toward a more equitable, more just, and more humane HCI practice.” [16]

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[5] I will use non-disabled in place of able-bodied within this text for many reasons including but not limited to disability is not only a factor of bodies but also of minds and brains, and in the words of Judy Heumann ”The likelihood of you acquiring a disability, temporarily or permanently, is statistically very high”.

[6] ”Crip” in this sense is “the non-compliant, anti-assimilationist position that disability is a desirable part of the world” as articulated in ”Crip Technoscience Manifesto” [15]

1.3 My words to you as a person

Conversations about disability can be uncomfortable, that is in part why this work exists. I have seen countless people who with the best intentions are made uncomfortable by explicit discussions of disability. This is for so many reasons (as will be explored in the coming chapters) but the overarching one is that ableism is embedded in social and political structures therefor beginning to dismantle it can be uncomfortable. When we begin to understand ableism we can see the hurt it causes and that we may have caused that pain or be at risk for it ourselves. That can be hard and messy, but we are humans, who everyday build and make the world we live in with tools that may not embody our values, the goal is not perfection, the goal is humanity.

In the next chapter, the research activities that have been conducted will be explained along with a high-level overview of the structure of the thesis.

Chapter 2

Research Questions and Description of process

Question the main research question for this work is:

How to inform designers and technologists about disability and problems with accessibility?

To gain a understanding of the task in practise:

RQ1a: *What are the current models, practices around, and definitions of disability that non-expert designers and technologists hold?*

RQ1b: *What are the current models, practices around, and definitions of disability that disability-expert designers, communicators and technologists hold?*

To understand how the tool kit will need to work:

RQ2a: *What are key features of a disability toolkit?*

RQ2b: *What are possible formats for a disability toolkit?*

To understand how to the toolkit will work in practise:

RQ3a: *How to evaluate a disability toolkit?*

RQ3b: *How critical are people about existing technologies when asked to analyse from the perspective of disability before exposure to the toolkit vs afterward?*

Research question 1a and 1b will be answered in chapter 6, research question 2a will be answered in ch 7, research question 2b will be answered in chapter 8. Research question 3 will be answered in Chapter 9. The main Research question will be discussed in chapter 10.

A number of research activities have been conducted for this thesis. They will now be briefly previewed as well as an explanation given about how they fit together.

Chapter 3 describes the first research activity conducted. This is an analysis of the state-of-the-art, this is done to identify current methods and tools being used in toolkits and other written media about designing and developing for disability.

Chapter 4 explains, the literature review that dives into disability, and how it is constructed socially as well as giving an overview on different issues and spaces that interface with disability.

Chapter 5 describes the first version of the toolkit and its objectives and iteration.

Chapter 6 describes the first data collection research activities. These are a survey and expert interviews. The survey explores how potential target group users understand and approach designing for disability as well as exploring the models of disability and how they are perceived. The expert interviews explore how experts for designing for disability go about their work and how they facilitate collaboration. This is done to deepen and contextualise the findings in the literature review and to ground in reality some assumptions and patterns that were found in the literature review. This chapter also serves as a way of finding patterns and methodologies used in the space (both the good and the bad)

Chapter 7 describes a number of scenarios that I have observed and the lessons that I have learned from them. This is where my personality and lived experience as a researcher made explicit. These experiences have shaped my approach and values as described in the personality section at the beginning and what would be reflected on in the conclusion.

Chapter 8 describes a framework that comes out of the insights of the previous chapters as well as a framework that can serve as a list of requirements for other designed interventions that aim to do the work of creating nuanced perspectives of disability within designers and makers.

Chapter 9 describes the design process, specifically two iterations used to distill the insights and content of the previous chapters into a version of the toolkit which was then shared with individuals to gain outside perspective. The feedback from these individuals fuelled the next iteration of the toolkit, which is the iteration that was tested.

Chapter 10 also discusses the evaluation of the toolkit and the focus groups that were conducted to evaluate the toolkit.

The conclusion and discussion in chapter 11 reflects on the research questions as well as my positionality as a researcher and whether the goals of the toolkit were achieved. There is also discussion of possible future work and a reflection on what it means to develop interventions that interfaces with disability and the context that the work exists in.

The last version of the toolkit along with a motivation for each card can be found in the Appendix.

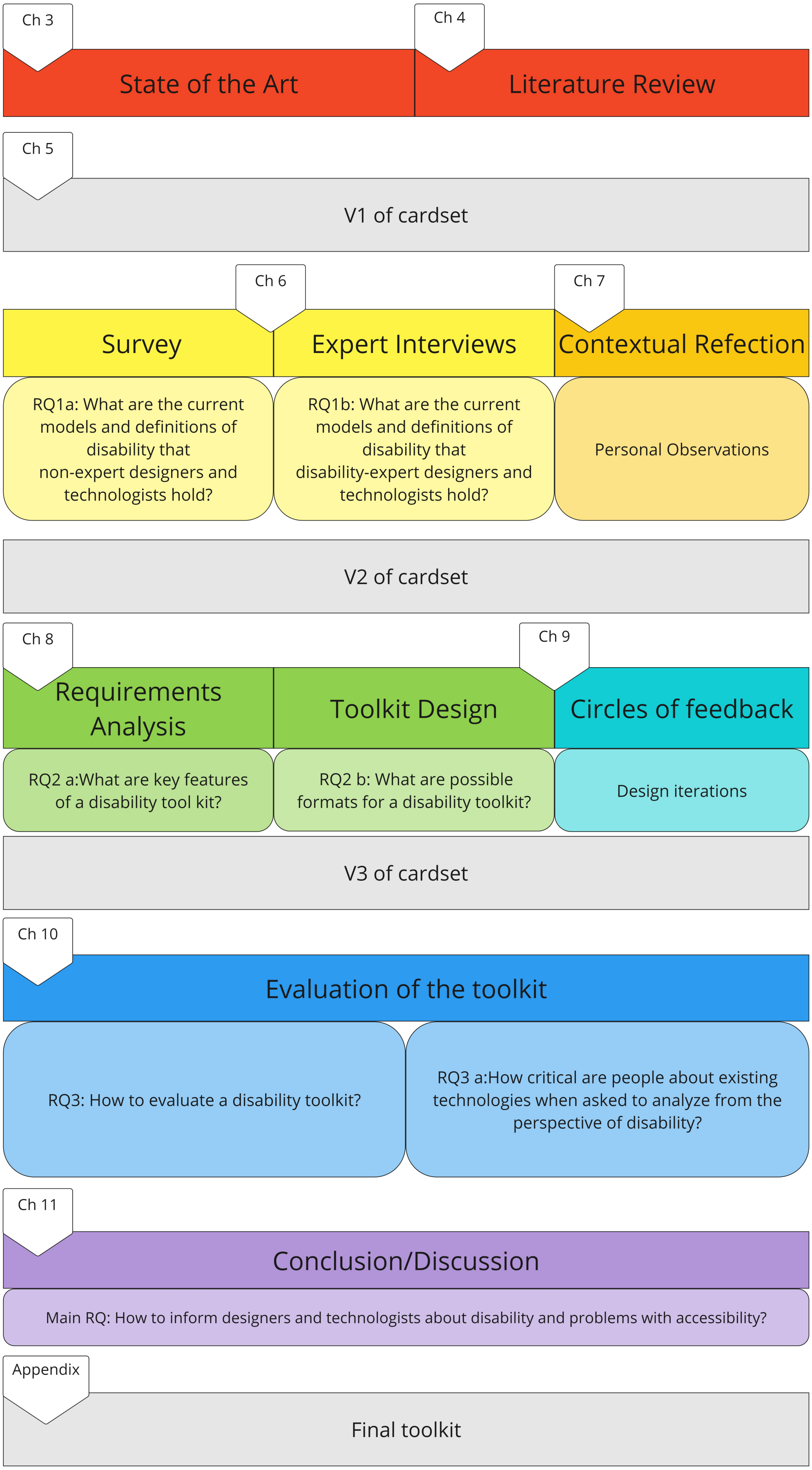

Figure 2.1: Visual outline of thesis

Chapter 3

State of the Art

The State of the Art chapter is work that was done in the Research topics phase that has been previously submitted with alterations made to adapt it to this document.

To understand how designers and technologists are currently working with disability in design, a literature review of current toolkits, was conducted. To account for the many overlapping methods used in the toolkits, some common methods are also analysed in addition to principle sets that where a common tool as well. There are also methods that do not explicitly name disability but do have some aspect of disability or universal access in their goals or outcomes, they will also be listed. There are many toolkits that use disability and disabled people to justify and strengthen their approach, although few name disability or discuss inclusive and wide definitions of disability. To ensure focus on disability, each toolkit must use language like accessible, inclusive, universal design or derivatives like accessibility or inclusivity. Some toolkits and principles sets where there was some discussion of disability, that component was analysed and recorded, not the whole toolkit/principle set.

3.1 Design Thinking

These toolkits, principles sets and methods are often described under the umbrella of design thinking. Design thinking is a way of doing that aims to tell designers (or more specifically anyone who makes) how to think about problems. It aims to build a full understanding of a problem by going through several phases. In figure 3.1 there is one of the common frameworks i.e. the d.school framework, in figure 3.2 is another replication, the double diamond. Both start off with an exploratory phase (empathise and discover) were the toolkits discussed below start their use. Design thinking presents a number of methods and tools to use with in the design process, including activities, methods, and principles.

Design thinking and the use of toolkit are not the only methodologies used in the development of technology but they are common and supported in western design education and in the space of Technological development. Design thinking in and of its self encodes ways of seeing (universality, neutrality, and outsiders coming in to solve problems) in to the products of its use, but is widely used and aims to be an accessible tool [18][1]. The biases that it may encode are related to upholding the status quo like reinforcing existing ablest, sexist and racist power structures by providing ”one right way” and having that one right way reflect what works best of a subset of the population, the ones with social power. [18].

3.2 Toolkits used for designing for Disabled Users

During the literature review 12 toolkits were analysed for their approach to designing for disability. These toolkits came from a variety of sources and ranged in goal and domain. When looking at the language, it is interesting that not every toolkit defined disability, even though they all spoke of people of varying abilities or with another euphemism. This was most likely done to circumvent the stigma, that is discussed in section 4.7 but as noted there it is not helpful when looking explicitly for materials on designing for disability.

Most often the toolkits were aimed at designers or decision makers. For

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[1] It is not that there is no place for these methods or perspectives in design simply that every method has benefits and detriments and the detriments of design thinking are not central to its process in the form of reflection or other methodologies.

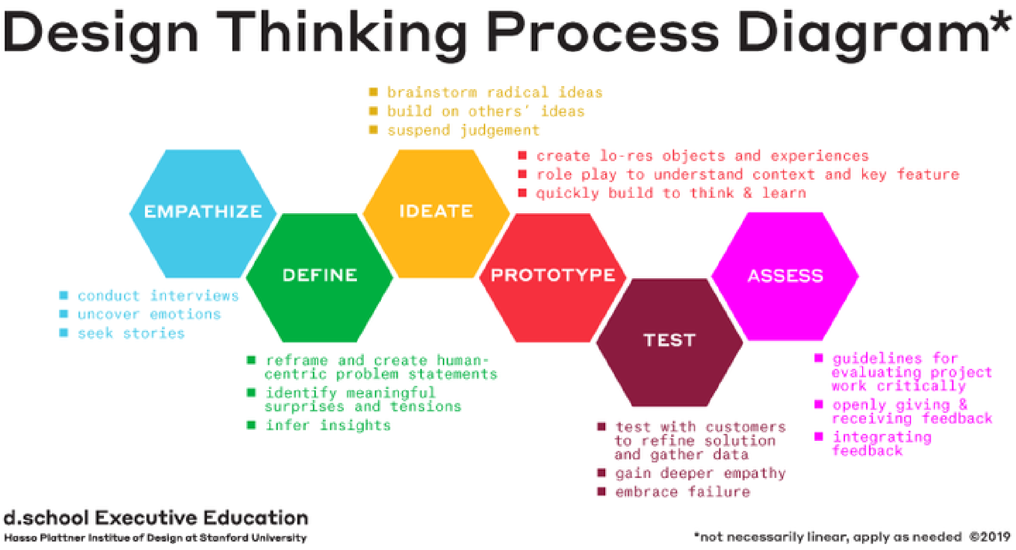

Figure 3.1: Design thinking Process Diagram by d.school

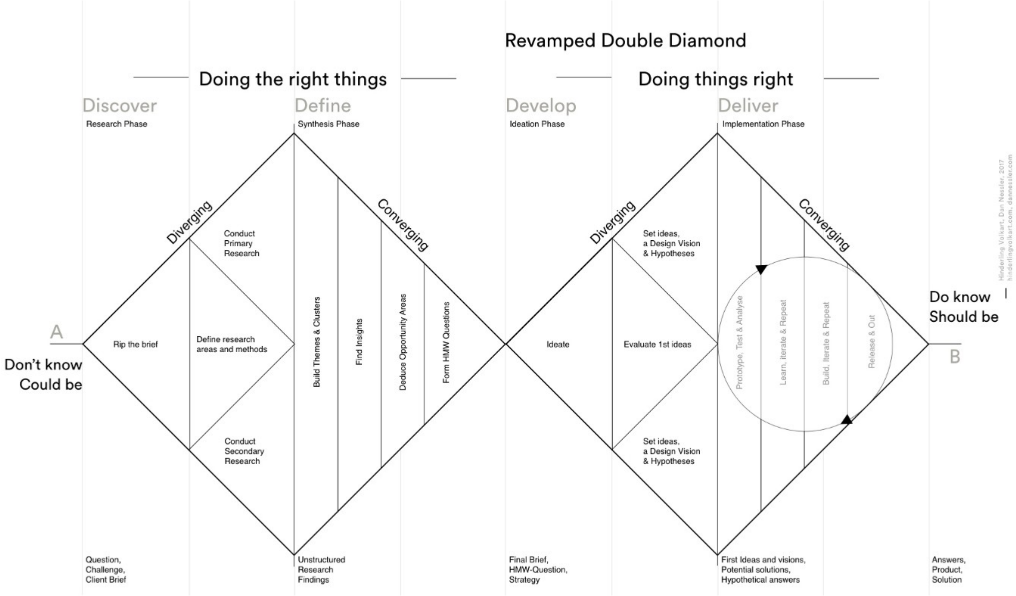

Figure 3.2: Double Diamond diagram

certain organisations they were aimed exclusively at developers which is understandable since web accessibility is oftentimes people first understanding of tech related accessibility. Very few toolkits described sources of bias while some did explain a need for inclusive design. Many toolkits explained common access needs (often without using that language) but most often in relation to physical disabilities or forms of sensory disabilities however neurodiversity, mental illness and physical illness were only discussed some of the time. Many toolkits included exercises.

Seven were standards focused whereas six were process focused, one toolkit with both standards and processes focused. One group is Standards focused looked at benchmarks and definable requirements like those built upon in WCAG2.1 whereas the other group tended to be process focused i.e. methodologies that were more likely to have inclusive outcomes. The United Kingdom Government's"understanding disabilities and impairments" was one that was both standards and process focused [19]. The domains were often classified as 1)software or digital,2) hardware or 3)service although there were a few that were agnostic or based on an entirely different domain. Regarding the formats, the formats varied but they often were booklets, websites or card sets, although posters and videos were also common. Many sources focused on different angles however few outside of the government space were focused exclusively on disability. More technical organizations tended to be focused on legal requirements and code implementations whereas others were focused more on the design domain.

Toolkits evaluated:

1. Microsoft Inclusive design toolkit [20]
2. ACCESSIBILITY TOOLKIT for Land Managers RETHINKING DISABILITY and ACCESSIBILITY FOR A MORE INCLUSIVE OUTDOORS [21]
3. CMD Methods Pack [22]
4. Humane by design [23]

5. The Inclusive Design Guide from the Inclusive Design Research Centre at OCAD [24]
6. Civic Service Design by Mayor's Office for Economic Opportunity New York City [25]
7. Design Kit by IDEO.org is [26]
8. IBM Equal Access toolkit [27]
9. Inclusive design toolkit Government of Ontario [28]
10. Accessibility in government and Understanding disabilities and impairments: user profiles from the UK government [29]
11. Designing With People [30]
12. Google Accessibility Material Design [31]

3.2.1 Product Impact Tool

A toolkit/reflective matrix developed by Steven Dorrestijn and Wouter Eggink is a reflective tool that looks to prompt refection on technologies, their impacts and outcome [32]. It overlaps with issues of disability as it looks at latter order effects as a well as a practical instances of the application of design. The tool uses four categories: before-the-eye, above-the-head, behind-the-back, and to-the-hand.

The before-the-eye category reflects on how guidance, persuasion and the image can affect use and acceptance of technologies. This section refers to disability with examples like tactile markers for navigation by blind/low vision people and references cognitive load constrictions with the example of a universal remote. It also situates persuasion as a tool. Which has implications for disability as persuasion and making unwanted paths more difficult can often interface with issues of disability as individuals will need to explore other ways of doing to get a given task done.

The above-the-head section uses speculative lenses to reflect on how a technology may be adopted, it looks at possible Futures like Utopia, dystopia and ambivalence. Here there are lens that can be used in conjunction with disability but they are not explicit as such, what is dystopia for some is benefits for other (at least in the early stages) and the utopic vision is also not push for the angle of disability, when disabled people are not explicitly listed as a part of the future, designer may inadvertently exacerbate the perspective that"the future is free of disability" instead of disability being integrated in to the social, physical and technically future (see **??**). There is also a reference to cyborgs in the ambivalent section, however it does not make step to centre disability in the discussions of cyborgs. [2]

The behind-the-back section has the subsections of side effects, background conditions and technical determinism. All three subsections can be looked at with the lens of disability but do not necessarily provide accessible hand hold for the knowledge or angle of reflection. It uses many examples that can centre disability like example of surrounding influence/support, the idea of unintended consequences like side effects or technology can shape possibility but it does not ask us to see form eye that are not our own, or that there are perspectives that we can not easily see with our mind-bodies and social contexts.

The To-the-hand section explores the physical experiences around technologies. The subliminal affect opens the door for looking at nudging and how physical manifestations may shape how a technology is perceived and its effect but it does not identity the different ways that can present for different disabilities. Embodied technology also look different from a disability perceptive, if a technology is assumed to be embodied but it relies on skills or capacity that the person does not have it will never be embodied for that person. Assistive technology is embodied technology at its core and this is a missed opportunity for centring

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[2] There is a rich history and future with disability and technology with cyborgs like work described by Williams [33], this can explore the angle of accommodation and adaptation if disability is centred but if disability is not centred in favour of the Popular culture example of Silicon Valley bio-hackers (or what is referred to in some literature as Tryborgs) lens we risk exacerbation the accommodation as social capital lens that can exacerbate ableism and techno-ableism as described by Shew.

disability. The sections coercion is also missing the opportunity to identify disability, coercion often has side effects against disabled people or is used against disabled people in a hidden way, as there are many“standards” that themselves encode some form of ableism an coercion often pushes for that “standard”.

Overall the framework can help understand the impacts of technology on human but it does not reach its full potential to centring disabled people, their experiences or knowledge. There are many ways in which disability is used but the tool can benefit from more depth and more practical understand what access, accessibility and ableism look like in practice.

3.3 Methods used in the State of the Art

There are few design methods and tools that look explicitly at disability, and the methods that do exist are limited in their effectiveness. The methods of simulations,“extreme users” and co design are assessed in the following section, the methods are chosen because they are presented multiple times by various sources and are focused on disability in some way.

Simulations and“empathy” building exercises

“Simulation” or“empathy” building exercise, are commonly used in classroom setting and education. The premise of activity to build an understanding of what it is like to have a particular disability so that one can design better for it. This is done by artificially taking away or limiting a person’s abilities. The most common disabilities to simulate are sensory conditions like blindness or deafness and fine or gross motor issues, by using noises cancelling headphones, blindfolds or dark sunglasses in-doors or restricting a persons moment or dexterity with restraints or clothing that limits them (like thick gloves).

This class of activity’s are widely negatively regarded by disabled people and have also been shown to do the vary thing they aim to dismantle [34]. They increase stereotyping, negative attitudes towards disabled people and increase feelings of pity towards disabled people [35]. They may also increase the superpower bias(4.5.7) as the participant has not been given time to obtain the skills that are needed to thrive with that disability. They also fail to build a nuance around how it is to live that disability, a short-term impairment in the space of a classroom or lectures hall is simply not representative and is seen as wildly inappropriate. Although there are applications of this method that are not harmful, most descriptions of the activity do not take the care that is needed for this to be the case in most applications.“Empathy” exercises are also not accessible to all as they have been found to be detrimental to disabled people and may not work for individuals who are neurodivergent or have certain mental health conditions [35].

Extreme users

Another tool used is that of Extreme user, this tool uses that perspective of an“extreme user” to gain an understanding of how the product interacts with disability and disabled people [26]. See figure 3.3 for an example from IDEO. This tool has the benefits of tying to get to the underlying process of how disabled people use a product but the process can be othering for disabled people. The disabled person has“extreme” ways of being and doing, not a natural adaption of process to their body or brain, thus promoting the superpower bias (see: 4.5.7). This method also has the risk of creating the assumption that disabled people are rare and it privileges certain disabilities over others in terms of desirability[3].

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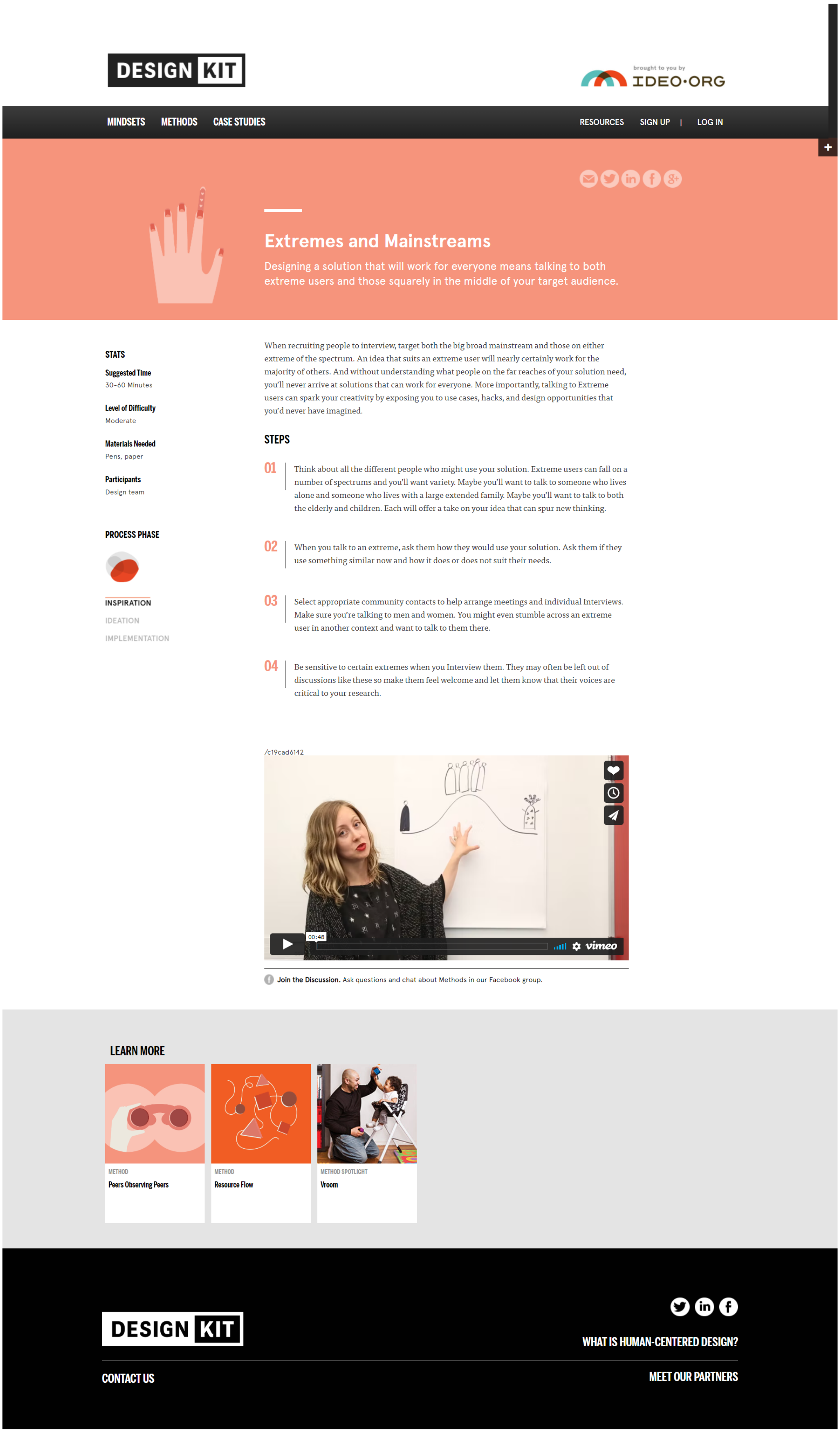
[3] It privileges visible and technological assisted disabilities over invisible disabilities and those with no AT



Extremes and Mainstreams

Designing a solution that will work for everyone means talking to both extreme users and those squarely in the middle of your target audience.

STATS

Suggested Time
30-60 Minutes

Level of Difficulty
Moderate

Materials Needed
Pens, paper

Participants
Design team

PROCESS PHASE

INSPIRATION
IDEATION
IMPLEMENTATION

When recruiting people to interview, target both the big broad mainstream and those on either extreme of the spectrum. An idea that suits an extreme user will nearly certainly work for the majority of others. And without understanding what people on the far reaches of your solution need, you'll never arrive at solutions that can work for everyone. More importantly, talking to Extreme users can spark your creativity by exposing you to use cases, hacks, and design opportunities that you'd never have imagined.

STEPS

01 Think about all the different people who might use your solution. Extreme users can fall on a number of spectrums and you'll want variety. Maybe you'll want to talk to someone who lives alone and someone who lives with a large extended family. Maybe you'll want to talk to both the elderly and children. Each will offer a take on your idea that can spur new thinking.

02 When you talk to an extreme, ask them how they would use your solution. Ask them if they use something similar now and how it does or does not suit their needs.

03 Select appropriate community contacts to help arrange meetings and individual Interviews. Make sure you're talking to men and women. You might even stumble across an extreme user in another context and want to talk to them there.

04 Be sensitive to certain extremes when you Interview them. They may often be left out of discussions like these so make them feel welcome and let them know that their voices are critical to your research.

/c19cad6142

Join the Discussion. Ask questions and chat about Methods in our Facebook group.

Figure 3.3: Screen grab of https://www.designkit.org/methods/45- The explanation for Extremes and Mainstreams [26]

3.3.1 Co-design

Co-design is an often-discussed method in the space of designing for disability. Co-design is the practice of involving a projects end user in the design process to make sure it works for them and their needs. At first glance it seems very appropriate because it involves directly asking disabled people how they feel and interact with a particular product or system. Although this is the case when done correctly and this can be an incredibly powerful method that empowers the voices of disabled people it is also a method that takes work to do correctly. Within the disability community there is a feeling that co-design often tokenises the experiences of disabled people [2]. There are also ethical concerns about the power dynamics, unpaid emotional labour and exploitation. The concern about power dynamics comes from that vulnerable people may feel that their care is linked to compliance. The labour of explaining oneself to researchers may not be adequately compensated and there is the risk that the image and perception of working with disabled people may outweigh the contributions that make making it to the final product [2]. Disabled people are consulted but they are often more observed and used as justification in a way that alienates the people that the designers are attempting to design for [2]. Many people see disability dongles (section:4.4) as an unspoken result of badly implemented co-design, co-design where the intention was to listen, but the groundwork was not properly done. That groundwork may be an analysis of the models people hold and the bias that are in our collective understanding of disability. Co-design with disabled people can be incredibly valuable and productive but that requires time space and money that not all projects have, and it also starts from a place of understanding not just a place of observation.

There are also several considerations that need to take place when co-designing with disabled people. Theses are highlighted in aspects of disability studies specifically disability justice. One of which is Forced Intimacy as described by Mia Mingus. She describes it as:

> “Forced Intimacy” is a term I have been using for years to refer to the common, daily experience of disabled people being expected to

> share personal parts of ourselves to survive in an ableist world. This often takes the form of being expected to share (very) personal information with able bodied people to get basic access, but it also includes forced physical intimacy, especially for those of us who need physical help that often requires touching of our bodies. Forced intimacy can also include the ways that disabled people have to build and sustain emotional intimacy and relationships with someone in order to get access—to get safe, appropriate and good access." - [36]

This is not to say that co-design always falls into the flaws of "forced intimacy" but it can impact the work and make inquiry (even when well-intentioned) feel unsettling for the participants. This is in part because ableism, its attitudes, methods, and ways of knowing are so deeply embedded in the structures of the modern world and science even when they do not serve our goals or values.

Co-design can work well in spaces where certain kinds of resources are more plentiful and one of those resources includes people who are trained in co-design which is not the case for every institution or team that needs to make accessible designs. Alternatives to or primers on co-design will hopefully yield better more equitable outcomes then badly run co-design. There may also be benefits in elaborating on how we do co-design in a way that is sensitive to how disabled people experience co-design.

3.3.2 Principles

In the analysis of toolkits that was another common theme/tool that came up was that of principles. Principles are described as guiding statements that can help a team or organisation understand how they want to deal with certain aspects they often seen as guiding. In Appendix:A.1 we can see several distinct kinds of guiding principles that were collected from a number of sources. The most foundational set of principles came from [37] WCAG2.1, these ones are understandable, practical and manageable. When each of these principles are analysed further, they come together to build systems that allowed to be built on top of and do not artificially limit the possibilities of users or further developments but instead focus on enabling others. Below is a set of principles that are potently use full for the main goal of this research, they are informed by the rest of the research and should be iterated on based on the outcomes of further research. The table of new principles is in the Appendix:A.2 was produced by analysing the collected principles and iterating on them with the short comings of existing models, the biases, and stigmas in mind, as will be explained in Chapter4.

3.4 Reflections on the state of the art

The methods and tools deployed in the service of designing for disability are full of unintended consequences. I think that this is because of a lack of structure in understandings to the fundamental issues. It starts with a lack of understanding of disability, which is understandable given the complex nature of disability, the naturalised state of ableism, and a discomfort or lack of time to reflect on what disability is. Not only are the definitions given (if they are given) flawed due to their narrow and one-sided understanding of disability, they also offer very few handholds for the practical implications.

3.5 Conclusion

The state of the art helps us understand the methods that are being used to design for disability, they aim to give designers a guild on understanding disability and how they may learn more but they lack practical handholds or ask for non-disabled ways of dealing with disability. They also build on top of assumptions (models, and story lines) that will be explored in the next chapter.

Chapter 4

Literature Review

> Disabled People have always existed, whether the word *Disability* is used or not. To me, Disability is not a monolith, nor is it a clear cut Binary of disabled and non-disabled. Disability is mutable and ever-evolving. Disability is both apparent and nonapparent. Disability is pain, struggle, brilliance, abundance, and joy. Disability is sociopolitical, cultural, and biological. Being Visible and claiming a disabled identity brings risks as much as it brings pride.
>
> *Alice Wong in Disability Visibility*

This chapter is the outcome of research topics phase. The Literature Review chapter is work that was done in the Research topics that has been previously submitted with alterations made to adapt it to this document.

The following chapter explores how disability is understood from a variety of angles. It collects and distils the main factors that shape how people view and understand disability, not just from an individual's perceptive but from a design and societal perspective as well. The main shaping factors are the **story lines**(section:4.2), **models** (section:4.5) that are held, as well as some common **bias** (section:4.6) we collectively have around disability. These views shape how design and technology address (or fail to address) the viewpoints, the insights, and the ways of being that disability presents [1]. The chapter also discusses how the intersections of disability and technology are addressed currently and outlines some options and alternatives that will be explored in the card set that will be described in the next chapter.

4.1 Understanding Disability

Disability is many things; it is a social and political phenomenon, a way of viewing the world, a way of being, and something that happens to people [38] [33]. It is defined in many different ways, and it affects every sector and industry. Disability is difficult to understand, especially since there is often surface level understanding[1] surrounding it. There are many biases and stigmas that prevent people from having a nuanced understanding, as will be explained in the following sections. There are also complicated dialogues behind what is a disability, some do not include conditions under the umbrella of disability if they can be accommodated in an environment like Deafness or Hard of Hearing (HOH), because with in their own homes they do not experience issues as their environment is adapted [1] [39]. Then there are the many neurotypes and dialogues around whether Neurodivergencies are disabilities. This conversation often comes down to ideas of“appropriate” behaviour, the level of“support” needs and visibility/perceivability, as identified during first-person observations and discussions. This pattern is reflected in literature as well [40]. This is only further complicated by chronic illness, cyclical disabilities and temporary impairments. This all combines to make the first step of understanding disability difficult, which makes the next step of introducing, building, and maintaining accommodations and access even harder.

For the propose of this thesis a Disabled Person is anyone whose body or brain has issues with a particular ability that most people do have, or that one is expected to use or has a surplus of something that most people experience in moderate amounts or short times like pain or sensory input. This includes sensory disability (hearing, seeing), mind (reading, attention, memory, psychiatric, mood), chronic illness (recovery, energy, pain) and physical (walking, breathing). I use an expansive definition of disability. Disability itself resists classification. Even the category of cognitive can have benefits and detriments from being split

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[1] that can conflict or fail to provide a full picture.

into other categories like neuro-developmental, intellectual, and psychiatric.

4.2 Disability and Technology

There is a complicated history between technology and disability, in one view, with one set of values, technology helps disabled people have to opportunity to live longer, healthier, happier, and more productive lives and in another view, with another set of values, technology and a collective imagination of the future would eliminate disabled people all together.

There are many manifestations how this elimination of disability vision operates in the real world, it is “solving” the disability instead of adapting the environment, coercive control and Technoableism. One lens, that of Technoableism is described in disability studies by Ashley Shew as she defines the word in a paper where she examines disability and technology as“Technoableism is a term I have coined to describe a rhetoric of disability that at once talks about empowering disabled people through technologies while at the same time reinforcing ableist tropes about what body-minds are good to have and who counts as worthy” [1]. The way people imagine the future shapes what we build it, and for some that future is one without disability. Within the space of Tech there are many articles like [41] that ask the reader to imagine how a future without disability looks[2]. Isvan writes about the cost savings, the push for innovation and elimination of disability. He hold up technologies like Exoskeletons, stem cells therapies and stair climbing wheelchairs as to solution to“eliminate” disability. He frames disability as a problem to be solved. This tradition is long in technology. Alexander Graham Bell, the person who invented to telephone and seen by many as a proponent of the deaf and hard of hearing community was also deeply ablest and promoted views that translate to Eugenics, Greenwald and Cleve state that“ bells ’campaigned for the sterilisation of deaf girls and the proscription of marriage between deaf persons’ and ’strongly encouraged educators, administrators and the Deaf community to stop marriage between Deaf

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[2] Tech is the terms that will refer to large organisations with origins in technology often Internet technologies

people'" [42]. The connection between technologies, their development and disability are often complicated even when the harms are profound. The tension between enabling,"solving" and the cost of support means that when the humanity of disabled people is not a given, elimination is seen as a cost saving measure. This issue of technical"solutions" to disability has also manifested in the design world. In an essay on critical design R.A.Hawly stated it clearly:

> "The world's remaining problems were technical, not political, and as such require solutions rooted in technological innovation rather than mass political action. Every convoluted technical stopgap designed in service of a fundamentally political problem, then, can be cited as evidence of the coming utopia." [43].

To say that our fixed political understanding of disability is correct, and we need technologies that enable that instead of shaping our politics (and thus our intentions around design) to be more just and humane.

There is a strong movement against this fixed normative view in part because Disability and a practice of care for disabled people is as old has humanity and older than modern humans [44][3]. In response to the article by Istvan [41] there are declarations of Disability resilience like that of Emily Ladau:

> "There is nothing that needs to be changed about my state of being. There is nothing I want to change. I am a whole human being whose body moves forward through life in turns of the wheel, and my reality is not for anyone else to decide." [45].

This counter-view celebrates the resilience and possibility of disabled people, it recognises the joy, pride, pain, and complicated nature of disability. This view also highlights that technology can be shaped for the better when the perspective of disability is used, many technological innovations have roots in and were pioneered by disabled people and their communities, not despite of difficulties

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[3] There is evidence to show that Neanderthals cared for their Disabled community members, in a way that let them live longer then expected even after traumatic disabling physical injuries.

and limitation but because of them. This perspective, that of using technology to enable people and their humanity, shapes what gets built. When we use disability as a critical lens on technology, we ask technology to serve people, not for people to serve technology.

When we do not understand what perspective we hold and what we feel the role of technology is in relation to disability, there is the potential for conflict. This is especially true when normative views often are the default and when political and interpersonal discomfort around talking about disability shape and guide what gets built and why.

4.3 Laws and Standards in the space of Disability

The rise of the legal codification that we see today has roots in the rise of disability as a human rights model. It is also connected to the spaces in which the political class and public see appropriate for disabled people to occupy. In early history the"place" for disabled people was in the community, the evidence for this lies in a number of archaeology sites where disabled people (both from birth [46], and acquired later in life [44]) are cared for within the community.

As we move forward through time, we see that place for disabled people shifts to Private and non-public spaces like institutions, asylum, and prisons. The first laws on disability can be regarded as inhumane i.e. the laws allowing for the institutionalisation of disabled people and laws that limit access to public space like "ugly laws" in the US. With the rise of disability as a protected characteristic under human rights doctrines we see once again a push for disabled people to be involved in and cared for within the community. That is why there are numerous legal standards around the world pertaining to disability, they often are Rights based and exist is spaces like education, public services (digital, built environmental and transportation) and employment. Different countries have different places where the rights of disabled people are codified but the EU uses The United Nations Convention on the Rights of Persons with Disabilities [47] and in 2025 the European Accessibility Act will come into enforcement.

Countries like the United States, Canada and Australia have their declarations in a Charter on Human Rights or an Act [4].

Features common around many laws are that:
1) Service providers are not permitted to ask for proof of disability if the service provider does not have appropriate medical training to understand the documentation.
2) Reasonable accommodation is required in the workplace and schools[5].
3) An open definition of disability that does not equal a list of disability's/conditions, but instead a definition of what constitutes a disability. This means that in some countries there are on going discussions as to what a disability is [6]. This creates for the possibility of miscommunications especially in international organisations or teams with a divers set of national backgrounds.

Many of the laws state that digital product must be accessible to disabled people, and there is a standard, the World Wide Web Consortium (W3C). W3C is an international community that develops open standards to ensure the long-term growth of the Web" according to the W3C [**?**]. The W3C publishes and maintains the Web Content Accessibility Guidelines (WCAG) which is now in version 2.1 and a product of the Web Accessibility Initiative (WAI) [37]. These standards provide guidance on many aspects of web accessibility along with testing criteria. They are also codified in an ISO standard: ISO/IEC 40500:2012 for WCAG 2.0 [7]. They provide a framework but compliance is still lacking, Web AIM found that for the top 1,000,000 website 98% failed WCAG 2.0 A/AA standards [51]. They fail their goal, that of enabling community involvement for disabled people in a digital sense. This shows that although there are guidelines in place not all are followed or enforced.

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[4] Americans with Disabilities Act(1990) aka the ADA for the United States, Canadian Human Rights Act(1977), R.S.C. 1985, c. H-6. for Canada and The Disability Discrimination Act (1992) aka the DDA for Australia.

[5] the definition of a reasonable accommodation varies but are often classified as an accommodation that does not place"an undo burden" on the provider although there have been issues with the actual implantation

[6] As of Aug 18 ,2022 a US appeals court has found that Gender dysphoria is a disability under the ADA. [48]. However, in the UK someone addicted to alcohol is not disabled under UK law [49] but is under some EU publications [50].

[7] ISO is the International Organisation for Standardisation

4.4 Disability Dongles

One of the symptoms of the problem is that of maladaptive solutions i.e. Disability Dongles. Described by Liz Jackson and Alex Haagaard as“A well intended elegant, yet useless solution to a problem we never knew we had.” They cite key defining factors as“an outcome in which designs or technologies “for” disabled people garner mainstream attention and accolades despite valid concerns disabled people have about them.” [2] The tools or“solutions” often ignore“the lived experience of Disability” [1] in favour of a design first object.

The makers of Disability dongles often claim to be the first to solve the issue (ignoring the role of a disabled creators) or use disabled people as a token as to why they should get positive recognition for their design, the opinions and insights of disabled people are often discounted or ignored as they should be“grateful” for the attention to their disability and/or needs [2]. They often account badly for multiple intersecting disability’s and or other intersections (most often cost/access to money). They arise when the methods in chapter **??** fail and there is also a lack of understanding of disability in a practical sense, which can result in“solutions” that are instead of addressing a need, make new issues that must be resolved.

Figure 4.1: Robson Square in Vancouver, Canada

It can be illustrated in this the example of Robson Square in Vancouver, Canada seen in Figure:4.1. This well intended design is often discussed in an inspirational light, however, is often badly received by disabled people, like an article from the national broadcaster of the country where stairs are quoiting a wheelchair user calling the stairs and ramps“dangerous to travel down” and a tripping hazard [52]. To elaborate it is also difficult to manoeuvre if you need handrails, are blind or visually impaired, have difficulty walking, if someone wants to use the ramp at the same time in the opposite direction (sight lines are difficult), or are trying to clear the stairs of leaves or snow. It also does not follow current conventions of building as not all risers are the same height and thus are tripping hazards. The original designer of the stairs had good intentions. Made around the rise of the Disability rights movement it was supposed to be inclusive and promote interactions between disabled people and non-disabled people. However the design lives in the much messier world where disabled people are not just socially disabled but also have disabled bodies (and thus logistical concerns).

4.5 Models of disability

Models of disability shape how we understand and view disability, it effects and role in society. To understand how people, approach disability we must understand the range of models that exist and how they may shape how individuals intact with disability. The following models are gathered from a number of sources and reflections are noted with each model. The most common models in a social context are the social and moral models with a hybrid models based off the social model being common in the space of design like, the disability as mismatch model (section:4.5.6). Models underpin how individuals and institutions interact with disability and disabled people. They provide a lens of assumptions about what it is to be Disabled, the role of disabled people, the role of technology and the role of society [1]. There are also some common practises that exist in the space of describing and understating disability , they are Bio-certification and bio-specimen, they will also be explained as they will help understand how this work is being done or not done in practice.

Personal Reflection: as will be explored later on the models are often not cognisant in individual minds and do not always align with their values. This may be a additional source of discomfort as it can cause cognitive dissonance. It is also not to say that they have no utility but that do provide a foundation that many other actions can build on.

4.5.1 Moral/Religious

The moral/religious model is one that views disability as an act of God or the will of God [53]. One angle of this lens sees disability as a punishment for moral short comings, either that of the individual or that of their family. Other explanations of the origin of disability are that disability is a test or special calling from God [54]. Both view offer little in the way of centring the Disabled Person in their own life. The religious model is one of the oldest models in western philosophy and is often one of the first models people are exposed to in an articulate manner in the authors observations. This model has the values of curing and may lead to infantilization (that doctors know best), normalized body bias (in the image of God), pity or inspiration.

4.5.2 Medical

The medical model that has replaced the religious model with the rise of modern medicine and scientific knowledge. The medical model views disability as the result of a defect in the human body, it“explains all disability as biological impairment.” [1], it puts the burden on the disabled person and frames disability as something to be solved or cured [53]. The focus is on medical cure or, if that is not possible, an existence that is as“normal” as possible [53].

However, this approach may promote masking which can make it more difficult to understand the individual’s design and access needs. This provides little practical structures for design. This model also has the side effect of creating the illusion that disabled people are confined to medical settings, thus make it easier to assume that disabled people are not a part of one's target market. It also presents a limited view that does not account for sensory needs or other non-medical access needs i.e., if the disability is not found in current and traditional empirical methods then does not exist. This is especially prevalent in conditions like chronic pain and its interaction with race and autism spectrum disorder (ASD) and its intersection with gender where bias compound to lead to a lack of care [55] [56]. There are highly gendered connotations of"normal" that centre"the ideal of the white, youthful, able, male body" which has led to large sections of the population not being well understood [54]. By building on the foundation of science, in the medical sense, people's understanding is limited and confined. Modern medicine is evolving and not always clear in its communication partly due to an evolving understanding in the field, some examples outside of disability are early communications in the Covid-19 pandemic, the discussions of the theory models underlying depression[8] and Alzheimer's disease[9]. This model also explains and underpin a phenomenon that is common within organisations i.e. the "need" to have medical diagnoses for care or accommodation, which exacerbates clinical gaze, high cost, stigma and inefficient tools. This model values curing, normative ways of being and decreasing inter-dependency. This model also pathologize[10] many parts of the human experience and can often limit the role of the human spirit. There are also newer views that health is not just an absences of disease but as a full understanding of an individuals needs, wants and ability to understand their situation [57].

4.5.3 Bio-certification as practice

The bio certification practice of disability has manifested out of the medical model. It centres that a valid disabled person has been certified as such by a medical entity. It is often seen in institutions and employed by governments as a way of limiting who has access to accommodation or assistance. This fram-

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[8] https://www.newscientist.com/article/2328700-no-link-between-depression-and-serotonin-finds-major-analysis/

[9] https://www.science.org/content/article/potential-fabrication-research-images-threatens-key-theory-alzheimers-disease

[10] to pathologize is to treat a characteristic as un-healthy and demand that it be treated, a common example is that gay individuals where pathologized as being mentally ill.

ing and practice not only exacerbate the medical gaze as it intersects with the biospecimen model which will be explained in the next paragraph. Also creates an artificial sense of scarcity surrounding resources and limits the implementation of not only universal design but the wide application of disability knowledge in a system. As a result of the bio certification practice accommodations are often seen as "social capital" which presents the (often) false assumption that accommodations will adequately or fully accommodate a disabled person in that space. This model is sits at the intersection of the medical model and that of the Economic. It has the flaws of decentering the disabled people and their experience in favour of bodies that do not centre disability knowledge, gatekeeping access to resources, privileging certain presentations of disability over others, situating accommodations and access in a way that makes it difficult to scale. Gatekeeping the identity of disability. Placing a burden on an individual seeking access or accommodations.

4.5.4 Bio-specimen as practice

The bio-specimen model of disability comes from a false understanding that all individuals with the same disability present the same. This is often exacerbating issues of race, gender, and other perceived characteristics as individuals whose characteristics fall outside what we see the bio-specimen model of that disability to be. An example to illustrate this is that individuals who present at a later age or who are women or people of colour asking for an ADHD diagnosis are often disregarded or identified as"complex cases" because they do not present with overlapping characteristics of the biospecimen model or have a common comorbidity with untreated ADHD. Some stereotypical presentations include young boys with ADHD, mute geniuses with ADS, happy children with cerebral palsy, wise and caring blind people. This means individuals can often not get the bio certification needed to access resources and accommodations in the spaces they occupy. This is a prevalent in workplaces, schools, and the issues that interface with government entities[11].The need to understand and have

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[11] There are many possible investigations on how systems misunderstanding of the presentation of disability further disables, disabled people beyond their natural debility. This could be investigated through a deeper understanding of neurodiversity expected presentations (tic disorders, ADHD, ADS, Learning disabilities)and mental illness expected presentation (like in the

tools to describe, diagnose and parcel disability is needed for people to develop with in the current systems that we exist in but the above two methods encode bias that may hinder the goal of humane design.

4.5.5 Social Model or Minority Model

The social model is a model that is often supported by many people in the disability community and is one of the most circulated models in media. It identifies disability as an inherently socially mediated phenomenon, it constructs disability as the results a limitations imposed on people by physical and social environments. Robert Murphy distilled it in his book The body silent as“The greatest impediment to a person’s taking full part in his society are not his physical flaws, but rather the tissues of myths, fears and misunderstands that society attaches to them.” [58] This model allows for there to be a world in where disabilities can be accommodated in to no longer being an issue for that Disabled Person and under this lens Deaf and hard of hearing people can be seen as not disabled in the context of there own homes or other environments that have been adjusted to them and their needs. This goal can apply to many groups under the umbrella of disability, it however ignores the realities of disabilities that are painful in ways that can not be or can not currently be cured and conditions with fluctuation impairments [59] [60]. This is the model that underlies many approaches and systems that are aware of disabilities, such as laws, schools/educational mandates and policies from organizations as it is often cited and the underling the definition they uses. This model also is connected to the disability as mismatch 4.5.6 model as it serves as the foundations for that models approach.

4.5.6 Disability as mismatch

The disability as mismatch is not traditional model as in attempts to explain disability by situating it in society, the approach is the underpinning of several sets of design principles and design toolkits like [20] [61] [62] and the work of

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work of Emily Martin). And how that impacts on care or how normative assumptions on moving through the world shape the treatment we give individuals who need help with mobility, but that work is beyond the scope of this one.

Kat Homes. It is instead a design-based approach that sees disability as the result of mismatch between a person and their environment [20]. It is common approach in technology development that aims to identity disability and solve it. However, this model leads to a definition of disability that can be solved via an intervention, it lives in a space where solving in implied and this definition does not identify of offer a handle to tackle disability's that are not“solvable”. It identifies sensory disabilities and some physical ones but does not leave space for invisible or painful disability. It offers the perspectives of other mismatch that are not seen as disabilities like language barriers or temporary impairments which can be useful but should not be privileged over other disabilities in terms of accommodation or attention.

4.5.7 Disability as Superpower

The disability as a superpower model is a model that is often seen in media. It frames disability as an inspiration, and that disabled people have a role in society only as an inspiration [63]. This model is Othering[12] and makes it almost impossible for disabled people to be ordinary members of society. It sets standards that are“superhuman” and eliminates space for nuance [64]. This model is also often criticised to be damaging to a disabled persons social and personal development [64].

4.5.8 Identity or Affirmation model

This socially situated model views disability as a marker of minority identity, with the goal being a political movement or organization [53]. This model gives little leverage for design but does promote to phrase“nothing about us with out us” and the“cripple the vote movements” it can be seen as a method for demanding changes and fosters community and identity for disabled people. This model is often used in conjunction with the social model and may push corporations and organizations to address the needs of disabled people because there is a

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[12] Othering situates individuals or communities as outside of the in group, it is a political and social phenomenon and underpins many different prejudices and bias like xenophobia, homophobia, racism, sexism, and ableism.

defined group with supporters that is demanding change.

4.5.9 Human Rights Model

Highly connected to the social model of disability is the rights or human right model of disability. This model views disability as a socio-political issue and construct [54]. It places Independence as a key goal and legal structures as a path to that goal. It identifies sources of oppression and can be useful when combined with other lens or models. The model is foundational in the policy spaces such as The United Nations Convention on the with Disabilities as the foundation for many countries approaches to disability and the law [47] [65].

4.5.10 Cultural Disability Model

”While the medical model and the social model each focus on only one factor in their approach to disability, the cultural model focuses on a range of cultural factors. Such factors may include medical and social factors but are by no means limited to these factors. Accordingly, the cultural approach does not seek to define disability in any specific way but rather focuses on how different notions of disability and non-disability operate in the context of a specific culture.” [53]. This model may help build an understanding for disability that build communities but can leave out invisible disabilities, disabled people isolated from others like them and those who’s disabilities are“rare or uncommon” or have no hereditary aspect (children with the same or similar conditions to a parent or relative have different experience as to those with no close links to others with the same disability). Some conditions have strong cultural components like Deaf/HOH and down syndrome and others do not.

4.5.11 Charity model

This model emphases pity. It is Othering and limits the agency and autonomy of disabled people. It is widely regarded as a deeply ableist model and is linked to eugenics by promoting the lives of disabled people as lesser than non-disabled people [53]. This model is not positively regarded by disability rights communities and limits the business case for accessibility, since disabled people are not seen as legitimate customers.This makes the model difficult to use by designers and technologists to advocate for disabled people. There is also little application for this model when it comes to design.

4.5.12 Economic Model

This model frames disability as a defect in economic productivity,“While the economic model insists on the importance of ‘respect, accommodations, and civil rights to people with disabilities’, such concerns are subservient to the economic model’s estimation of a disabled person’s ability to work and contribute to the economy” [53]. This model can make the cost and benefit of accessible or universal design look only economical. Although there are cost to both disability and inaccessibility, they are often hidden in ways that are not easily added to a spread sheet. Since most of development and products are coming out of entity’s that have an economic obligation it is import to not underestimate the effects of this model on the perceptions of disability.

4.5.13 Western models vs other models

The models discussed above are predominantly western in origin, but disability exists in every cultural on earth. So, what do models look like in other part of the world? Sadly colonialism has shaped how many cultures see and deal with disability. The role of community vs individually manifests differently in different cultures and this, in turn, has implications for the treatment of disability and the role of community [66]. Often the power structure that are imposed on communities, geographies, and people, via colonialism, limit our ability to learn and care in appropriate ways for the wide range of conditions and ways of being. Given the interpersonal nature of disability it is important to remember that distinct cultures and languages have different approaches and that they may provide insights as to how to think about disability and how it works within our systems and what we build. In India there is a rise in amputations that started with the introduction of motorised vehicles and thus a need for artificial limbs rose. However, Western limbs are not adapted to the cultural needs of the users, most Western artificial limbs are developed for siting on chair and not the ground. In the region of Juapuer,India there was a need to be“cheap, enduring, and efficient.” [67]ch 4. To meet the needs of the people the artificial limb built of wood is arguably more humanising than that in the standards of the West thus showing that they may shape how disability acts in society differently then in the west. There are lessons to be leaned from many diverse cultures and not all Western standers are appropriate for all situations. There are also encoded stigmas in different languages in their words for disability (like Spanish and its Catholic underpinnings) therefor to understand any individuals understanding of disability we must see the variety of contexts that may shape it.

4.5.14 Conclusions on the Models

Whether or not we can identify the model we use to define and understand disability they do effect how we interact with disability and disabled people. Some promote engagement with the needs of disabled people. Other will minimise the ubiquity of disability. All ask for an understanding of who, why, and how, but most offer little in the way of providing logistics and logic for how to address the needs of disabled people. Given the variety of models that people may hold it is understandable that not all conversation can lead to helpful understandings and that with a wide range of models teams are not on the same page as how to proceed.

4.6 Biases

The products of the models and other factors are the stigma around disability and the many bias that manifest, broadly they can be seen as Ableism, but it is useful to identify the underlying classes of bias. Some primary biases will be named, described and manifestations will be show where possible. These biases manifest from the models that we have discussed in the previous section but also from the practical realities of how societies discuss and interacts disability. Although the following section is not exhaustive in the biases within ableism it is it beginning of understanding the biases. As with all bias based on human characteristics the bias and level of bias compounds and manifest differently for different situations and different people. Individuals are not bad for having bias, often they come out of recognising patterns in how we collectively interact and individuals replicate the patterns. Tools like `http://www.criticalaxis.org/` can show media examples of some of the bias like Infantillisation and Exploitation Inspiration (they call it Supercrip), the visual examples can help provide a way of looking out for the bias.

4.6.1 Normative bias

Normative bias is based on an assumption that the default body is that of a non-disabled white young adult cisgender[13] heterosexual man [54]. These bias effects not only disabled people and how they are understood but also women, racialised communities, the elderly, and anyone who's being, or characteristics fall outside of that assumed "normal" [68]. This bias is seen in many different disciplines but is the deeply embedded in medicine because that is where it has the greatest consequences[14]. It is difficult to understand how much these bias effects disabled people because there is little good data but examples of cars not being as safe for women (when compared to men) because crash test dummies are male body default and certain kinds of image recognition routinely failing on people of color [68] [69]. These examples begin to help us to understand the depth of this bias and its effects. This bias is often difficult to identify because it is to a certain extent built into the systems of design we use in the form of standards, data sets and models. This bias is also at risk of showing up in non-direct non-human decisions like those made from data that have encoded existing biases as will be discuss in section 4.6.7.

4.6.2 Rarity bias aka Few and far between

Rarity bias is the idea that disabled people simply are not that common. This bias is a legacy of institutionalism, it is the product of individuals with physical

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[13] cisgender meaning having the same gender as one's sex assigned at birth

[14] for misdiagnosis, lack of treatment, late diagnoses, and increased Morbidity and mortality

disabilities not having full access to public space and is exacerbated by ableist hiring practices and education's inability to adequately accommodate some disabled people [70]. Designers do not interact with disabled people daily or the individuals that they are interacting with are masking or hiding the extent of their disability it means that designers have a limited understanding about the ubiquity and commonness of disability. This makes it easier to discount the need for accessible design and the perspective of disability in technology. This bias is also exacerbated by ableist images of the future and the medical model of disability. There is also a concept with in the disability studies commonality known as"invisible disabilities", i.e. a disability that has no traditional visible markers (like assistive technology[15] [71]). Invisible disabilities make up a large number of disabilities so this may lead people to discount the number of disabled people in a designers environment[16].

4.6.3 Gratefulness bias

Many of the models we have identified above have a thread of an idea, the idea that disabled people should be grateful for the care they get, this is in the moral/religious, medical, charity models, and can limit a designer's ability to listen and design what people actually need. This bias can limit how critical people are about what they make and what they design. It also is a response to the criticism coming from disabled people. It shapes the effort to address disabled people's needs to be automatically "good" based on design's existence rather than its effectiveness. This erodes the quality of the design, technology, and shapes what people see as"good" accessible design. This is often seen in the responses and dialogues around disability dongles and the instinct for many to praise the effort of the creators over critical opinions of disabled people [2]. The fact that the creator took effort seems more important than the negative

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[15] Many of the images of disability are around their technologies, as of mid 2022 there are no emojis (the shortest of short hand) that show a Disabled Person with out their AT but many with only AT.

[16] It is difficult to find statistical on invisible disability in part because they are invisible however if one looks at the number of conditions that have no visible AT, limb differences or distinct physical characteristics one can begin to understand that this group is under represented, a 2010 Americans with Disabilities Census Report lists that"only about 6% of who reported disabilities use visible supports" [72]

outcomes of the design as expressed by disabled people.Not to say that designers can not be proud, but that refection on the outcomes and underlying philosophies of the work is key in producing the best work.

4.6.4 Infantilization

Another vary common biases against disabled people is that of Infantilization, this bias implies that disabled people are less able to make adult decisions, this often means that control is removed from disabled people and that they are "spoken" over. This bias is often reinforced by the methods we use and how we gain knowledge from disabled people, there are disability adjacent communities where discussions are most often with the non-disabled parents of disabled children and seldom with the disabled adults with the same condition, this is especially true for ASD and Deaf/HOH people where both population are ignored for the options of there caretakers or interpreters. When intersecting with the medical model this can manifest as other parties know more about a Disabled Persons body then they do in the form of unsolicited advice or doubting the knowledge of their own mind-bodies and other microaggressions [73]. This manifest in many ways including, interacting to a Deaf/HOH persons interpreter instead of them, disability targeting organisations having leadership with few to no disabled people on them and the phenomena in media that seeks the opinions of the caretakers of disabled people and not Disabled adults with that same condition. This bias means that many voices of disabled people are filtered through parties that are non-disabled thus making it more difficult to understand and build for Disability.

4.6.5 Exploitation Inspiration

One of the biases that comes out of communications around disability is that of exploitation inspiration, this bias is one common in media communications and is a manifestation of the Disability as superpower model4.5.7 and has many of the same flaws [63]. Silva and Howe put it well as"Social expectations are so low for individuals with a disability that any positive action may induce praise from others" [64]. The risk is that this overlaps to built and designed technologies and that the critics on what gets built is“good” simply for meeting the bare minimum and not its quality. There are also the risks to disabled people that come from this bias, it can lead to exoticisation [17] which when linked with other identities can lead to increased risk of exploitation and objectification. In addition to setting inappropriate expectations, it also leads to the exploitation of disabled people for political and social reasons. It is also worth noting that many disabled people experience this bias as a micro-aggression and this may make collaboration difficult.)

4.6.6 Intersections with other bias

The biases above can all compound and intersect with other bias human’s experience, the way bias manifest for a Black disabled women are different then for a trans disabled man are different than a technology assisted disabled white man. That is to say that the views that shape the way Tech and people interact with disabled people also have matching, overlapping, and compounding bias related to factors such as race, ethnicity, gender, gender expression, age, access to financial resources, sexual orientation, religion, immigration status, and national origin. Intersections with other identities may mitigate or exacerbate a Disabled Persons experience with ableism and how technologies and people respond to them and their needs. When we understand the intersections of disability with other marginalized characteristics we can better understand how our technologies will operate in society.

4.6.7 Data and “AI”

Data is increasingly being used to make decisions in what gets built, how and who builds it. There are not only flaws in how data is collected[18] (using non-Representative data sets) but also by the way biases have effected what data can be collected[19] (the way the bias effect what is possible to measure.) Bias in the data impacts“who benefits or carries their cost” [75]. There are documented

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[17] The practice of portraying or regarding someone or something as exotic [74]

[18] data on disability is often not collected.

[19] who get hired is the results of what hiring managers think are“good” workers not who is actually capable of the work.

issues with hiring practices in relationship to disability because they codify the bias listed above [70]. There are also concerns regarding the data that is collected in general for testing and development purposes not just in respect to disability but also race, class, cultural context, geography and gender [76] [77]. The underlying concern is that this shapes the outcomes that systems have and that since the outcomes contain Prejudice against disabled people and other identities that the outcomes will hurt or incorrectly classify people at the intersections and that the harms will be difficult to find and hard to correct since they are encodes in to the systems and outcomes. To understand disability from the perspective of data is to have it be fully defined with boundaries that are agreed upon.

4.6.8 Conclusion on the biases

The bias listed above compound and intersect with the models listed in 4.6 to degrade the quality of technology (from the perspective of disability) that are built with them.

4.7 Stigma

Within and around conversations of disability there is often a stigma around the word“disability” and being perceived as disabled.

During this literature review there were a myriad of different phrases or words to describe disability and its related conditions. These words and phrases often attempted to circumvent the stigma around the word disability and its potential negative consequences but it ended up making it very difficult to find materials explicitly related to disability, it makes it difficult to collect requirements and deepen our understanding of how to build for disability. These phrasings were often done with the best intentions, but they often have the side effect of minimising the role of disability in an individual’s life, and inadvertently increasing the stigma around the word disability. Another side effect of this refusal to use the term disability is that it obfuscates the group, it makes it so that it is easier to view disability as rare because it has been fractured into all these small independent groups[20].

The term disability and disabled people is used explicitly within this work to include the widest range of people and experiences. The word disability is often only used in the literature when the authors are talking about statistics or when they are discussing the legal ramifications because in many jurisdictions' disability is a protected class (like that of race or gender). A side effect of using euphemisms around disability is that could potentially remove the legal protections and limit the collective power of disability. These euphemisms are often well intentions to avoid discomfort or pathologizing individuals and their experiences and to avoid the stigma around disability, but this often does does not work and is most likely a wider problem in how individuals gain knowledge about how to design for disability. Some of the common euphemisms are"differing degrees of functional loss across the spectrum of capability" [30],"Inclusive design" [20] [62] [61] [24],"Accessible design" [25],"Designing for accessibility" [19],"Handicapped", differences in ability, special needs, adaptive athletes (in a sports context),"(Dis)Ability", a person facing the disability, or person with physical limitations. [21]

This wide range of words and phrase means that we see the words"disability" and"disabled persons" as inappropriate and inadvertently further stigmatise disability. This stigma means that designers and technologist disregard there own experience with disability because"my sibling/friend/co-worker/self is not disabled because they are competent" or many of the other limiting stereotypes we collectively hold around disability. It limits the knowledge and lived experience that people have and removes it from a common place experience to

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[20] In some contexts this may also remove legal protection from disabled people as the euphemism is not a protected characteristics, there is no obligation to accommodate"special" students in schools but there is often a legal obligation for disabled students.

[21] This phenomenon will come up time and time again and has been observed so often that I now call it "the Voldemort problem". There is a hesitancy to use the word disability, by not using the word disability we construct it socially as an unspeakable thing, a thing that can never be named because no good person that we interact with could ever be "that". But it is also used as a tool to cloud the political/legal protections around disability and divide communities and dismantle inter-disability solidarity.

something that cannot be explicitly discussed.

4.8 Access Needs

One method of framing disability for the purposes of developing technology is that of access needs, often described in services outside of the technology space like education or other public facing services. The lens of access needs is not currently being used to its full potential in the literature that was reviewed (outside of one toolkit i.e. a toolkit about making accessible outdoor spaces, and the public library of New York's website) however it is a possible method of concretising the needs of disabled people in a way that is accessible to non-disabled people. The table in Appendix A.3 shows potential access needs collected from a variety of sources such as [21], [78] and observations I have made over time working and participating in disability centred spaces. Inspired by the tagline AccessIsLove, it aims to reflect that access is the first step in making the world and technology inclusive and that the needs of disabled people are non-negotiable needs. When we meet the common access needs and do not wait for issues to arise, we (as designers, developers, builders, and policy makers) show that disabled people belong in our spaces and that we see their value. This is one of the methods that will be assessed in the evaluation process.

4.9 Disability as Critical lens

This thesis centres disability and disability studies as a critical lens because access and accessibility are not yet full bloomed in our collectives understanding. Access is difficult to describe, it is not a check list nor a pass/fail criteria, it is more like belonging, safety and acceptance then a set of requirements. Disability studies lets us understand what access is because it lets us“see” what inaccessibility looks like. It has the unique ability to“look” and“see” from an angle that is so deeply human, not interfaced with economic or clouded by what is supposed to be but to see what is. It lets us see from the perspectives of real mind-bodies, real human beings. It also allows for uniquely different ways of seeing and approaching different problems. The spirit of adaptation and “working with what you have” is truly seen and understood differently through disabled experiences.

4.10 Conclusion on the Literature Review

After reviewing availability literature on the topic of designing for disability, and possible underpinning constructions it is clear and understandable that what gets designed is often flawed from a human use prospective. The system, tools and underlying assumptions uphold normative structure that privilege certain ways of being. If we expect technology to solve the problems that we currently face, we can not expect it to work with the same attitudes and approaches that got us to where we are now. Therefor in this thesis I aim to propose a toolkit that **centres disability as a method of critically refection on the technology** that will build and promote speculation on what technology and disability means for the future.

Chapter 5

Prototype check-in one

In the previous chapters I have identified and explored current situation as it is presented in the state of the art and the corresponding literature. There is a lack of understanding of the role of bias, models, cultural dialogues(stories) and history (as will be explored the next chapter) in what gets built and what standards are in place currently. When these two issues are combined with methods that inadvertently encode the bias it is not surprising that we as a society have not reached the full potential of technology to serve people, both disabled and non-disabled. Additionally there is little to no critical refection on potentially harmful design-outcomes and little opportunity to follow though on lessons learned since ableism has devalued the voices and lived experiences of disabled people, and/or designers lack the correct tools, methods and languages to communicate with disabled people.

The key takeaways from the State of the art and the Literature review:

1. Disability is a complicated multifaceted “thing” it has many understandings and this difference in approach can lead to not ideal outcomes.
2. Discomfort can come from stigma and differing underlining assumptions can make it confusing to understand foundational assumptions of other party’s.
3. The practical tools are needed, there are options but many of the disability explicit ones centre non-disabled understandings of disability.

Understanding that designing is often a collaborative activity, and the discussions and perspectives around disability effect what gets built and how, the place I have chosen to intervene in is conversations. Conversation acts as the primary location when meaning is being made, this is true for almost all social conversation but especially for disability. Disability and its experience is heavily socially mediated and this is impacted by language (shared and not) and the assumptions we hold around disability.

5.0.1 Objective

There are repeated patterns (biases, models, stigma) that lead to conversations that do not meet the goal of making accessible and appropriate design interventions. This is often to a lack of practical tools to do this work that meet the values that people hold. There is also disconnected language that may make conversations difficult.

This leads us to the main objectives for this round of artefact production:

- **To capture the depth and width of the conversation so users know the scope of the conversation.**
- **To parcel information in to digestible pieces of information.**
- **Shift disability from a “edge case” to a central conversation piece and work against stigma by having repeated exposures to it in a multiple formats.**

5.0.2 Ideation

The tools as identified in the state-of-the-art build on top of foundations that are flawed. These foundations are made up of assumptions informed by non-disabled perceptions of disability. To prevent people from encoding these assumptions into their designs, it is important to intervene on these foundations, which are first made salient in conversation. The toolkit to be designed in this thesis needs to work in spaces of conversations, wherein the focus lies not with the physical tools of the work but on the conversations being had.

Something that was lacking in the state-of-the-art were artefacts around the task of designing for disability. Artefacts in a design sense and in knowledge work are “any tangible, portable object that holds information” [79]. “artifacts make it easier to keep track of information by making it part of the environment” [79]. By externalising information we can focus at the task we are working with and given that designing for disability often means keeping track of all the different types of disabilities there are and all the different ways disability manifests it is useful to have concrete tools that allow for externalising information and keeping track.

In the early stages mapping (see fig5.1) of the concepts was also explored but the maps if granular enough to give deep information became overwhelming and difficult to apply to a situation or context as extra information remained visible. In other explorations of how to organise and externalise the information a common tool was used, that of cards, which allowed the information to gain other levels of meaning based on physical layout.

There was also the idea explored of prompting the conversation via questions but this was not deemed the most efficient way as it does not guarantee the perspective of disability as the value of disability generated knowledge is not guaranteed to be valued or listed to[1]. The idea prompting conversations did make it to the first presented iteration in the form of the questions that can be seen on the bottom of the cards (see 5.2 for an example.

5.0.3 RQ2b: What are possible formats for a disability toolkit?

A card set was chosen due to its ’overviewable’ (overzichtelijk), digestible nature and its commonness in the state of the art [23] [26] [40]. The target of the cards are people who have a hand in designing or implementing technology, not those with a disability studies education, the system also aims to be useful for them but not tailored to them. The state of the art had several card set, and this method is

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[1] this in of its self is a task that requires work

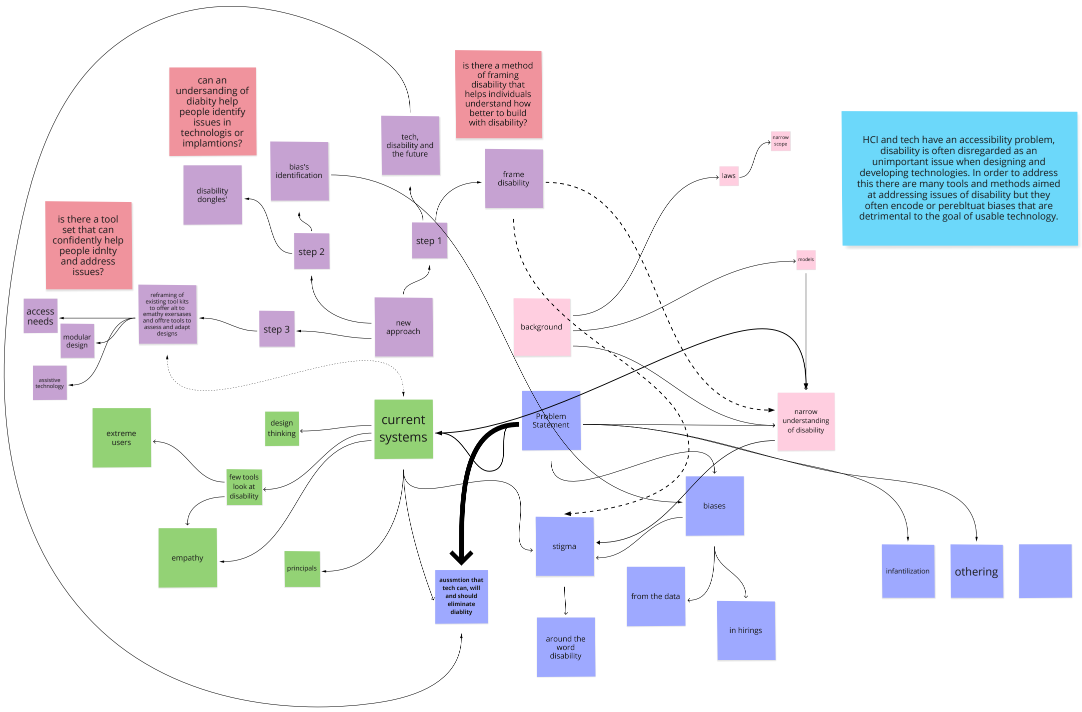
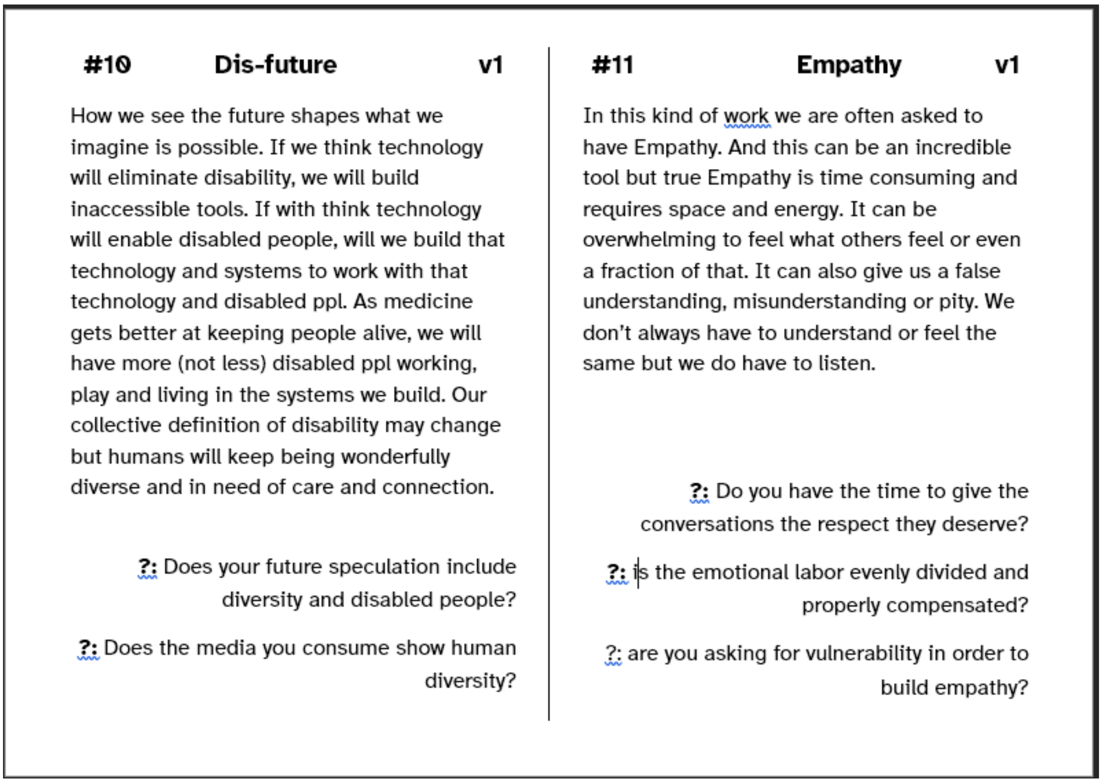


Figure 5.1: An attempt at mapping the problem space of design for disability disability



#10 **Dis-future** **v1**

How we see the future shapes what we imagine is possible. If we think technology will eliminate disability, we will build inaccessible tools. If with think technology will enable disabled people, will we build that technology and systems to work with that technology and disabled ppl. As medicine gets better at keeping people alive, we will have more (not less) disabled ppl working, play and living in the systems we build. Our collective definition of disability may change but humans will keep being wonderfully diverse and in need of care and connection.

?: Does your future speculation include diversity and disabled people?

?: Does the media you consume show human diversity?

#11 **Empathy** **v1**

In this kind of work we are often asked to have Empathy. And this can be an incredible tool but true Empathy is time consuming and requires space and energy. It can be overwhelming to feel what others feel or even a fraction of that. It can also give us a false understanding, misunderstanding or pity. We don't always have to understand or feel the same but we do have to listen.

?: Do you have the time to give the conversations the respect they deserve?

?: is the emotional labor evenly divided and properly compensated?

?: are you asking for vulnerability in order to build empathy?

Figure 5.2: Version 1 cards with questions at the end of the card

common in the domain of design education. This is most likely due to a number of factors including the affordances and ease of distribution. A card set as a physical object has a number of affordances, to flip, to shuffle, to edit/mark up, to hang, to pile [79]. They adapt themselves to physical spaces and offer a tangible interaction for a group of participants. They are also relativity easily to adapt to digital methods and spaces like Miro, mural, or other online/digital white broads. The cards also distil what are often complicated ideas in to smaller peaces. The content can be found across articles, books and in conversions, but in the card set synthesise in to more accessible language, along with tools or frames that have been developed for the card set. Cards also allow for rapid iteration both in this stage of development and its possible real world use.

5.0.4 Card set version 1

The first version of the card set instils the main possible lenses found in the literature review i.e., the **bias**, the **principles**, the **models**, and the **access needs**. There where also reflections on what kinds of friction or misunderstanding there is between disabled people and non-disabled people. This forms the more activist work in the disabilities studies space, especially reflections on tech by disabled people like [1], [13], [2], [45]. Version 1 of the card set has 60 cards plus the title card and 3 information cards, most of the cards have guiding question and can be found in AppendixA.9. The short coming of the state of the art have also influenced what is presented in this version of the card set.

Cards 2-20 are with the goal of starting conversations and providing and expanding the disability foundation that the reader already has. The cards cover a number of topics from definitions to different terms and concepts that are from disability studies and the perspectives of disabled people on technology.

Cards 21 to 35 are the access needs. Access needs are something that all people have, they are the parameters of use that an individual needs to be met to safely and enjoyably complete a task. This is one possible method of framing the practical implications of differences between people and was the chosen method for exposing designers and technologist to disability. This framing was chosen since it can help people understand the overlaps in different disabilities and conditions and moves conversations out of the moral and social and in to the practical.

Cards 36 to 42 explore common principles from the literature review synthesised from the available toolkit, these will be assessed to see if they are“liked” by participates or if the concept come up in the expert interviewers.

Cards 43 to 48 are the bias, they come from the literature review in particular [75], [63], and other works in the data discrimination space. The bias is also another way of presenting the effects of the Models of disability.

Cards 49 to 60 are a condensed version of the models, the models are from the literature review and personal observation have found that if two or more conversation partners have conflicting models then conversation can enter an unproductive circular state. The models are incomplete, and others may be head by the target audience (hence the model survey in ch A.4) and others may be held by disabled people[2]. However, the models are predicted to be foundational to a nuanced understanding and they underpin all the work that is being done in the space of designing for disability.

Outside of the content of the cards a few design decisions where made, mostly to provide foundation for later steps (see 5.3 for an example). A size, layout and font where chosen. The size of a card is A6, this means that 4 cards can be printed on a A4 sheet of paper, that makes to simple to print on available non-north American printers, it also means that if users want to add cards it is easy to do. The layout has the card number found in the top left-hand corner, centred on the same row is the title and then in the right-hand corner is the version number. The version number will most likely drop in the last version as it serves an organisation purpose in v1. The font chosen is Atkinson Hyperlegible by the Braille Institute in 12 pt for the body and 14 pt for the header, the font was chosen because of its readability and that sans-serif fonts are generally more accessible to neurodivergent people. The main body text is left aligned

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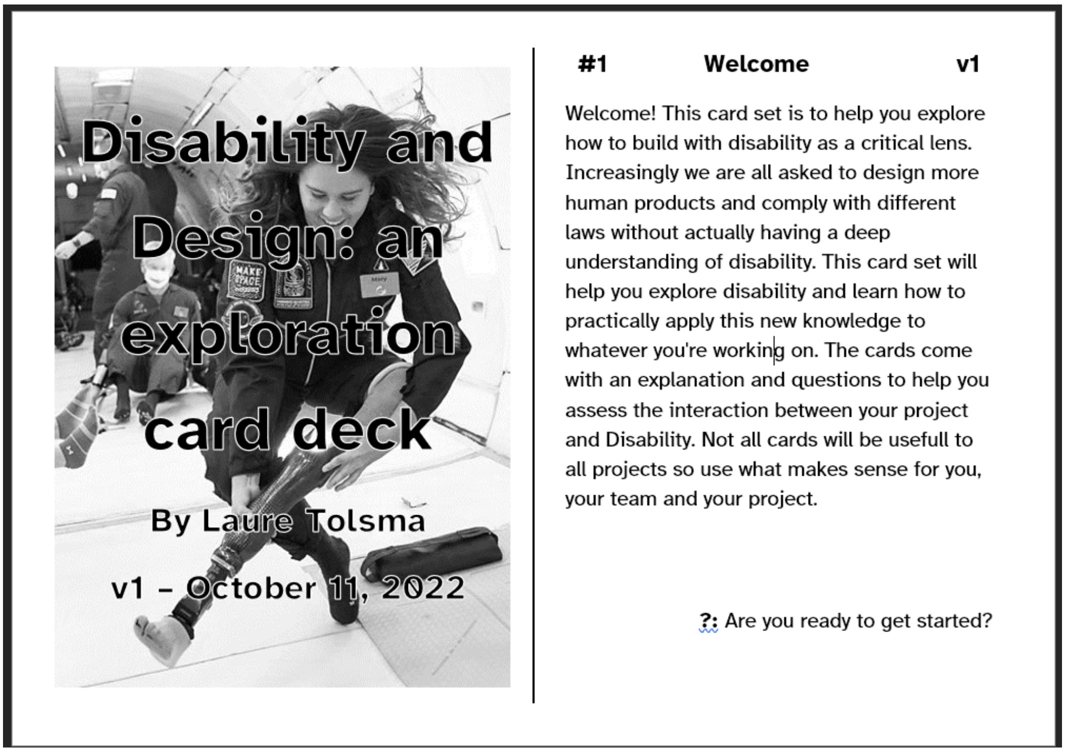
[2] The authors own model has yet to be articulated.

with the questions right aligned to visually differentiate them. The header image is from the first launch of a disabled crew on a a zero-gravity flight, the woman in the image is of Mary Kate Cooper taking off her prosthetic leg during the flight. Although this image is a place holder it embodies the spirit the card set is trying to capture, that of disabled joy and possibly, both now and in our imagined future.



Disability and Design: an exploration card deck

By Laure Tolsma

v1 - October 11, 2022

#1 **Welcome** **v1**

Welcome! This card set is to help you explore how to build with disability as a critical lens. Increasingly we are all asked to design more human products and comply with different laws without actually having a deep understanding of disability. This card set will help you explore disability and learn how to practically apply this new knowledge to whatever you're working on. The cards come with an explanation and questions to help you assess the interaction between your project and Disability. Not all cards will be usefull to all projects so use what makes sense for you, your team and your project.

?: Are you ready to get started?

Figure 5.3: First two cards of v1

5.0.5 Conclusion

This chapter described the first iteration of the toolkit. One of the main issues identified was the large amount and broad scope of information that needs to be accounted for when designing for disability. In an attempt to make this information manageable and tangible an artefact has been produced. The artefact is a card set, developed by collecting reoccurring and foundational themes on cards and then sorting, adding and removing cards based on the salience and impact of the information. The first version was made at this stage to gain a handle on and externalise the information gained in the state-of-the-art and literature review. Most notably, the lack of practical tools for understanding needs across disabilities has led to the development of ‘Access needs’ as a possible alternative to focusing on diagnostic labels.

Chapter 6

Exploring existing perspectives Disability

> ”it is not possible to understand one paradigm through the conceptual framework and terminology of a rival paradigm. It requires a fundamental shift in mindset and vocabulary, and this is what makes moving to a new paradigm so difficult.”
>
> *P. Gardien, J.P. Djajadiningrat, C.C.M. Hummels and A.C. Brombacher in Changing your hammer : the implications of paradigmatic innovation for design practice [80]*

The aim of this research is to understand how individuals in real-life practice understand and go about designing for disability. This chapter outlines two of the research activities conducted to gain insight into this. The first is that of the survey and the second the expert interviews. This chapter will explain the method and outcomes for both, then outcomes will be synthesised into a new framework (8) which will inform the next version of the card set.

The main research question for this chapter is ***RQ1a: What are the current models, practices around, and definitions of disability that non-expert designers and technologists hold?*** This will be supported by the ***RQ1b: What are the current models, practices around, and definitions of disability that disability-expert designers, communicators and technologists hold?*** for the expert interviews. This was done to gain an understanding of how the topic is understood and tackled by both the wider target group (technologists and designing) and experts doing this work. The outcomes are then implemented into the next version of the toolkit.

6.1 Survey on non-expert perspectives on designing for disability

The purpose of the survey is to achieve a better understanding of what are the current models that designers hold. It also explores what views people hold and aims to understand what biases may exist in the wild, this is to support findings for the research and re-evaluate what is needed to make the toolkit more relevant. The survey answers will be analyzed to find themes and common conceptions of disability.

6.1.1 Methodology

The survey considers of a number of open and scaled questions and is a digital survey, made and data collected in Microsoft Forms. Ethics approval was obtained form the Computer and Information Sciences (CIS) Ethics Committee under application number 22003. In addition, care was taken to promote autonomy by making nothing other then consent mandatory and gender demographic question best practices were followed

Procedure

The survey that was sent out on the 11th of November 2022 and ran for 5 weeks during which 15 responses where collected. The full survey can be found in the appendix: A.4. The survey starts off with an assessment of demographic data to gain insight into whether level of education positively or negatively impacts a persons depth of understanding of disability. The survey includes open questions on approach to designing for disability, and scaled questions which aim to gain an understanding of models and comfort levels.

Measures

The data that is being collected with the survey is that of open answers to questions and scaled answers. The scales collect data on the comfort level and the open answers allow for an understanding of approach and perceptions.

There are a number of scales from strongly agree to strongly disagree related to a number of statements about disability, the statements are derived from the models and use language that is reflective of possible models. The theory is that if a person responses in line with a particular model then they have that model, if a person respond out of line with all models then they may not have a model or if meany give that same or similar set of answers they may share a model that is not defined. Ether way understanding what models are held will help tailor the card set to the models that people actual hold as no information about the prevalence of models could be found in the lit review.

Question 11 is also a scale, but this time from always to never with the option of"can't remember/ don't want to say"[1]. They ask about past interactions and the emotional responses to disabled people that people have had. This aims to get an understanding of wider comfort levels that people have, this kind of research has been done but not for the target group, (was conducted for parents), the level of comfort and the kind of discomfort with shape how the card set talks about disability.

The last two open questions ask about a definition of disability and the approach that people have, this is to gain an understand about if definitions are common and to understand what people understand related to designing for disability and what disability is.

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[1] to promote autonomy and choose by the participant

Participants

There was a total of 15 participants. After coding, nine identified themselves as woman/females and six identified themselves as men/males. One participant self identified as having a disability (man). The education/experience distribution was three undergraduate/bachelors students, nine graduate students/masters, six working in industry or non-profit, and three free-lancers. No-one identified themselves as being in a teaching position.

6.1.2 Survey Analysis

The scales are analysed via tabulation and support the open answers which are analysed with coding according to thematic analysis. To analyse the text component of the survey, thematic analysis was used and the outcomes will be described and discussed on a section-by-section basics, the outcome can be seen in A.5 and A.6. The social model is the strongest but not a clear signal that it is being held with no other models in the mix. The mix of the social and medical models is the most common but charity and moral models also had presence in the answers.

Quantitative analysis procedure for scaled questions

The figure 6.3 shows that outcome of the survey converted to numbers i.e. each possible answer was given a score (+2,+1, 0, -1,-2) based on how that answer show correlation to the models, in the second set of columns that strength of the model is then divided the number of questions that show that model, in order to account of un-equal questions for each model. This shows that nine responds hold the medical model the highest, six hold the social model the highest and none hold the moral as the highest. This analysis was conducted on the discomfort metric, which show there is slight discomfort with disabled people over all which the toolkit will hopefully address.

Perceptions

This section of questions was amid at gauging at the level of interpersonal comfort of respondents in regards to disability and disabled people. As well as a gauge some of the social political issues that are common. Co-design is an often celebrated and recommended methodology (also amongst participants as will be seen later on) for designing for disabled people however if there is no priming done to open up the designers to the insights of their co-designers they may not benefit fully from the co-design process and in turn create discomfort for their disabled co-designers.

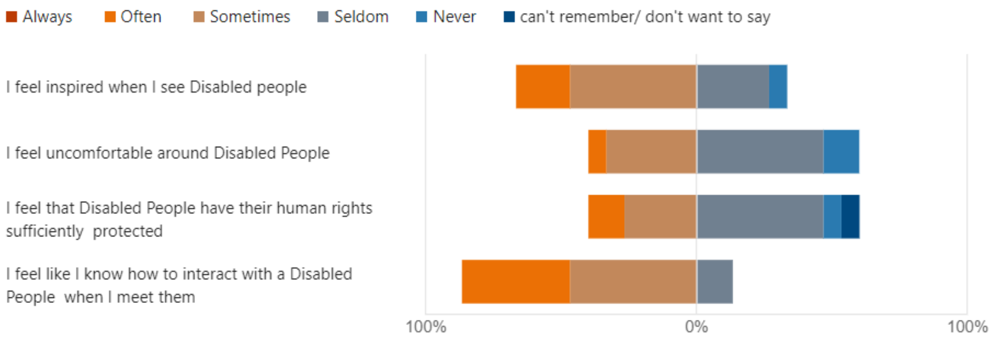


Figure 6.1: response to question aimed a gauging level of interpersonal comfort.

The figures 6.1 and, 6.2 can illustrate a number of things. One that there is a spread of comfort level in both knowing what to do as well as other factors identified in the literature. There is also not a clear pattern of a particular model, this is also collaborated by the answers we see in 6.1.2 and 6.1.2. The answers seen above support the need to work on the humanisation of disabled people in general, which is an insight also found in the literature.

Thematic analysis procedure for open questions

The survey open answers were printed and cut out to allow for mapping. Reoccurring wording of ideas were highlighted and then the highlights grouped into

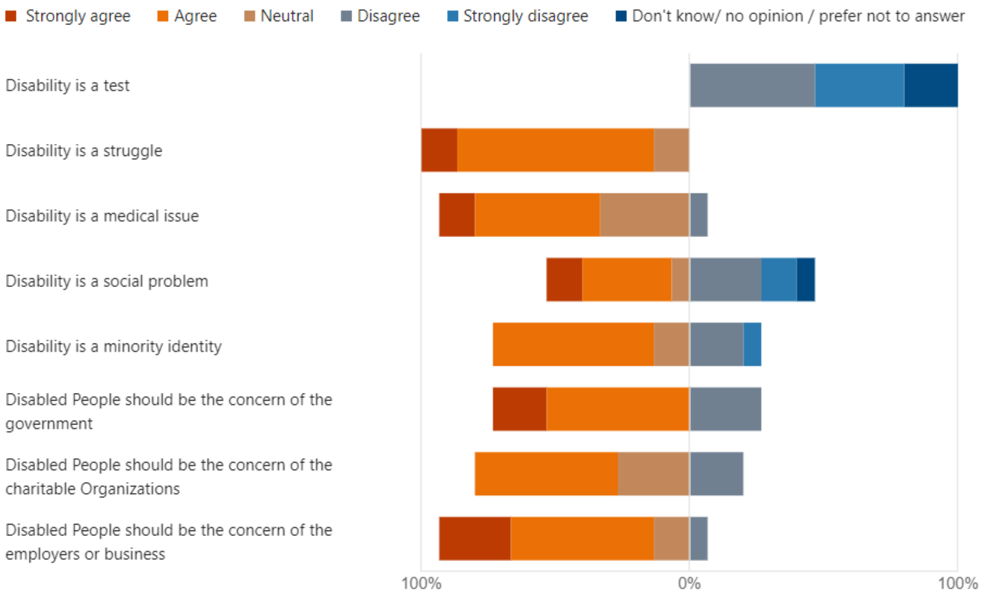
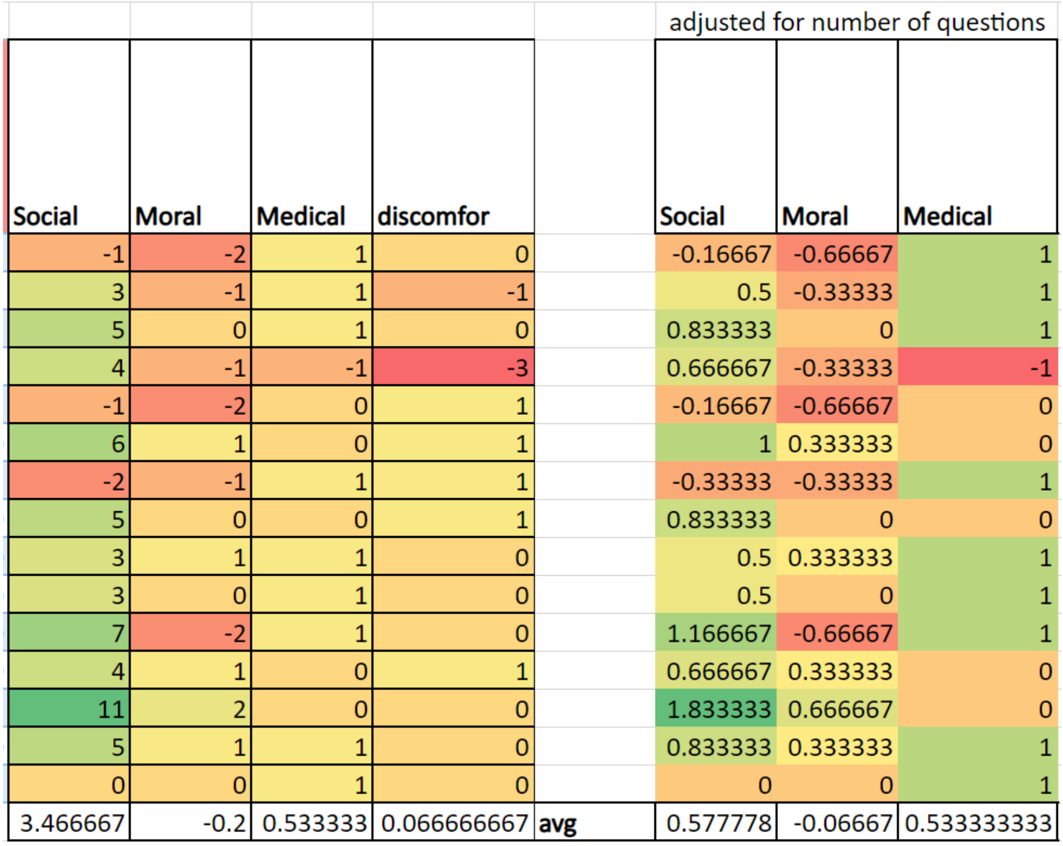


Figure 6.2: Likert scale responses to model investigation questions

categories based on the other contextual data given (the rest of the answer). Since the surveys come after the literature and SotA, themes/patterns explored there in are some of the frames that shape the analysis. These themes/patterns have also been observed in other forms outside of these research activities. I have recognised them from past experiences and used those experiences to make sense of and highlight certain data points (they will also be explored in chapter 7). The survey was looking for the models and found them in a derivative way. Disability design methods as seen in the SotA also presented themselves in a way, though differently than described there. The categories that were identified were mapped against a classification system that is based on shared experience and using diagnostic markers (i.e. someone's identifiable differences that correspond to a particular diagnosis), but purposely avoids the markers of severity. As the literature shows the assumptions of what disability is and how it works shapes how people design for it so that was also of concern. During the sensitising process of the analysis it was noted that there is an "assumed context" for disabled people; a location where people assume disabled



					adjusted for number of questions		
Social	Moral	Medical	discomfor		Social	Moral	Medical
-1	-2	1	0		-0.16667	-0.66667	1
3	-1	1	-1		0.5	-0.33333	1
5	0	1	0		0.833333	0	1
4	-1	-1	-3		0.666667	-0.33333	-1
-1	-2	0	1		-0.16667	-0.66667	0
6	1	0	1		1	0.333333	0
-2	-1	1	1		-0.33333	-0.33333	1
5	0	0	1		0.833333	0	0
3	1	1	0		0.5	0.333333	1
3	0	1	0		0.5	0	1
7	-2	1	0		1.166667	-0.66667	1
4	1	0	1		0.666667	0.333333	0
11	2	0	0		1.833333	0.666667	0
5	1	1	0		0.833333	0.333333	1
0	0	1	0		0	0	1
3.466667	-0.2	0.533333	0.066666667	**avg**	0.577778	-0.06667	0.533333333

Figure 6.3: Outcome of answers converted to numbers

people to be. In addition to what was said, I also analysed the language that was used when answering the questions. This was also coded as it may be an aspect that needs to be addressed.

Personal Refection:
Many of the themes that I coded and explored farther come from where my personal assumptions do not match the ones presented. Such as the classification systems used, appropriate language or development stage of regulations.

Analysis and outcomes Question 11: Defining disability

To analyse the currently held definitions of disability by the Target group, the definitions collected in question 11 were first analysed and coded for reoccurring themes/language patterns and notions. This then provided the categories for the section below which shows the number of answers that exhibit the pattern as well as describing the pattern.

Personal Refection:
This set of results led to me reevaluating the models and how I wanted them to work in the toolkit, I models where interesting to me since they show and understand disability is a mediated identify, to say that what people think the role of disability is, where it comes from and what it means to be disabled is important to understanding what we expect when we build for it. However this data and its analyses shows that the models are not in practise the way they are described in the lit. I still believe they can be valuable since they can show patterns in bias, assumptions and approach but they will need to adapted to how people see disability in practise.

Each pattern was chosen because it shows how the target group may frame the task of defining Disability and it was reoccurring or had an identifiable pattern. That thematic analysis is in the appendix under A.5.

In answer to the question 'What is your definition of disability?', the definitions broadly fell in to 3 categories. 1) the disability as socially situated difference (11 respondents) 2) the disability as technical difference (3 respondents) and 3) disability as consideration (1 respondent).

1) Disability as a socially situated difference is like but not the social model. It see the social as a key determent on the capability and expectations on disabled people but it frames it not necessarily as the source of pain, the social model in contrast views the source of all limitations on disabled peoples as a result of social expectation, the younger siblings of the social model may in fact prove to be more beneficial to shaping dialog then the social models as it is currently constructed. Disability as a socially **situated difference** was the found lens vs disability as a socially **constructed difficulty** is the social model.

2) Disability as a technical difference has a similar relationship to the medical model like the above has to the social model, it views disability as a result of technical difference much akin to how the medial model views disability as a flaw in the mind-body.

3) Disability as a technical consideration is an echo of the 'mismatch model' as it views disability as a reality that shapes how interactions happen and that it must be accounted for.

Following this line of analysis we may begin to think that the cognitive models as described earlier are echoed in people's current understanding of disability, but that these echos are distorted and reshaped by people's own experiences. This makes it difficult for them to recognise themselves fully in one of these twelve models. As such, these models are not conducive to building a deeper understanding of disability. Instead three lenses wherein less strict barriers exist may make it easier for people to recognise and accept one's own lens. This re-framing is more conducive to the goal of having people recognise their own biases and cultural stories around disability, but that notion could be refined by the results of the next section, the approaches the people take.

The language respondents used also can give insight into the depth and frame they use for disability. Many participants listed some of the common categories of disability like physical disability (60%), mental disability (53.33%), cognitive disability (6.67%) and sensory disability (6.67%). It is common for people to identify physical disability as they are the most visible and the identifying of mental is also a step towards nuance. However it is unclear if mental and cognitive disabilities are understood interchangeably or if mental is understood in the mental health capacity (with conditions like depression, anxiety, ex) and cognitive in a intellectual capability (down syndrome, fetal alcohol spectrum disorders, fragile x, ex) or in a neurodiversity capacity (like ASD, LD, ADHD, Tic disorders, ex), this can shape both peoples attitude, discussions, design decisions and shape the kinds of interventions that are constructed[2].

There were also several patterns that arose out of the thematic analysis. 50% of respondents referenced to“normal”,“average” or “able-bodied” which is notable since this framing is a normative one that can shape how we understand disability. It can limit the role of disability in how we design since it shapes disabled people as exception. 20% referenced to the“medical” thus invoking the medical model by framing disability as a medical issue. 40% referenced“limits” or“restriction” which although objectively true it has the possibility of framing disability solely as a deficit and can silo and limit disability. There were also references to AT in 13.33% of responding and no reference to social/cultural accommodations. This is notable since some of the respondent’s self identified as having some interests, experience and education in design and still only two respondent identified or described one of the most common ways systems interfaced with disability.

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[2] There is also a complicated relationship between all three, their perceptions, how they are addressed, and what expectations we have of them.

Personal Refection:
Cultural and social accommodations are common “hand hold” for designing for disability is clear when you have been living and working with disabled people for a while but is not often identified in the space of technology which may lead to the tenancy to “fix”, “cure” and “overcome”. Resistance to “fix”, “cure” and “overcome” disability is a key part of Crip approaches like in [15] [40] [16]

Analysis and outcomes Question 12: Approach to designing for disability

The responses as to the approaches that people have fall within 3 themes that will be elaborated on more deeply: 1) the sources that people value and aim to explore, 2) what input designers want from disabled people in collaboration and 3) the contexts in which we expect disabled people to exist in.

Valued sources

I am making the assumption the people will list sources in their answers that they value before ones they do not. If we take this assumption, we can derive that not all people value all types of sources equally: three respondents indicated reaching for the **standards** first (like laws, coding requirements), six indicated reaching for the **literature** first and 10 indicated reaching out to the **disabled people** first. This can give us an understanding as the bias that may be (unintentional) encoding in the methods that people use. The standards encodes and frame disability as a cost it also gives a narrow lens as to how to approach disability [3]. Literature sources can often encode ableist biases, as reflected upon in the state-of-the-art. There is a variety of perspectives within the literature. Disability studies literature offers a anti-ableist perspective on how to interface with disability whereas other literature sources like the DSM-5 or medical descriptions of disability may further encode biases. There are also issues in the quality of literature as not all sources that explicitly discuss a disability are equally humanizing. The disabled people first co-design method was described a hopefully number of times but it still exhibited some potently bias which will now be listed with quotes.“I first begin by understanding the specific disability

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[3] One that does not work for emerging technologies

as much as I can, either by speaking with intended users or from secondary sources like online studies.” This can silo disabilities into a specific condition, although this may be an appropriate method if the scope is too broad it may not reflect the lived experience of disabled people but instead a clinical understanding.

What people want from disabled people, the main themes where“issues they encounter”,“solutions they seek”,“how they would like to be treated”, experiences focused on pros and cons of their disability, how they view their disability,“problem to be resolved” and specific needs. Most of these are valid lines of inquiry but depending on the frame and method (which can not be assumed from the data collected) they may enact bias like normative wants, and they may enact forces withing ableism like that of forced intimacy. It may also be othering to describe needs in the manner.

Respondents also wanted input from disabled people in respect to testing and evaluation which is an appropriate methodology. However it does construct a narrow understanding of how disability manifests because the experience of disabled people is non transferable and if a the solution being tested is profoundly inaccessible it will be very difficult for a disabled person to articulate what needs to be fixed. One can not describe text as confusing if they can not read it. An object cannot be uncomfortable in the hand due to a form issue if it is not possible for that person to pick it up.

Contextual expectations surrounding disabled people

The contextual expectations will be explored via a quote form a respondent.“if it is a specialised product for a specific disability i would likely go to a centre where i can speak to many people with various levels of the disability in order to understand what specific needs have to be met.” This invokes an image the disability is culturally siloed (which is sometimes true), this does have the side effect of monolithing that group and to the idea of a location where lots of disabled people exist is in and of its self can be an act of ableism which will encode its own bias. It also presents connotation of the only disabilities that designers would concern themselves with are those with an institutionalisation“level of severity”.

There is also is response that is reminiscent of using a method discussed in the state of the art, the method of“empathy exercises” is often seen as a learning tool to gain a understanding of the perspectives of disabled people but was in this case recommended as a testing tool,“For physical disabilities, I will try to replicate it during the usability testing process as closely as I can, such as oiling up my hands, binding my arms, blindfolding myself, etc.” This approach strips the context from the disability and situates disability and the experience of disability as transferable.

6.1.3 Survey Discussions

No definitive models where found, instead overlapping lens of understanding that echo the models, the lens are shaped by the fact that non-academics were using the models and shaping them with there own experience and perspectives. This givens the indication that in order to make the connections between the models and one’s own perception of disability clear (and to build on the kind of understanding that people actually have) it will be beneficial to view disability as being“situated in” and not“construct by” medical and social factors, there has bean in this activity and wider discussions the understand that the line is bury between disability and non-disability and this is a messiness that may foster deeper and wider understanding of disability. There were other repeated patterns that were identified that if address may help peoples design for disability specifically cultural vs technical interventions, access needs, lenses instead of models, fracturing disability, and simply more exposure to disability.

6.2 Interviews and Activity

To gather how experts design for disability expert interviews were conducted with 4 people all connected to disability (in design or policy formats), there where experts with lived experience, neurodiversity specialisations and experience with designing for physical disabilities. This activity was conducted in parallel with the one above-mentioned with the goal of answering the research question*What are the current models and definitions of disability that disability expert designers and technologists hold?* and to learn the tools and methods they use in their approaches and collaborations.

6.2.1 Methodology

Experts where interviewed digitally and in person with answers recorded on paper to protect privacy. Ethics approval was obtained from the Computer and Information Sciences (CIS) Ethics Committee under application number 220049.

Procedure

In order to ground the discussions on a definition or lens I used collaborative sketching/annotation. Cooperative sketching in this instance was inspired by [81] with the goal of externalizing the process of language in a way that is less temporary and where capture of the content is part of the process and does not hinder the discussion but support it. As conversation is often shaped in small ways (individual words, tone and gesture), I wanted to focus and allow the experts to highlight these textural elements of conversation as I think they are important to how conversations are perceived, received and interpreted. The process here was adopted from the inspiration to be hopefully more accessible as it does not rely on any one particular skill(drawing) and instead focuses on externalizing a relationship to textual language ie the definitions. There are 2 versions in order to address the needs of participants. One in person and one digital to keep the activity safe and accessible for the widest range of people and public health requirements.

Notes will be taken on the Capture Template for interviews and activity – Disability in technology sheet and the physical copies will be stored securely till they are destroyed. This will be the step where anonymisation will take place as a number code will be placed on the paper records and the key will be linked to the content form in a secure location. This will allow for earlier anonymity and still holding a data withdraw window.

Both activities will begin with introductions (both of my self and the participant, consent). Then I will explain the propose of the interview and activity.

”I am working on my masters thesis of I-tech, my goal is to make sure that disability is understood and represented when people make technology. Part of that is needing a definition of disability that reflects the nuance, but most definitions are medical or do not help people understand disability and how it may interact with the technology.”

I will then reaffirm consent and that we can stop or move on form any topic or question at any time because this has the potential to be uncomfortable. A deliberate choice was made to steer participants away from medical understandings as I do not aim to intervene in the space of medical practice or field and individuals tend to move to this framing very quickly when it is not a framing i am looking to explore.

Measures

The data collected is in verbal open answer format with answers recorded on paper (to protect privacy). The conversational format allows for elaborations where needed, the notes are coded and analyzed using thematic analysis. The questions asked are:

- Question 1: How do you describe or define disability?
- Question 2: In what context is your connection to disability? (Do you work with disabled people? Design for Disability?) if a particular disability, what kind?
- Question 3: What kind of language do you use and why?
- Question 4: When you are designing what are approaches you use to understand how to build for your target group?

- Question 5: When working with collaborators how do you approach discussions around disability/ your target audience?

The definitions explored are:

definition 1: “A disability is any condition of the body or mind (impairment) that makes it more difficult for the person with the condition to do certain activities (activity limitation) and interact with the world around them (participation restrictions).”

This definition comes from the WHO, it has been re framed as the WHO and other international organisations evolve their definitions of disability. It reflects medical understand but framed under the legal and social models.

definition 2: “Disability is a way of being that is different then the common understanding of the standard. This difference can be in approaches to human activity’s and requires tools and processes to adapted to peoples changing and evolving needs.”

This is a definition built on by my personal ethnographic understanding of disability, it also attempts to reflect the realities of cyclical/ fluctuation disabilities, invisible disabilities and intersections on multiple disabilities.

definition 3:“Persons with disabilities include those who have long-term 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” [47]

Participants

There were four experts who where interviewed. They worked in policy (1), physical objects (1), and design research (2). Their experience stem from background/education (1), personal connecting to disability (2) and work (4). Three described their work as bridging connections between disabled people and non-disabled people and the other described their work as building Assistive Technology. There was one women and three men involved in the interviews.

Analyses procedure

Each interview was not transcribed (duo to ethics) but notes where translated to a digital white bored where each idea was placed on a different “sticky note” like in fig:6.4 Each participant had the same colour to identify the role of background on answers, from there clusters where made based on the content of the idea and each cluster was described in the below sections. The use of colour-coding allowed for self refection as some answers where more inline with my own and thus my own position became more clear. This is useful as it can tell me about the ways my perspective is informed by my background.

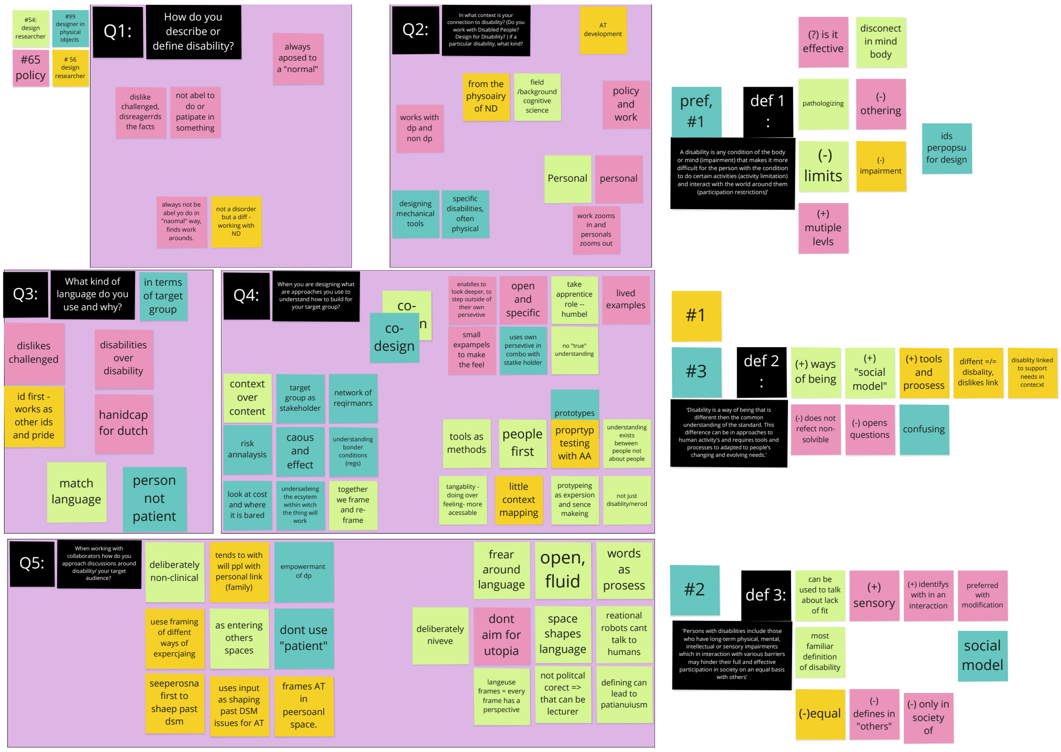

Figure 6.4: thematic analysis of experts answers

6.2.2 Expert Interviews Analysis

The interviews were sectioned into small segments of information and grouped in to response to questions. From this several observations and conclusions where made.

Q1: How do you describe or define disability?

The richest answer came from the Individual who was working in policy. They contrasted disability as always apposed to a“normal” and further elaborated it as a not being able to do or participate in something. The other description was around adaptation or different ways of working/being i.e.“ not always being able to do in a“normal” way, having to find work around”. For the participates focused on neurodiversity the push as for not seeing neurodiversities as a disorder but as a difference.

Q2: In what context is your connection to disability? (Do you work with Disabled People? Design for Disability?) if a particular disability, what kind?

This question produced demographic information, therefor the results are described in the 6.2.1.

Q3: What kind of language do you use and why?

All participants stated that they tried to use humanizing and non-medical language, and there were more phrases that were to be actively avoided than recommended i.e.“challenged” and“patient”. There was also a push to match the language of the group they are working with and to match the tone they use. When discussing person first versus identity first language there was mixed preferences, Identity first proponents gave the example that we do not use person first identities with other minorities[4]. Whereas person first proponents stated that it was to humanise and de-medicalise the experiences and the discussions with their target group. All participants thought that it was appropriate to match

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[4] a person experiencing gayness vs a gay person.

the language that the other party participant themselves used. This information and framing triggered a reflection on materials that were assessed in the literature review and the corresponding conclusions will be found in the conclusions for next steps.

There was a discussion about language, specifically the translation from English to Dutch, where there is often a frustration around not having a“good” word in Dutch for the concept of disability. The most common are 'invalide' (invalid) or 'gehandicapt' (to have a handicap), 'invalide' was disliked with participants (especially in the context it came up most often in i.e. accessible toilets). The second was preferred but also has particular lexical origin, so this may build a model more salient in peoples minds[5]. The use of English disabled is a common workaround, but this also builds an Anglocentric expectation that many artificially disconnect Dutch speaking people from their own connection to disability. This has been noted since most of the target group that I have access to is Dutch-speaking and language is a key part of how we understand the world around us.

Q4: When you are designing what are approaches you use to understand how to build for your target group?

Two of the participants described their methods as co-design. A few of them specifically worked with prototypes and used testing as a tool and the 4th primarily used dialogue and examples as a tool to build understanding. A methodology that bridged Most of the participants was using concrete examples and moving into tangible where possible, the individual who worked predominantly with policy said that they use small examples to make participants feel what other people are experiencing and enable them to look outside of their own perspective, the researchers used prototyping as “exploration and sense-making”, for participant working predominantly with developing assistive technologies use broader context tools like networks of requirements cause and effect risk analy-

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[5] The term“handicapped” originally comes from a game called“Hand in Cap,” which is a game of chance in which every person would have an equal chance of winning in each succeeding game that you played. Later it was applied to horse racing. You would handicap a fast horse by hanging stones on it to slow it down. [82]

sis. The participant who used contacts also said that they looked out where the costs are and where they will be barred which is in perspective that is important to highlight because the systems that we build end up existing in pre-existing systems.

Q5: When working with collaborators how do you approach discussions around disability/your target audience?

In the conversations three kinds of situations were discussed, 1) work done to guide students (often bachelors and masters project students), 2) work done with in groups of target audience people and 3) work done with others non-disabled people and disabled people in non student teacher relationships.

1 and 3 had the common goal for three of the participants. The goal of framed their work with others (non-disabled people) as humanizing work. One stated that they put emphasised with students on learning about the person, what they like, what they hobbies are and the like, so to build a full vision of the person in the target group. Another noted that most of the people they work with already have some form of personal connection to the work (via family or friends). The third said that they spent a lot of time simply exposing people to the lived experience of disabled people in the form of examples. This is very much inline with a phenomenon we saw in the literature review i.e. that many people need to be exposed to disabled peoples in order to complicate their models and the place society assigns disabled people.

The second situation described was that of work being done in target groups. There the concern was to humanize (and actively de-pathologise) their experiences, via taking a humble naive angle of approach and a full person perspective that looked at not only the medical (or diagnosed) needs but also that of the full experience of the person. Here matching language was important, and the perspective and insights of disabled people are important. One of the participant working with physical AT noted that the concern for social stigma was identified from the participant and not the researcher first and that was an“enlightening” moment.

The last kind of situation identified was that of working with non-disabled stakeholders, this was predominately form a policy perspective but it id tools of small practical handholds of understanding and that often there is a utopic goal but that this often places goals as out of reach which can make it difficult to practical make steps for reaching said goals.

Definitions

The definition activity was conducted with all participants and the outcomes where mixed. Policy and AT development found definitions 1(WHO) and 3 (UN) the best with 2(self-developed) the most confusing, the experts who worked with neurodiversity found 2 to be the best since it embodied a phenomenological approach[6].There was no clear answer so a further analysis was done. There where several remarks that where recurring for each definition (in terms of strengths, weaknesses, likes and dislike.).

Definition 1(WHO) was disliked for its othering language, its use of limits and its pathologising language (limit, impairment). It was also understood to“disconnect the mind and body”. Its efficacy was questioned. It did have the positive identification the it worked on multiply levels (a body and society).

Definition 2 (self-developed) was disliked for its confusing wording, its vagueness (One participant stated that it opens too many questions) and that it links disability to difference. There was also an interpretation that linked this definition to a solvable nature, a curative possibility, this was rejected with the underpinning of“what about disabilities that can’t be solved”, this was a vary important criticism that shaped the approach that will be explored in the next section. The strengths where around the use of“ways of being”, the use of the social model (although unintended in its development) and the angel of tools and process.

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[6] Phenomenology is a philosophy of experience. For phenomenology the ultimate source of all meaning and value is the lived experience of human beings. All philosophical systems, scientific theories, or aesthetic judgments have the status of abstractions from the ebb and flow of the lived world. [83]

Personal reflections:
Since the original developments of this definition, I have developed a deeper understanding of disability. I will now reflect on the original definition, its intentions and why it may have been over-adapted to neurodiversity. When this definition was constructed (in an earlier phase of the research) there was less of an understanding of the richness and diversity of the experiences of disabled people, the way I saw disability, its proximity to cure, adaption and possibility was heavily shaped by my comfort with neurodiversity. It has strengths of pushing back on some of the more paternalistic and ableist views but it still encodes other aspects of ableism (like normative assumptions on what a Disabled person is *supposed* to want). In the process of reading more on how different disciplines define and use disability, it became clear that“disability evades easy definition”. This leads to a possible framing of disability as a phenomena specifically a social, political and economic phenomena and that disabled people enact this phenomena and thus situate disability in the real world, however this also fell short because it Situates disability as existing outside of mind-bodies and thus limits the possibility for disabled people too truly bring their own voice [84]. For this to be true disabled people would not be disabled outside of a given context, but this also pushes back on by a variety of disabled scholars including Alex Haagaard work on their own model of disability [7]. This framing is incredibly valuable because they bring to surface the real experiences of real people and not just how they are thought about. They show us not the models, theories or hypothetical but the real concrete pain points that can be used for design. How do we reconcile these two issues will be explored in the conclusions and implemented in the card set.

The third definition was disliked for the use of othering language and it’s formatting of disability only existing within social contexts it was however a popular first choice with the addition of some modifications since it was the most familiar definition for at least one of the participants and can be used to talk about a lack of fit it identifies that that lack of fit is within interactions. The addition of the sensory disabilities was appreciated as that it expanded past just physical disabilities.

6.2.3 Expert Interview Discussion

In the process of doing these interviews and having a number of discussions about why we use the language we use and the reasoning behind it and how it feels to disabled people, I have made an observation that can connect this research activity to the literature review i.e. one of the potential reasons why person first language is so divisive. **Person first language implies a curative possibility for disabled people** and to many disabled people this is experienced as curative violence.

Personal reflections:
The idea and language of curative violence was later found in the work of Eunjung Kim specifically Curative Violence: Rehabilitating Disability, Gender, and Sexuality in Modern Korea. She describes it as “Curative violence occurs when cure is what actually frames the presence of disability as a problem and ends up destroying the subject in the curative process.” although my contexts and observation space is different than hers as explained in the book, the fundamental idea of curative violence does map over. This insight was obtained before I became aware of the work of Eunjung Kim through her work gives words to things I have seen but not had the language for.

It can be frustrating and harmful when something that cannot be cured or should not even be attempted to be cured is treated as curable. Think of neurodiverse people, people with conditions from birth or people with currently complex medical bodies for whom the cure, or the search for a potentially non-existent cure, has taken up so much time and space in their lives that they have had to devote to it (often with little choice do to age, access to information, possible restrictions on care, normative assumptions and the role in society for disabled people [85][8]). When we use ideas like curative violence, we can see how this language of person first can feel violent and upsetting to disabled people which

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[8] such as people whose bio-specimen expected presentation is out of line with who they are. See for4.5.4 for examples

can have impacts on design activities like co-design and user relations [86].

However, with a different lens and with a different personal history, we can see how some people might feel that person First language better embodies their experience. They no longer or never felt that their difference or condition constituted a disability and its impact is something they can manoeuvre past or around. There is the possibility that there is a logic or equation that can tell you which is more appropriate, person first or identity first, for a situation based on a mix of understanding of an individuals condition, originating time span, level of stigma, level of pain, context of their pain but no definitive answer has been found in the interviews[9].

Personal reflections:
Insights were reached at this stage but not a resolution, simply the knot was loosened and and one can now more clearly see the threads that make up the knot. This is also a point that illustrates the reality that disability is not a monolith and the tendency to portray it as a monolith can be harmful and non-productive.

As a result of the definition exploration activity, it was decided that for the card set it would be more beneficial to frame disability in multi-part lens. This decision was made in part because to define the manifestation of a social phenomena instead of understanding how that phenomena works means that we artificially limit the understanding that it can give. Disability is inherently fluid, it is constructed by circumstance, biology, society, and time frame. Conditions that we consider disabling today may not be disabling in a few years, conditions that we had no understanding of collectively,that did not exist a few years ago may be the disabilities of tomorrow. No matter what disability will continue to exist and be constructed socially. However only constructing disability as a phenomenon limits the realities of existing with disability today, right now, and devalues the impact of a lived experience on how we solve the disparities and harms that come out of the phenomena of disability. As a result of this complicating understanding the card in version one card set “what is disability?” it has

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[9] nor do I think that is that, is an appropriate approach

been split up into three cards “disability as a phenomena”, “What can disability tell us about technology”,“the mind-body in disability” and “what does it mean to be disabled”. These are reiterated in later phases and evolve as understanding is built.

6.3 Discussion

6.3.1 RQ1a:What are the current models and definitions of disability that non-expert designers and technologists hold?

The models that are used by non-expert designers and technologists are related to but not the models found in the Lituiter review. Because of this it may be beneficial to open, and loosen the way we describe the models and frame that knowledge (the fact that we have understandings of how disability work, comes in to being and what it means) in other ways that is more organic and more reflective of the diversity of how disability in contextualised and understood. There is also here evidence that people want to use“handholds” on the design process, they use methods and want approaches to the task not just theoretical approaches.

6.3.2 RQ1b: What are the current models and definitions of disability that disability-expert designers and technologists hold?

The models that are held by experts are less detrimental to designing for disability then in the non-experts, in part since the experts have a more rounded and deeper understanding of disability in part due to more exposure. It is also worth noting that the experts I spoke to for this attribute full person-hood to the disabled disabled people they work with. They do not, as far as I can tell, do their work out of pity, this is not always the case. Since they have give disabled people full person-hood some of the key questions and answers the models present are less important, if a disabled people is a full person capable of self direction it is not up to the expert to determine what disability means and where it belongs as that is left up to the disabled people and their autonomous decisions. //

The methods they use do impact the approach to the toolkit however as the work that they find themselves doing is also work that the toolkit will also need to do.

6.4 Conclusion

As a result of these research activities a few changes in approach have been made to the toolkit, they are impart new cards but they are also edits to the card set, and the additions of some activities. The first addition is to spilt the explanation of what disability is in to three part; the social, the mind-body and the possibility.

The social is framed by the experiences of disabled people and how it is performed in the world. It is understood by stigma, social expectation, performance/visibility and ableism. This may help people to understand the perspective of the social model without limiting their understanding to the social model.

The mind body is the site where the social in enacted. It is marked and derived by the different ways the mindbody can be different or maladapted. It is the site of the logistically considerations and the site of the insights for the needs of disabled people and access needs. Access Needs are human needs on a granular and explicit level. This is an messy space for understanding since there are many spectra that people exist on, and all are perceived first within a person and then translated to the outside world.

Disability possibility is the space in which we can recognise that disabled people see problems from a different angle. It can serve as a catalyst for design and technology. It takes the knowledge produced in the mind-bodies of disabled people and shapes the world with it. It is held back by disability as a social phenomenal and the limits society places on disabled people. This is the angle that offers insight for design and technology.

This chapter also leads to the decision to move the models to the background and instead forces on the outcomes of the models i.e. the bias. In the next chapter my observations of how people approach (in a variety of contexts) describing and developing for disability will be described.

Chapter 7

Contextual reflections

> Many societies think about disability as a life-altering, world changing thing- something that lasts forever and nothing will ever be the same for you - but the fact of the matter is that humans are plastic, adaptable and Malleable. we Learn how to live around what we are, and we learn it vary quickly
>
> *Damien Patrick Williams in"Heavenly Bodies: Why It Matters That Cyborgs Have Always Been About Disability, Mental Health and Marginalization*

In the spirit of CripHCI I will lean into the friction that happens in conversations around disability, using my lived experience as a tool. This chapter describes a methodology of auto ethnography which has been used in works like [87] to identify a lived bottom up angle on how the technology is experienced. However, in this case the technology is not a built or coded object/system, it is instead a conversation about technology's role in disability. In the following chapter I will describe the costs and deficits of conversations. That is not to say that conversations about disability are unproductive, simply that I identified a need to intervene in a space where they fail. The goal is to find the points of friction and use those to steer the conversation towards productive outcomes.

Because ableism has decentred and isolated disability as a topic of discussion, the only individuals who are practised in conversations about disability are disabled people themselves, their advocates, and diagnosticians[1]. Especially disabled people have valuable perspectives, however I found that in these conversations predominately the advocates and diagnosticians are consulted. This has both benefits and detriments. The latter is why I choose explicitly to look at my bottom up lived experience with conversations about disability from the perspective of disability that has been cultivated over a number of years and various contexts.

This chapter serves as a way of making my observations and the outcomes of my positionality explicit. I have been observing this space of work since before the start of thesis, they are in part the experiences that lead me to this topic. I have chosen to be explicit about my observation since it will effect what gets built whether or not I articulate it.

The experiences I have, the conversations I have been part of and witnessed shapes not only my values in this work but also gives me the opportunity to see what has occurred and failed in the real world. A reoccurring theme in designing for disability is the involvement of disabled people in the process and having conversations about disability and how it works in the environments we live and work in. There are ways this often happens in the real world that if referenced sometimes in disability studies work but is not often formalized. I have had the opportunity to have participated in this work and now will discuss some reoccurring themes, methods and pitfalls that present in this kind of conversations. Each section presents a context and then the useful themes that come from them.

7.1 Methodology

The contextual observations come from a number of situations including previous education, projects, a council position and disability focused events and

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[1] There is a general believe that diagnosticians are not underrepresented in these conversations as interacting with experts on a given disability is a common methodology to ask doctors and medical experts so that is not a perspective that I will explore here. I will instead hold “disabled people as knowers and makers” [40]

spaces. Some recent events include DE&I week here at the UT and an online event called Temporaries of Access by Wysing Arts Centre.

Each context comes from a refection on a situation that reflects the context, if a data point (observation) was presented more then once it was recorded, then the points where sorted and reworded for clarity. If there is a instance of this observation in the literature is also noted as the“things” I see doing this work are also often observed by others, most often in disability studies. The conversation take place within a western context and the educational context is technically oriented universities in Canada, the Netherlands and Australia. My being marked with disability ranged from assumed non-disability (i.e. being perceived as “able-bodied”) to more explicit self disclosure/non-self disclosure of disability (and neurodiversity) and an advocate role [2].

7.2 Results

Context 1: Dialogues between disabled people and non-disabled people in built environment settings[3]

1. Using disabled people opinions too late makes it hard to shape the final product. This happens more often than not.
2. Often there is more emotional labour from the disabled people then what is compensated. And little recognition or reward. This is also seen in Amy Gaetas “Cripping Emotional Labor” [89]
3. Angle of approach matters, shapes what solutions looks like, shapes the value of perspectives. If the models (underling understanding of the what,

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[2] This variation in level of visibility is in of its self a way I understand disability and its cyclical and in sometimes invisibleised nature and the role of how perceptions of disability changes how we develop for disability and how we treat disabled people. The role and place of my perception of“advocate” or“activist” is also changes what I am able to observe but that activism is not always completely voluntary and the question and role of advocate is shaped by the fact that disability is preserved as a defect and a burden, when other groups are advocating for people like them it is seen and contextualise differently. Katta Spiel work helps me bring language to this experience when they describe their own perspectives like in [88]

[3] buildings, in particular universities and physical access to those spaces

how and why of disability) are not the same or matching, then this will be a point of unspoken conflict that can affect collaboration.

4. Narrow definition of “valid” disability shapes what options are valued. Disability “experts” are often valued over the disabled people in the room. Visible disabilities are valued over invisible disabilities.
5. Assumptions of what work is to be done differs. Quick fixes versus systematic issues.

Context 2: Explanations of disability in various contexts

1. People’s understanding of how a disability is diagnosed is not always inline with reality especially in in terms of scope and complexity.
2. Even in countries with clear laws there is often a misunderstanding of what disability means and its legal framework.
3. The idea of “reasonable accommodation” is loose and has little practical context.
4. There is an instinct that others think/see/act/feel like you, this is only more unquestioned with neurology/neurotype.
5. There are assumptions that capacities and difficulties are linked to each other or clumped in a way that is not always true or helpful. This is frustrating for both disabled people and non-disabled people.
6. When we privilege the medical, we bend people and our expectations of them to fit that diagnose instead of bending the diagnoses and our understanding of the diagnoses to them. This is often shape with the language of “but do not look like ’disability A’ ” instead of taking the opportunity to learn about another person and another presentation of that disability.

Context 3: Education on disability from a non-disability first perspective

1. People often have limited sensory imagination and are often asked to imagine something out of reach instead of asking to reflect on what they have seen or experienced.

2. Paternalistic conversation come up easily and often there is no understanding of how to depart from this dialog.

3. The distinction between disabilities from birth and later in life is not really referenced or understood.

4. Understanding is often limited to 1 disability and not an intersection of multiple disabilities.

5. There is often a lack of comfort around the intimacy and vulnerability that comes up in many authentic discussions of disability.

Context 4: Discussions in disability first spaces

1. There is a wide spread of language and understanding among disabled people.

2. Nero-supremacy[4] is a real-world phenomena that may limit cooperation and collaboration between people of different disabilities and limits the potential of disability solidarity. it can also fundamentally change the dynamics of co-design in a way that makes space difficult for everybody to be honest clear and themselves.

3. There is an unspoken presumption hierarchy of disabilities. This can look a bit like the Rosser's Classification of Illness States an as it privileges preserved intelligence with connotations of"normal" visual presentation [5] and visually perceived characteristics (like gender and race) creating a damaging hierarchy with negative impacts on learning form a variety of perspectives. This is not to say that people are explicitly using hierarchical models of disability in an academic or dialectical sense it is more often in their actions, tone, and interactions.

4. Accommodations and access have interactions but seldom irreconcilable differences.

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[4] The myth that some forms of neurodivergent are "better" then others, it aims to create a hierarchy can classes some forms of neurodivergent as "smart" and others as intellectually inferior

[5] markers of visual disability

5. Disabilities interact with other disabilities to make each persons experience unique.
6. Access needs are the handhold on public space. To exist in public space you need your access needs to be met to safely exist.
7. “Access in and of its self is a Creation act” [6]. This is to say that in the process of building and making spaces and processes accessible we create. Access is a generative act that enriches.
8. Vulnerability is often demanded and vary little rewarded, this spans over time and across spaces making bad experiences out-way the good.
9. Insights as to the needs of a Disabled Person need come from that disabled person, not their support people or medical professionals. Information often comes from others but is aggregated and interpreted in that individual.
10. There is an experience of disability that is uncoupled from any one disability that is shared. Two people can have no overlaps in presentation but still share experiences. This is an opportunity for solidarity.

7.3 Conclusion

This chapter has looked at different observational contexts for the work that the toolkit aims to do. This formalises information that is being used in the design of the toolkit. The key points that come out of this that shape the coming work will also be seen and discuss in the framework in the next chapter. The next chapter will discuss the framework which is the requirements of the toolkit and the outcome of the insights from all the research activates.

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[6] online event called Temporaries of Access by Wysing Arts Centre

Chapter 8

Requirements Analysis

> What we practice at the small scale sets the patterns for the whole system
>
> *Adrienne Maree Brown in Emergent Strategy Shaping Change, Changing Worlds*

This chapter will describe the work of refine the insights of the prior chapters in to a framework that can serve as a requirements for this and other projects like it. The research question that will be answered is

RQ2: What are key features of a disability toolkit? What are possible formats for a disability toolkit?

This Framework can serve as a list of requirements for a tool that aims to help create a more nuanced understanding of disability with in a group of people. This framework has shaped the toolkit that I have made but can also in theory be applied to other activities or products like educational materials or other card-sets with in the toolkit.

8.0.1 Method

Insights and outcomes of the prior research was noted on digital sticky notes, common reoccurring pitfalls in conversations where translated to their possible solutions and noted as well. Thematic analysis then was done. From there like and over lapping groups where created based on task and colour-coded, the group was then given a task name (the headings below). The sticky notes where then resorted in to other groups, the second sorting and goals.

8.1 Framework- What are key features of a disability toolkit?

The framework below distils how disability is discussed and understood (and more specifically the pitfalls their in) in the literature and in the target group. It identifies common shortcoming and presents guidelines as to how they may be addressed. Each guideline is supported by sources in square brackets. This then serves as a list of requirements for the toolkit. The insights from each research activity were collected and sorted twice, as presented in figure 8.2 and 8.1. The sorting for the framework as seen below is the task-based sorting, the one listed at the end is the goal-based sorting.

1. **Highlight bias and ableism**
    - (a) Highlight how current methods fall short of goal of humane technologies. Sources[4.44.6.1 7.2]
    - (b) Highlight the ubiquity of disability and why that ubiquity may be hidden. Source[4.7]
    - (c) Make bias apparent. Source[4.6].
    - (d) Identify how Disability is siloed, limited, and minimised. Sources[4.6.7, 4.2, 6.1.2]
    - (e) Describe how there are widespread bias and assumptions that lead to lacking solutions. Source[7.2]
    - (f) Use the word disability, avoid euphemisms. Source[4.7]
    - (g) The outcomes of biases shape what is built. Sources[4.4,6.1.2]
    - (h) Identify how the monolith understand of disability may hamper design goals. Source[6.1.2]
    - (i) Fracture the monolith understanding of disability. Sources[6.1.2,7.2]

2. **Value the perspectives that disability gives**
    (a) Refection on what is “known” and how, ask people to reflect on what they know about disability and how they know it. Source[4.6]
    (b) Highlights the perspectives and insights of disabled people. Source[7.2]
    (c) Highlight the role and prevalence of disability especially in design and technology. Source[4.2]
    (d) Explore and privilege disabled ways of knowing. Sources[4.6, 4.4,4.9]
    (e) Highlight that disabled people are able to speak for themselves (even without spoken language), allow that. Sources[4.4,6.1.2]
    (f) Describe Stigma around disability limits the effectiveness of existing methods and the conversations that are had. Source[4.6]
3. **Ground disability in the real world**
    (a) Disability is often understood in narrow one dimension lens, split this view. Source[7.2]
    (b) Build understanding of functional problem not just the cultural understanding. Source[7.2]
    (c) Overlaps between disabilities should be a explored. Source[7.2]
    (d) Builds more understanding than requirements. Source[7.2]
    (e) Give practical examples both tied to existing technology and separation of existing technology. Source[4.2]
    (f) Identify handholds for design. Sources[6.1.3,6.1.2]
    (g) Explore technical vs social/cultural accommodations. Sources[6.1.3,6.1.2]
    (h) Access needs are universal, but particularly strong among disabled people. Source[7.2]
    (i) Use small practical examples. Source[6.2.2]
    (j) Understanding of functional problem not just the cultural understanding. Sources[6.2.2,6.1.2].
4. **De-medicalise and build practical understanding**

   (a) Use the word disability, avoid euphemisms. Sources[4.7, 6.2.2]
   (b) Clear simple language. Sources[4.7, 6.2.2]
   (c) Use of humanising non-medical language and tone. Source[6.2.2]
   (d) Recognise discomfort. Sources[7.2,7.2,6.2.2]
   (e) Complicate,and enrich the methods and approach to disability, prime for co-design. Source[6.1.2]
   (f) Agnostic of any one domain, applicable to different technologies. Source[7.2]
   (g) Humanize disabled people.Source[6.2.2]
   (h) Non-clinical frame. Sources[6.2.2, 6.2.2]

5. **Prime makers for learning from disability**
   (a) Complicate the methods and approach to disability, prime for co-design. Source[6.1.2]
   (b) Be agnostic of any one domain, applicable to different technologies. Source[6.1.2]
   (c) Make it easier for disabled people to interact with designers by making the work on the designers' end. Source[6.1.2]
   (d) Identify how our normative expectations may lead us to develop solutions to problems that are the not problems that need to be addressed. Sources[4.4]
   (e) Identify adaptation vs cure as goal of technology and intervention. Sources [6.2.3]
   (f) Explore access statements as a tool and why. Sources [3.3.1]
   (g) Name different ways to break-down and understand the diversity of disability. Sources [7.2]
   (h) Identify emotional labour usually done by disabled people. Sources [7.2]

6. **Explore Language**
   (a) 'Disabilities' over 'disability' to highlight width and depth. Source [6.2.2]

  (b) Explain language, its impact and reasoning. Source [6.2.2]

  (c) Explore the idea of curative bias in language. Source [6.2.2, 6.2.3]

The framework roughly falls in to 3 goal categories. 1) to convey that ableism is real, and leads to problematic outcomes. 2) to show how Disability is grounded. 3) to convey that this work is work, it can not be done without disabled people, so the question becomes how you do it then. Those are the three overarching goals, but they are split into the different tasks in order to get granular on what needs to be done. The tasks can be seen in figure 8.1 with the overarching view in figure 8.2. The three goals will serve as the principles for the next iteration.

Figure 8.1: framework understood in categories

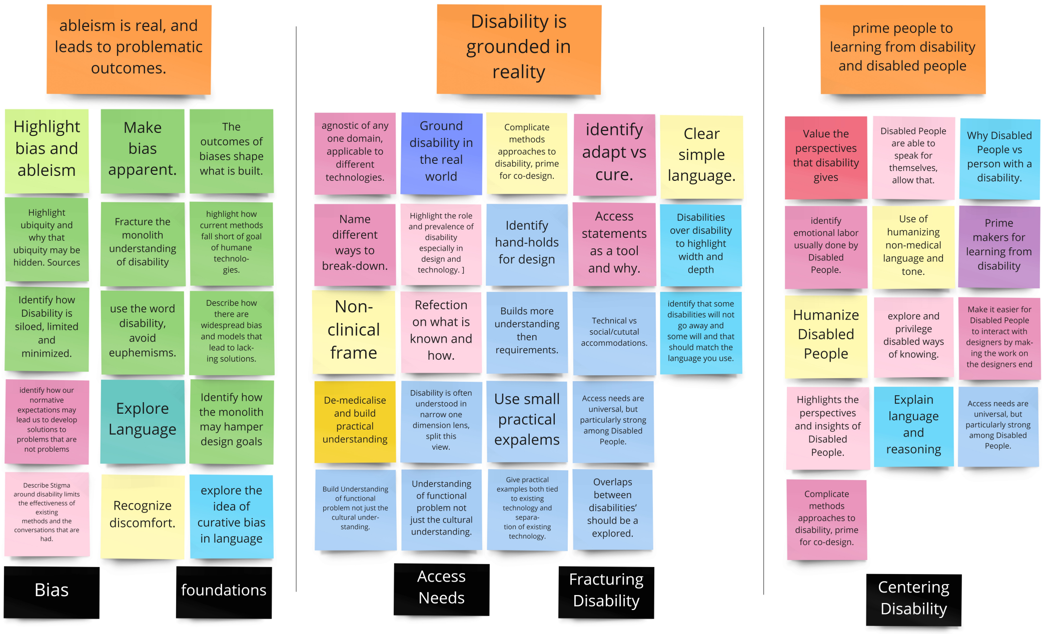


Figure 8.2: framework guidelines in 3 overarching goal categories

8.2 Discussion

8.2.1 RQ2a: What are key features of a disability toolkit?

The key features are the identification of issues in current approaches and then the alternatives to thous approaches. The issues are bias, assumptions and broadly the effects of ableism. The alternatives to approaches are practical tools and identification of what needs to learned and how to learn it.

8.3 Conclusions on framework

The framework has been constructed out of the insights research activities. This framework serves as a refinement tool for the toolkit and design process. The design process and 2 iterations will be discussing in the following chapter.

Chapter 9

Toolkit design

> I want readers to understand that when I critique the direction of research inquiry in our field, I am attempting to hold us accountable to our participants, their communities, and their future. The assumptions and frameworks we use to ground our inquiry has consequences. These consequences ripple outward, from individual interactions in the lab, to the research community, to public discourses, to individual interactions in the world. When I demand this accountability from you, it is because I hold you in the highest regard. I believe in you, in us. I believe we can do better.
>
> *Anomous, Katta Spiel, Os Keyes, Rua M.Williams, Judith Good, Eve Hornecker and Cynthia L.Bennett in "I am just terrified of my future" – Epistemic Violence in Disability Related Technology Research*

This chapter describes the process of the refining the toolkit and outcomes of a round of peer editing. I will describe two sets of iterations. The first my own iteration by applying the requirements framework to the previous version of the toolkit and the second the outcomes of outside feedback and input on the toolkit, the feedback was mixed with several several iterations and the section 9.2 describes reoccurring feedback points and how I implemented them, for the feedback points I did not make changes based on I have included justification and reasoning on why.

9.1 Prototype check-in two

This section will discuss the second iteration of the toolkit following insights gained from expert interviews, surveys, contextual reflections and its resulting framework.

9.1.1 Objectives

The second framing has refined the role and importance of how we understand ableism and disability. Check-in one served to create practical tools and techniques that offer more nuance in disability. In the first check-in the objective was to*shift disability from an "edge case" to a central conversation piece and work against stigma by having repeated exposures to it in multiple formats*. Through the expert interviews, surveys and contextual reflections I realised that it was not enough to centre disability in the abstract, but that we need to centre disabled people and make it easier for them to exist and actively participate in the work. Therefore, The objective has now evolved to *recognising the role and importance of disabled people being involved in the work in such a way that their autonomy is respected and their well-being guaranteed*. If a project is to enact the motto "Nothing about us without us" then it must make it easier for disabled people to do the work. In line with the first iteration, this is done by externalising the information, giving practical tools to talk about disability and, newly, to shift the knowledge responsibility to the toolkit and the designer.

9.1.2 Ideation

Each card was evaluated with the framework in mind, the inverse was also done, so each category needed to have a card addressing it. Other ways of taking about the subject of each card was also sought for in order to find the best way of describing the concept.

9.1.3 Prototype 2

The second prototype is seen in A.10. The sections are foundations (7 cards), Access needs (14 cards), biases (9 cards), Fracturing disability (10 cards), Centring disability (11 cards) and four tools. The v1 foundations section has been split in to foundations and Centring disability. The section foundations works to establish a baseline understanding and shared language, Access needs to give practical understanding, the fracturing disability to deepen the knowledge and centring disability to present insights from a disability first angle.

	Foundations	Biases	Access needs	Centering Disability	Fracturing Disability
Highlight bias and ableism	x	x		x	x
Value the perspectives that disability gives	x		x	x	x
Ground disability in the real world	x	x	x	x	x
De-medicalise and build practical understanding	x	x	x	x	x
Prime makers for learning from disability	x		x	x	x
Explore Language	x	x	x	x	x

Revisiting the existing sections

The cards set was first divided into the topics to make manageable chunks for editing. Each section was split up for a total of six sections with 60 cards in total. After that, each section was expanded to include any missing components that where missing from the requirements. The tools section came out of this phase with the goal of exposing the Target group to concepts in separate ways. The cards were iterated over several times each time with a different editing goal in mind, the goals include tone, adding practical examples, clarity, consist language. The 6 sections are foundations (25), models (11), bias (9), access needs (13), principles (7), and tools (4). Each section includes a first explanation card.

The foundations were revised primarily with clarity regarding language in mind and to link cards that contained connected ideas. What was "what is disability" in v1 is now three cards expanding three ways disability is constructed. The reliance of a definition of disability was removes in favour of the disability lens. An identification of disability as a stigmatized issue was also added to address issues identified in the understanding phases. This section at this phase is disjointed and will benefit from outside perspective.

As a result of the surveys and expert interviews, the models section is a candidate for removal as the models in practice are not often clear in the real world application however there outcomes are. They are not an efficient way of meeting the goals. The outcomes of bias are often a result of models but have overlapping origins, therefor the bias where expanded to include visibility bias (social, medical, moral), diagnostic bias (medical) and siloed bias (social, medical, charity and moral). This choice was also made to make the toolkit smaller.

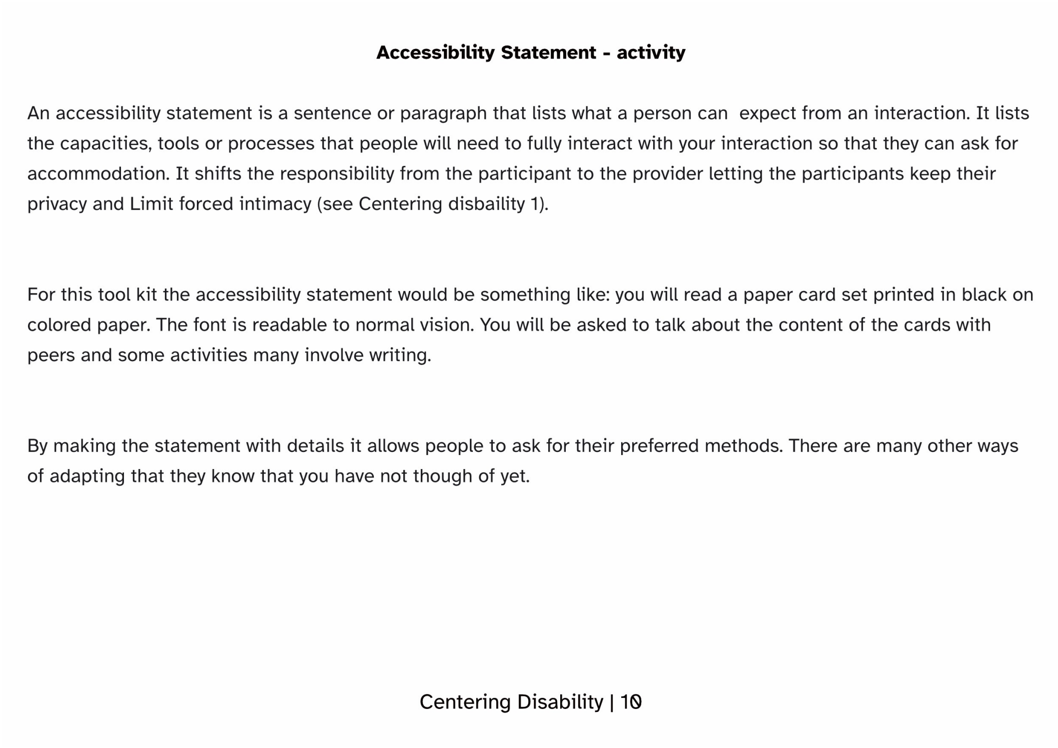
The access needs were revisited with real-world observations (being cognisant of disabled people in public space and the access needs of myself and others) being used to expand them. This was done over time and when occupying different spaces and contexts for full richness and granularity.

The principles are another candidate for removal as the have only come up in the state of the art and are the least in depth contribute, there have been no reference to the concept of principle in any of the conversation that are connected to this research. This may be do to the academic nature of the conversations (principles are more often used in industry) or principle may have fallen out of design fashion, no matter the reason the principles are a candidate for removal and are removes since there is no ask for them in. This was also a decision made to make the toolkit smaller in size.

New additions

Iteration v2 of the toolkit contains three new tools. They solidify and bring in to practice ideas from the rest of the card set.

The first tool (see fig:9.1 is that of an accessibility statements, although access statements are a know part of inclusion work they often fall short of their goal and may exacerbate issues of Forced intimacy [1] and are a possible first step in co-design.



Accessibility Statement - activity

An accessibility statement is a sentence or paragraph that lists what a person can expect from an interaction. It lists the capacities, tools or processes that people will need to fully interact with your interaction so that they can ask for accommodation. It shifts the responsibility from the participant to the provider letting the participants keep their privacy and Limit forced intimacy (see Centering disbaility 1).

For this tool kit the accessibility statement would be something like: you will read a paper card set printed in black on colored paper. The font is readable to normal vision. You will be asked to talk about the content of the cards with peers and some activities many involve writing.

By making the statement with details it allows people to ask for their preferred methods. There are many other ways of adapting that they know that you have not though of yet.

Centering Disability | 10

Figure 9.1: accessibility statements card

The second tool is also developed to be used in or before co-design, the tool is titled “fracturing disability”. It is in part to address the siloing bias and the ten-

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[1] as described in [36] and in 3.3.1

dency to view disability as a monolith see fig:9.2 for version 1. It also addresses an original goal of this theses i.e. to not design for a single disability but to understand the interaction between disabilities and intersecting needs. The tool can be used in a co-design setting to plot people on the different spectrum's described in the image on the card. Several different ways of conveying this work were are so explored but discarded for a number of different reasons.(over simplification, infinite number of combinations in flow chart lead to an unmanageable number of combinations as seen in fig:9.3.)

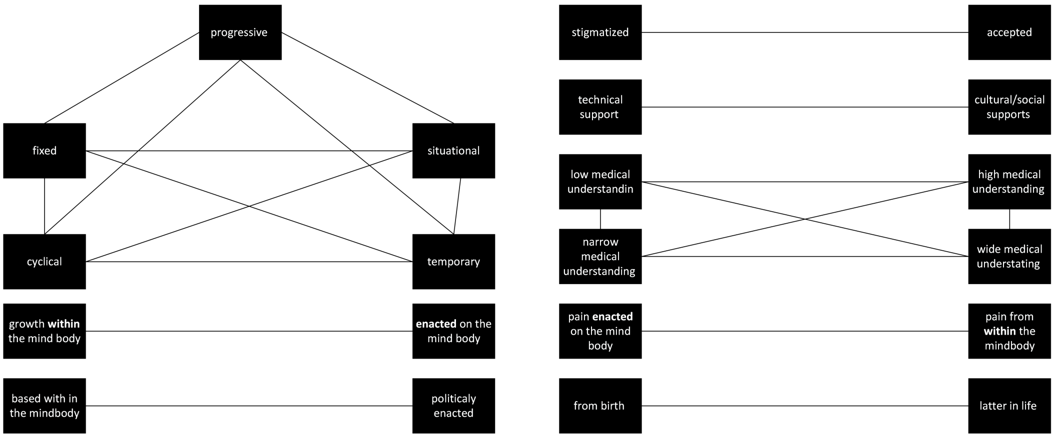


Figure 9.2: disability spectrum v1

The last tool is that of "find your access advantage" (see fig:9.4). This aims to bring the access needs to life and help bring the access needs from a place of"burden" to the possibilities that they actually are. Technology has always relayed on using capability to use tools to meet goals and this activity asks people to see the handholds for new ways of doing and to develop a more realistic understand of how people can use the projects they are developing.

With the addition of tools and the activities the card set was resorted into some new sections. Biases and access needs remained the same whereas foundations was re mapped into foundations, centring disability and fracturing disability to allow for elaboration. A navigation section to outline how to use the

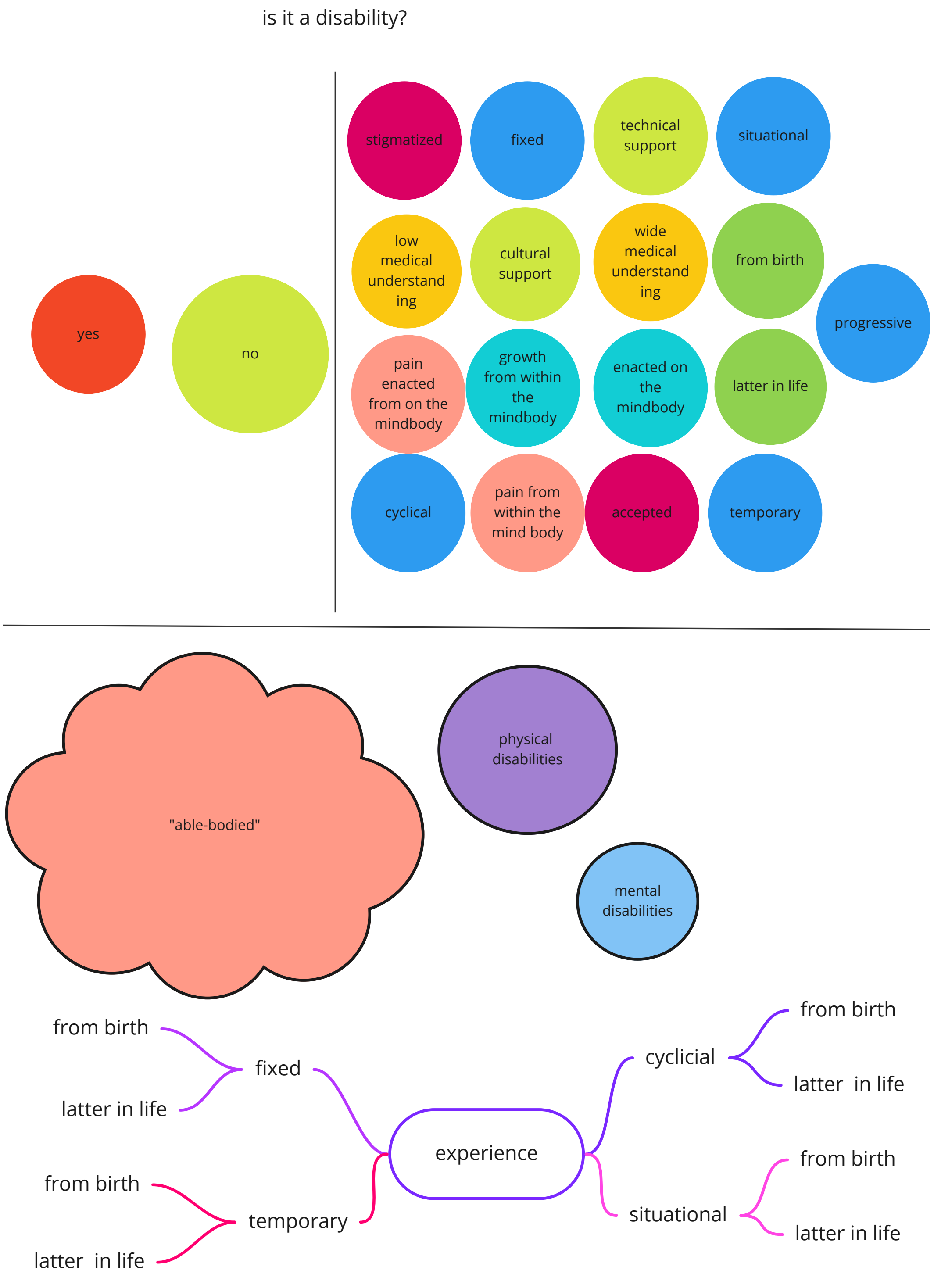
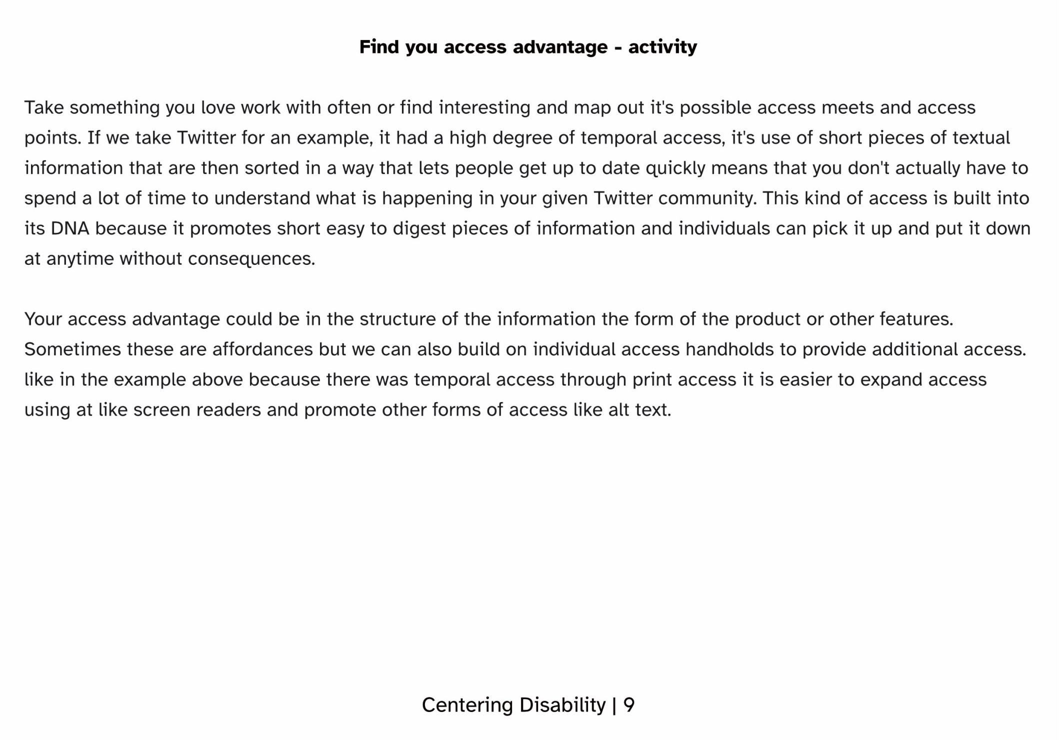


Figure 9.3: 3 attempts at exploring the diversity of experiences within disability



Find you access advantage - activity

Take something you love work with often or find interesting and map out it's possible access meets and access points. If we take Twitter for an example, it had a high degree of temporal access, it's use of short pieces of textual information that are then sorted in a way that lets people get up to date quickly means that you don't actually have to spend a lot of time to understand what is happening in your given Twitter community. This kind of access is built into its DNA because it promotes short easy to digest pieces of information and individuals can pick it up and put it down at anytime without consequences.

Your access advantage could be in the structure of the information the form of the product or other features. Sometimes these are affordances but we can also build on individual access handholds to provide additional access. like in the example above because there was temporal access through print access it is easier to expand access using at like screen readers and promote other forms of access like alt text.

Figure 9.4: Find your access advantage card v3

toolkit in the design process was added at the beginning of the toolkit and the first card/explanation,and additional important cards (like the map for fraction disability) was then made twice as large to allow people to more easily find it. This can be seen in appendix A.10.

9.2 External feedback and critiques

To gain a deeper understanding of what works in the card set a number of discussions were had to evaluate the card set and identify space for improvement. The toolkit was presented to peers and supervisors, where the points of feedback collected and then mapped across parties to find the reoccurring feedback points and critiques. Below are the reoccurring themes and how they where addresses, if they were addresses for the next version of the toolkit.

9.2.1 Increase Navigability of Content

The comment was made to increase the navigability of the card set to make use more manageable. This was iterated upon, and colour, numbering and mapping were introduced to make clear each cards place in the toolkit. Plotting the different uses of the toolkit at different stages of the design process was also developed out of this feedback.

9.2.2 Simplify

The comment of simplifying the language and content used on the cards came up in several iterations. This may refer to the overall presentation of the toolkit and its contents, or on the complexity of the subject itself. The former may be in line with and is reflected upon in the previous section. The latter refers to the way the toolkit explores the depth and breadth of disability and how this is different than the way we normally talk about and understand disability. Simplifying this was not fully implemented due to the observation that other toolkits and communication tools around disability often oversimplify disability. To retain the integrity of the information being conveyed it needed to be somewhat more complicated then what we see in many other toolkits. Issues of disability are so often simplified and oversimplified in a way that removes the possibility for insight and nuance in our discussions about disability. It becomes an endeavour in removing human difference and then often results in monolithing the identity of disability which is precisely something this card set aims to address.

The goal of a plain language version of the toolkit is recognised, however structurally and societally that language does not exist right now. The work of constructing that language is well beyond the scope of this thesis.

9.2.3 Prime and Justify the toolkit and it's use case

In the use of the toolkit, it was often recommended to justify its use i.e. explain why the work is important. This line of inquiry is understandable because it comes from an understanding of design as business tools and creators are always asked to justify why their design is important. In this context that comes down to"why is ableism bad?" and "why is it difficult to design for disability?". To justify the context of the toolkit would be opening up the discussion for whether the effort of designing access is worth it. This discussion happens all the time, it has happened regularly in the environments I have observed as well as in the state-of-the-art and the literature. However it almost always pulls the attention away from the implementation of access and learning from disability to a question of the worth of that effort. This ultimately always ends up being a conversation about whether or not disabled people are worthy of the additional effort which is a tool that, whether or not the conversationalists having the discussions know it, is a tactic preferred by eugenicists (to frame care as cost and to demand its efficiency above all). A conversation that, when it takes place in the real world, devalues the lives of disabled people even when they are in the room where the conversation is happening. This conversation frequently boils down to economics, the worth of a human life and what cost we collectively are willing to bear.

The act of debating the worth of disabled people is potentially deeply painful for the disabled people present. In a paper on Epistemic Violence in Disability

Related Technology Research, the authors word it as;

> "As disabled scholars researching our own conditions, we are deeply hurt. We read about ourselves as disordered, as an emotional, financial and overall burden to the people around us, as incapable of forming social relationships, undesirable, less than, limited, incapable, as fundamentally lacking—echoing the worst nightmares of our internalized ableism." [14]

I think this extends to anyone whose activism leads them to a space of debate. To be informed on the state of the discussion is to open up oneself to hurt.

With the toolkit I aim to shift the conversation from why to how, and disabled people from objects to participants. Conversations centred on the why instead of the how are dehumanising, which is why it was purposefully left out of the toolkit. Not only is the amount of data in this conversation well beyond the scope of a card or set of cards, it is also one that is being actively interpreted on a political, economic and moral stage every day.

The how has been attempted many times as shown in the state-of-the-art and literature review, but the execution often lacks nuance around disability. This brings us to the second question: why is designing for disability difficult? The toolkit in a way answers this question by showing and giving tools to address the stigmas, models and biases around disability and by facilitating a better understanding of what is means to practically experience disability and of the overlapping and intersecting nature of disabilities. Its practical and expansive nature that centres disability and disabled people's perspectives of disability is what sets this toolkit apart from existing tools and methods that take non-disabled perspectives on disability where the ultimate goal is often the minimisation of disability.

So focusing on the how instead of the why, and providing practical tools with which to do it, makes it easier to design for disability and for disabled designers and disabled people to interact with designers and participate in these conversations.

9.2.4 Tone and Neutrality

A number of discussions involved a concern about the tone and neutrality of the language of the card set. The point of feedback was around not wanting to potentially alienate users of the card set by taking a strong tone or increasing its acceptability by remaining neutral. This is understandable given that people do not want to feel attacked by the tools they use. The language of the card set was then adapted to be more approachable but not to fundamentally changed the perspective of the card set. Given where designing for disability currently sits (politically and in terms of adoption) neutrality may allow some of the more pitying and paternalistic camps in this field to unquestioningly adopt the tool.

The work of designing for disability has diverse range of perspectives, approaches and individuals who do disability related work. Not all of it centres and amplifies the voices of disabled people. Some of the voices that potentially can cause damage to real disabled people do so with very pleasant tones. The work of designing for disability especially in the current political social and philosophical landscape is messy. It is messy and impassioned because it is real people fighting to address real harms and other work in this space often takes a very passive and positive perspective when that passiveness and positively often works to operate within the status quo where this toolkit would promote users to question the status quo as it does not serve all people.

9.3 Conclusion

This chapter has described the construction of the final toolkit, the toolkit has gone through iterations, its content validated through different lenses and methods and explains the decisions that were made and why. This toolkit version can be seen in A.15. The next chapter will validate and evaluate the toolkit.

Chapter 10

Evaluation

The evaluations is focused on identifying to what extent the card set can change the understanding of disability that people have. This is done to answer the research questions:

RQ3a: How to evaluate a disability toolkit?

RQ3b: How critical are people about existing technologies when asked to analyze from the perspective of disability before exposure to the toolkit vs afterward?

To assess the toolkit and its effectiveness a focus group where held. A focus group is when a group of people are brought together to discuss their experience with a topic, in this case it is disability and then the toolkit. A focus group will allow for the participants to explore the card set and to see how the card set interacts in conversations.

Since I have chosen to intervene on conversations the focus group has been chosen for evaluation. The goal is to see if the dialogues improve. Improvement is defined as an increase in in the depth of discussion, more nuance in questions and the possibility to make connections between past experiences, the card set and the product to be evaluated (as part of the game). The role of the deeper discussion as a primary goal is to reflect that the issues facing adoption and understanding of disability as a critical lens on technology is that of out personal and interpersonal dialogues about disability.

10.1 Methodology

Ethics permission was obtained under number 220070. Extra concern and care was taken around the privacy and comfort of the participants because disability is a stigmatized issue.

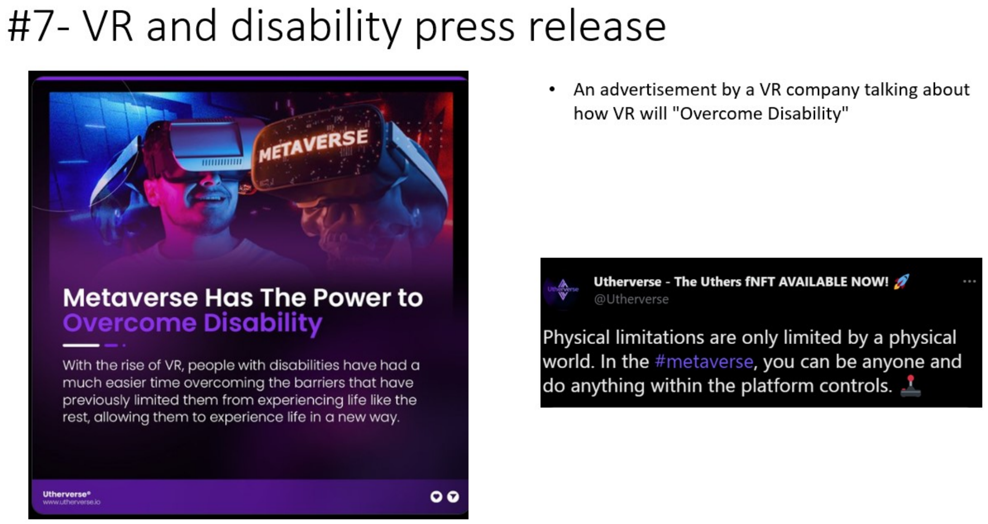
10.1.1 Materials

The materials used are:

- markers and pens
- card set copies with 5 foundations sections and 5 welcome sections, and one each of the testing sections (see A.15)
- laptop with slides (see A.14)
- TV screen to show laptop screen
- a 12 sided die
- game answers sheet

The“game” used in the focus groups was developed to facilitate a conversation about disability and technologies that explicitly interface with disability. On a slide was presented 1 of 12 different products that intersect with disability explicitly, ranging from assistive technologies to built environment accommodations for disability to ways of adapting technologies to accommodate disability. There are many products that aim to help disabled people but do not identify that in their communications. Participants where asked to identify positive points, negative points and things they had questions about. They where asked to write the answers down before talking about them. Image 10.1 is an example of the slide shown: the slide number, a title, an image or video, and a short description.

Some of the slides shows disability dongles (see 4.4) as they exhibit a number of problematic instincts around designing for disability that have been documented and that they are inherently messy and require a nuanced understanding of disability to identify their flaws. Other slides contain examples that at first



#7- VR and disability press release

- An advertisement by a VR company talking about how VR will "Overcome Disability"

Metaverse Has The Power to Overcome Disability

With the rise of VR, people with disabilities have had a much easier time overcoming the barriers that have previously limited them from experiencing life like the rest, allowing them to experience life in a new way.

Utherverse®
www.utherverse.io

Utherverse - The Uthers fNFT AVAILABLE NOW! 🚀
@Utherverse

Physical limitations are only limited by a physical world. In the #metaverse, you can be anyone and do anything within the platform controls. 🕹️

Figure 10.1: Product 7

glance can look like disability dongles but actually do not have the detrimental characteristics of disability dongles. Identifying these, the errors in logic they present and the logistical interactions with disability requires a nuanced understanding of disability. The focus groups are conducted with 4 groups of a 2-3 group members. The script can be found in the appendix A.13.

10.1.2 Measurements and Data processing

The measurements that are collected are the demographic forms which are tabulated and described in the Participants section. The notes recorded are notes taken by me during the actual focus groups with additional clarifying questions asked where possible and a recap recorded directly after the participants left. The notes then are analysed and described in on a section by section bases in Feedback by section - Observed (section: 10.2.2). The participants are also given the opportunity to write, draw and otherwise mark up the card set they got. This is looked at and supports the reflections that come up in the section10.2.2 which will be used to answer RQ3b. The last data set that was collected is a survey containing scales and open questions wherein the participants were asked about how they experienced the exercise, the toolkit and the conversations it elicited. This is analysed in two ways: 1) the scales are presented and reflected on in the section Comfort and Confidence 10.3.1 with the debriefing to contextualise it and 2) the open answers are described and a thematic analysis is done in the other subsections of the section “Survey”.

10.1.3 Participants

An open call for participants was placed in my social circles and peer network. In total ten people participated in the focus groups split among four sessions. Six participants identified themselves as women or females, and four participants identified themselves as men or males. Six participants were in the masters phase of their education where three were in industry. All participants stated that they were familiar with disability, nine participants stated that they were familiar with neurodiversity, one stated that they were unfamiliar with neurodiversity. Six stated that they were familiar with medical complexities or chronic illness, the four stated that they were not familiar with these. Four participants stated their background as design only, three participants describe their background as design plus technical or computer science oriented backgrounds, and one participant describes themselves as a design plus technical plus social sciences background. One participant describes their background as only social sciences. All participants fully consented and seven survey responses were collected.

10.1.4 Procedure

The session is split in to two phases, before the toolkit and after exposure to the toolkit. This allows for an assessment of baseline knowledge and approach by the participants. All notes are taken on paper. Everything was fully anonymity at the earliest stage possible. The group are be between 2-5 people and take 2 hours. The focus group follow a safe space methodology to make sure that the group feels comfortable with discussion.

Each focus group started off with a moment to read, ask about and sign the consent form, the voluntary nature of the study was reaffirmed. I then introduced my self and what we will do today, the participants are then given to opportunity to introductions themselves to each other. This moves us to the“game” part. Participants are given the option to pick the color of the section of the card set they are working with (all previous sections are removed as options), and asked to pick a number between 1 and 12 (a dice was also on hand and listed as an option to avoid putting participants on the spot). The number chosen is the slide they work with A.14. Participants where asked identify positive points, negative points and things they had questions about with the description being asked as:“Your task is to note different ways that that object, product or feature interact with disability. This can be issues, things that are done well and other things that stand out, good, bad or don’t know yet.” .The recording sheet is handed out and the slide presented, the participants are then asked to write down the answers before talking about them.

When the group is ready for the toolkit the sections are given in two steps (to avoid overwhelming them) first the “welcome” and “foundations’ and then the section they picked. Here they are given the opportunity to talk about them, if they need prompting they are reminded that we will be looking at the same slide again and redoing the activity. When they are ready to revisit the activity or the time is coming to an end they are asked to once again fill out the sheet and then a debriefing is conducted. The survey is sent to the participants as they leave.

10.1.5 Analysis Method

The method of analysis used for the focus groups was similar to the one used in the expert interviews. The focus groups were externalised by using a digital whiteboard where each new idea got its own sticky note from there the data was sensitised to and the other tools were used to contextualise the comments, this includes the markings on the physical papers and the outcomes of the surveys also provided additional context. The surveys were evaluated using the same method as the surveys above as each open answer was placed on a digital white bored order to sensitise and derive categories and evaluations like in fig:10.4.

This process resulted in themes that were then compared between the different research activities to contextualise what they meant.

10.2 Outcomes

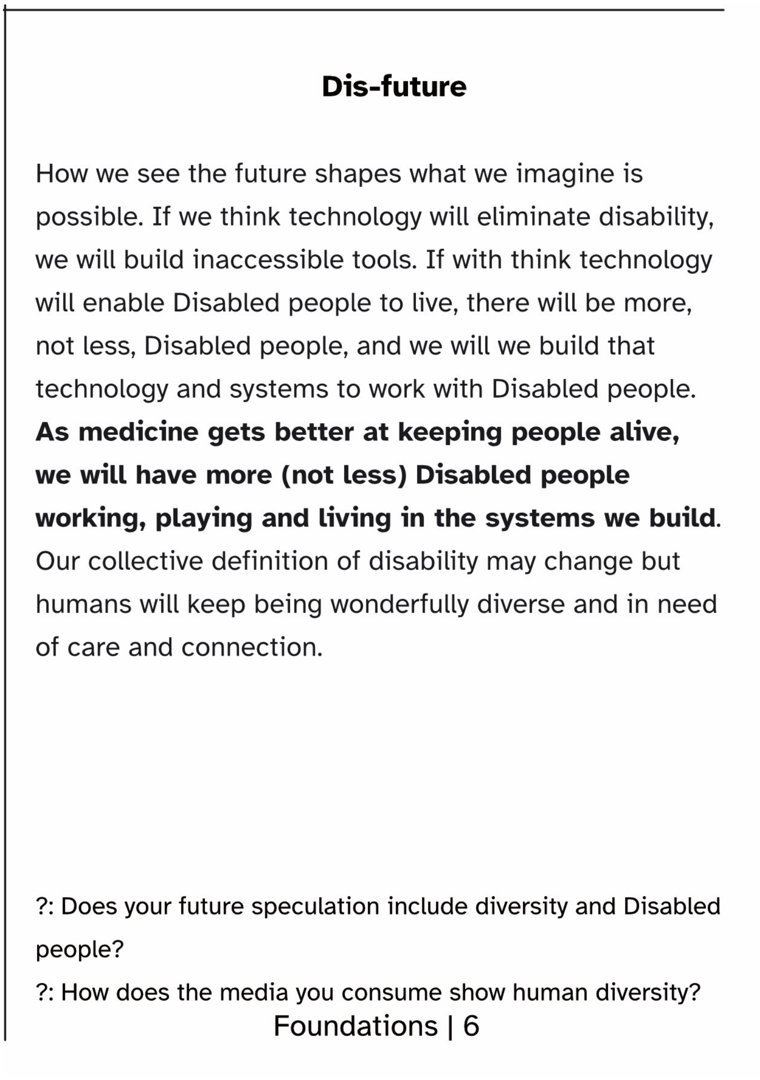
10.2.1 Overarching usage of the cards by focus groups

The focus groups were diverse in how they used the card set. Each group approached the task differently, treated the cards differently, as well as the knowledge of their fellow participant. Some groups went through methodically card by card discussing how the cards connected to their task, other groups individually made assessments and they came together. The groups were drawing on different backgrounds and experiences and the level of comfort was different not only amongst groups but amongst participants in groups. The global impressions of the “welcome” were neutral and more often seen as housekeeping but many said that it was good to start off with an introduction. The tips card was often ignored although an individual who works in industry stated that they would be using one of the tips as a phrase in their work, specifically “that defaults need to be accessible customizations don’t”, This concept of flipping the responsibility, to making it accessible now instead of this philosophy of band aids to solve the problem, was appreciated.

10.2.2 Feedback by section of the card set - Observed

The foundation section was often received differently based on the previous levels of experience with disability that people had. Some groups saw the “welcome” section as very rote fact and not a point of discussion whereas other groups saw it as a jumping off point to ask questions about what they did and did not know.

The “dis-future” card (see fig:10.2) was the most explicitly mentioned card as it is concept and re-framing of the role of disability moving forward was a clarifying aspect that helped people make a connection as to why the issues mattered.



Dis-future

How we see the future shapes what we imagine is possible. If we think technology will eliminate disability, we will build inaccessible tools. If with think technology will enable Disabled people to live, there will be more, not less, Disabled people, and we will we build that technology and systems to work with Disabled people. **As medicine gets better at keeping people alive, we will have more (not less) Disabled people working, playing and living in the systems we build**. Our collective definition of disability may change but humans will keep being wonderfully diverse and in need of care and connection.

?: Does your future speculation include diversity and Disabled people?

?: How does the media you consume show human diversity?

Foundations | 6

Figure 10.2: Card Dis-future from the final toolkit

The laws section was also discussed explicitly as in it prompted people to reflect on the lack of knowledge they had around the laws.

Access needs

The access needs were primarily logistical, in both discussion and product reflection. This section started off with questions about how the product works and how they would interact with different types of people. They also quickly mapped over to their own personal experiences in both work and life. The cards were seen as more of a technical jumping off point as there were many reflections on the access needs, how they manifest and how they can be addressed but the access needs are experienced in both work and life. There were also discussions about access tools that were not listed on the cards i.e. described video (for visually impaired people was discussed specifically its implementation and how to do so in industry which is an access tool that was left out in the previous writings of the toolkit). After the discussion of the cardset the concerns were again more logistical. There was the identification of safety hazards specifically overheating. In general the response was a gentle positive response as in as it is a ”stepping stone” and is better than exclusion but there were also worries about the cost and the lack of further development.

Fracturing Disabilities

The fracturing disabilities activity/section was described as a possible research asset. This group had industry knowledge but not high confidences in their disability knowledge, duo to in part the product and its corresponding disability specifically in the space of deafness/hard of hearing. The group asked many questions about deafness/HoH mainly logistical concerns. Prior to the toolkit their concerns were primarily logistical and context based whereas after they were more critical and they were confused as to who the product is actually for, which is in line with my personal observations of the product.

Centring Disability

The Centring disability section was used in a more dialect aspect. This group spoke less about what things mechanically do or do not do but more about what society does around them. This could be in part due to the section or in part due to the example that was given. Their responses tended to talk more about the expectations that we have of not only the product but of people who want to use the product. It also prompted more reflection than research as it shifted the conversation away from assuming about disability (curative language limited expectations of disabled people “why would a blind person need something to look good”) to a more humanised centring of disability. In the second refection this group’s primary comment was around but ”why is it not included as a standard, if they make inaccessible products they should have to give the accessible options in the box.”

Biases

The biases section was well utilised in that it changed the answers of the participants two more critical perspectives as well as outlining the different biases that were presented. This group’s product was easier to explicitly identify as in there were not many positive aspects to this particular example, the VR example, the cards built on the existing knowledge about VR and disability and sharpened the answers of the participants. The conversation was nuanced and critical as well as easily prompted by the cards.

10.2.3 Debriefing

In the debriefings some limitations were discussed. How critical are people willing to be about their own designs, the number of questions asked but not business solutions that are presented and that certain sections of the toolkit were seen as obvious by some groups but completely unknown by others. This makes it difficult to give the right amount of information to the right people at the right time. This is a problem not only with the toolkit but with the work of designing for disability in general as the number of backgrounds and perspectives and knowledge is diverse. In the comfort question people's comfort seems to be very much in line with what they experienced beforehand, there were a few participants that said that the shared language made it easier to communicate but not necessarily that the toolkit makes a big dent in people's upbringing around disability and those biases [1]. This discomfort is often around being afraid to say the wrong thing and not wanting to construct disability as"only-suffering" but not knowing how to construct it instead[2]. This issue is seen throughout my interactions with not only this thesis but in general this work, there is a want to do better and an understanding of issues but not often a permission or a comfort to move and speak with confidence. This is a wider issue and may require a deeper understanding of how we facilitate these conversations and may in fact be less about the content of the conversations but instead the perceived safety in those conversations and a structure around mistakes. It is from what, I can obtain from conversations, less about the fear of making a mistake and to more about the fear of hurting an disabled people as individuals and this is something that can be in part addresses with however it is not fully dealt with by the toolkit in this form, on this timescale in these conversations.

It was observed that the discussions had in the focus groups did have a form of evolution, the act of discussing in a group context seemed to complicate and deepen the answers that people gave as in the answers discussed were often more nuanced than the answers written down originally by the participants and this is to be expected. The toolkit seemed to be able to facilitate shared language amongst participants and ground the discussions. It also allowed people to ask without centring themselves if they found that to be uncomfortable. Table10.1 shows the changes in the answers before and after the toolkit however it is notable that whereas the first discussion was often well recorded on paper by the participants the second discussion was more often missing points of dialogue in the written responses. This is potentially due to cognitive load restrictions and that the conversation took precedent over the writing of the answers in terms of the participants mental energy and time. Although the increase in

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[1] more the one participant self identified that their cultural upbringing did not foster a sense of persons-hood or respect for disability

[2] it is worth noting that neither of the participants who self identified this worked with the biases section

depth of the discussion cannot be seen in the written answers, the in-person discussions continued to improve in their depth and nuance after having used the toolkit.

10.2.4 Analysis of the written answers

When looking at the recorded answers of the participants there is an over all a change in answers, between pre and post toolkit, that can be interpreted as a trend to more critical and reflective.

The trend is not the same among among all sections, there are different improvements with the different sections. The group working with the bias had the most improvements in being critical of the product, they also had less questions but a clearer understanding of the refection points they made (the language was more precise and uses words from the toolkit). The Fracturing Disability group had more questions after after the toolkit and did not identify positive points in the second round, this is reflective of the product they evaluated. The centring disability group had a slight reduction of points they identified but the points where now opinions and not just questions. The biases group had less questions but did also identified safety concerns and although they remained positive about the product they identified spaces for improvement and that that problem may be address by a better version of the product or a different product.

Table 10.1 with the coded results of the written answers can be seen below. Each row is a results of a individual participant, only the card section they worked with is listed in order to provide an additional layer of anonymity with still giving an indication to how well the section worked. R1 refers to round 1, the pre-toolkit answers answers and R2 to round 2, the post toolkit answers. The numbers in the table are the result of coding each answer answer sheet, each time a point (critical, positive, question or refection) was stated it was recorded (no distinction was made on the ”correctness” of the point, simply that it was noted) , below are the results of the coding in a pre and post toolkit, participant by participant bases.

Sections	**R1 Critical Points**	**R1 Positive Points**	**R1 Questions**	**R1 Reflections**	**R2 Critical Points**	**R2 Positive Points**	**R2 Questions**	**R2 Reflections**
Bias p1	2	1	1	1	3	0	0	1
Bias p2	1	0	1	1	2	0	0	1
Bias p3	4	0	0	1	4	0	0	1
Fracturing disability p1	0	2	0	0	1	0	3	0
Fracturing disability p2	1	0	3	0	0	0	2	1
Centring disability p1	2	2	0	0	1	1	0	1
Centring disability p2	1	1	0	1	1	1	0	1
Access Needs p1	0	1	0	1	0	1	1	0
Access Needs p2	0	0	1	1	0	1	0	1
Access Needs p3	0	0	2	0	0	1	0	0

Table 10.1: table with the pre and post toolkit reflections on the product in the“game”

In the table we can see minimal changes before and after the toolkit, this is because the written answers do not fully capture the discussions that the groups had and the improvement there in. This does not mean however that there was no improvement, simply that the improvement, was not captured through the written answers. Participants discussed answers that they did not write down and although the answers that they did provide became more nuanced and had more complications than their prior answers this was not captured in the way I intend to code the answers. Identifications of ableism and its manifestations increased (at least in discussion) post toolkit and although these are not necessarily perfectly captured by the written methodology they are an important part in understanding how disability manifests and how design interacts with disability. The improvements were different than the ones I expected and that is in part why this form of capture does not fully represent the improvements that I saw but overall individuals did provide “better” answers in my opinion.

10.3 Survey

After the focus groups where conducted, the participants where sent the digital survey, 7 of the 10 filled in the survey. The survey was conducted to gain impressions as to how the participants felt about the toolkit and the focus group. For the open answers thematic analysis of the answers was done and the scale questions are analysed below.The thematic analysis can be seen in figure 10.4.

10.3.1 Scaled questions - Comfort and confidence

The outcomes of this question are inline with the impressions from the focus group, that the discomfort is deeply intertwined in to peoples understanding of disability, this is seen also in the models and also will be reflected on in the refection. The results can be seen in 10.3

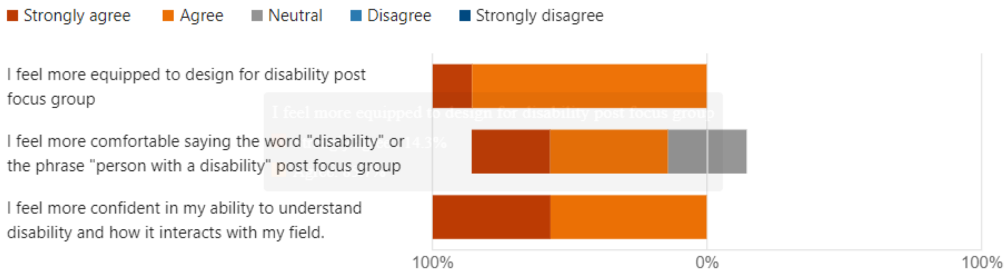


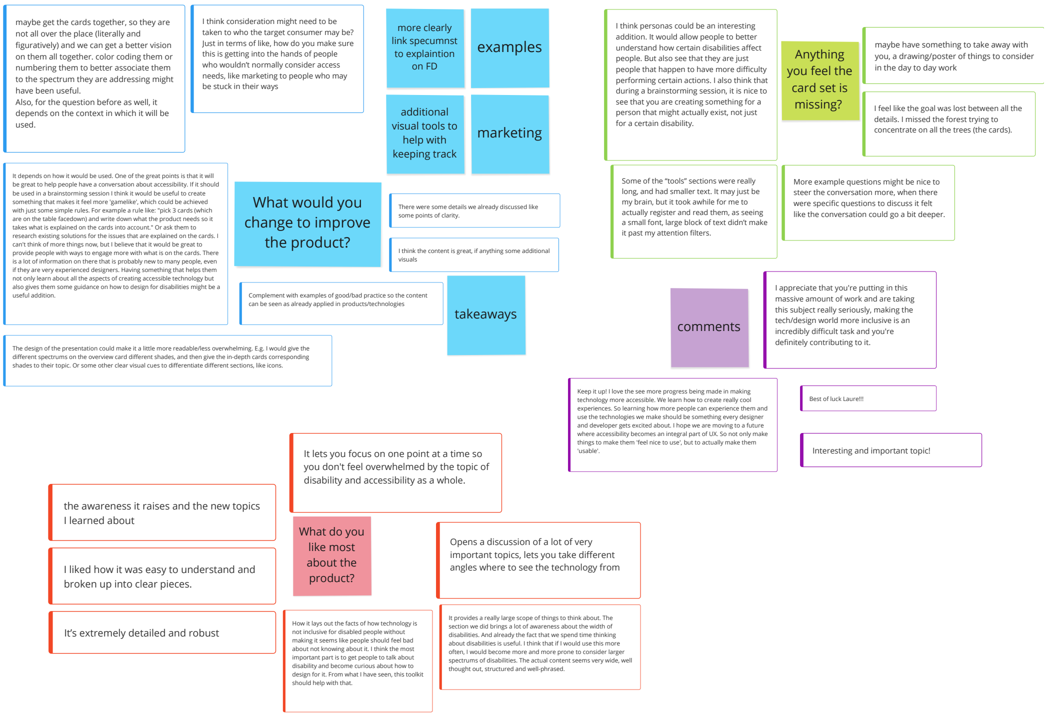
Figure 10.3: Comfort and confidence questions in the survey as a results chart

10.3.2 What would you change to improve the product?

The main themes are around the aesthetics of the toolkit, there are comments on the clarity that can be added through methods like adding icons and other visual sorting tools. There are also comments about what they would want to add to the toolkit, like takeaways (to move the toolkit in to the real world) examples and adding more tools for convincing others of the importance of the work in general.

10.3.3 What do you like most about the product?

The main themes of the feed back are the completeness of the toolkit“ The actual content seems very wide, well thought out, structured and well-phrased.” and“It’s extremely detailed and robust”. The parcelling of the information“It lets you focus on one point at a time so you do not feel overwhelmed by the topic of disability and accessibility as a whole.” and“How it lays out the facts of how technology is not inclusive for disabled people without making it seems like people should feel bad about not knowing about it. I think the most important part is to get people to talk about disability and become curious about how to design for it. From what I have seen, this toolkit should help with that.” and the lens that it provides:“Opens a discussion of a lot of very important topics, lets you take different angles where to see the technology from” and “already the fact that we spend time thinking about disabilities is useful. I think that if I would use this more often, I would become more and more prone to consider larger spectrum of disabilities.”



maybe get the cards together, so they are not all over the place (literally and figuratively) and we can get a better vision on them all together. color coding them or numbering them to better associate them to the spectrum they are addressing might have been useful.
Also, for the question before as well, it depends on the context in which it will be used.

I think consideration might need to be taken to who the target consumer may be? Just in terms of like, how do you make sure this is getting into the hands of people who wouldn’t normally consider access needs, like marketing to people who may be stuck in their ways

It depends on how it would be used. One of the great points is that it will be great to help people have a conversation about accessibility. If it should be used in a brainstorming session I think it would be useful to create something that makes it feel more 'gamelike', which could be achieved with just some simple rules. For example a rule like: "pick 3 cards (which are on the table facedown) and write down what the product needs so it takes what is explained on the cards into account." Or ask them to research existing solutions for the issues that are explained on the cards. I can't think of more things now, but I believe that it would be great to provide people with ways to engage more with what is on the cards. There is a lot of information on there that is probably new to many people, even if they are very experienced designers. Having something that helps them not only learn about all the aspects of creating accessible technology but also gives them some guidance on how to design for disabilities might be a useful addition.

There were some details we already discussed like some points of clarity.

I think the content is great, if anything some additional visuals

Complement with examples of good/bad practice so the content can be seen as already applied in products/technologies

The design of the presentation could make it a little more readable/less overwhelming. E.g. I would give the different spectrums on the overview card different shades, and then give the in-depth cards corresponding shades to their topic. Or some other clear visual cues to differentiate different sections, like icons.

I think personas could be an interesting addition. It would allow people to better understand how certain disabilities affect people. But also see that they are just people that happen to have more difficulty performing certain actions. I also think that during a brainstorming session, it is nice to see that you are creating something for a person that might actually exist, not just for a certain disability.

maybe have something to take away with you, a drawing/poster of things to consider in the day to day work

I feel like the goal was lost between all the details. I missed the forest trying to concentrate on all the trees (the cards).

Some of the “tools” sections were really long, and had smaller text. It may just be my brain, but it took awhile for me to actually register and read them, as seeing a small font, large block of text didn’t make it past my attention filters.

More example questions might be nice to steer the conversation more, when there were specific questions to discuss it felt like the conversation could go a bit deeper.

I appreciate that you're putting in this massive amount of work and are taking this subject really seriously, making the tech/design world more inclusive is an incredibly difficult task and you're definitely contributing to it.

Keep it up! I love the see more progress being made in making technology more accessible. We learn how to create really cool experiences. So learning how more people can experience them and use the technologies we make should be something every designer and developer gets excited about. I hope we are moving to a future where accessibility becomes an integral part of UX. So not only make things to make them 'feel nice to use', but to actually make them 'usable'.

Best of luck Laure!!!

Interesting and important topic!

It lets you focus on one point at a time so you don't feel overwhelmed by the topic of disability and accessibility as a whole.

the awareness it raises and the new topics I learned about

I liked how it was easy to understand and broken up into clear pieces.

It’s extremely detailed and robust

Opens a discussion of a lot of very important topics, lets you take different angles where to see the technology from

How it lays out the facts of how technology is not inclusive for disabled people without making it seems like people should feel bad about not knowing about it. I think the most important part is to get people to talk about disability and become curious about how to design for it. From what I have seen, this toolkit should help with that.

It provides a really large scope of things to think about. The section we did brings a lot of awareness about the width of disabilities. And already the fact that we spend time thinking about disabilities is useful. I think that if I would use this more often, I would become more and more prone to consider larger spectrums of disabilities. The actual content seems very wide, well thought out, structured and well-phrased.

Figure 10.4: Thematic analysis of survey answers

10.3.4 Card set Impressions

The card set has room for improvement, the overall visual design of the cards is focused on utility over aesthetics. The aesthetic requirements would take work to develop as the visuals are secondary to the accessibility of the cards.

10.3.5 Anything you feel the card set is missing?

The request to add tools like personas, take away tools with outcomes and more example questions. There was a comment about the goal being unclear.

There was also a comment “Some of the ‘tools’ sections were really long, and had smaller text.“ It may just be my brain, but it took awhile for me to actually register and read them, as seeing a small font, large block of text did not make it past my attention filters.” which came from a participant in the only online group, this points to any online version will need to be adapted to the format more precisely. The results can be seen in fig:10.5

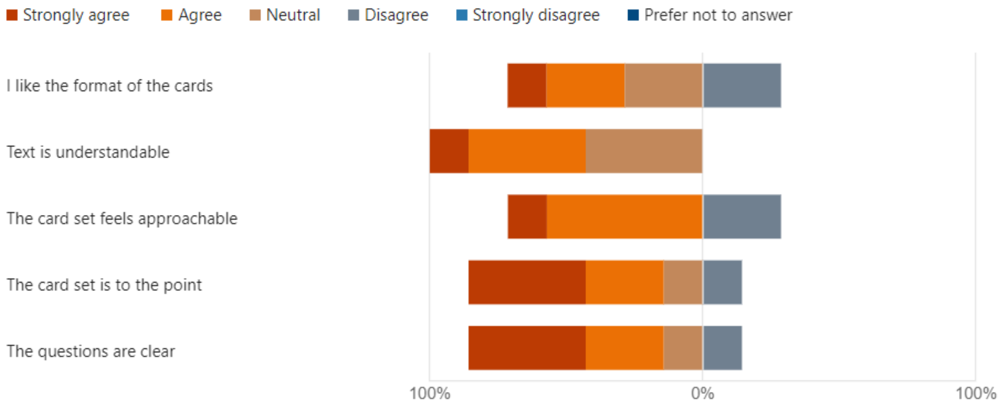


Figure 10.5: Card set Impressions questions in the survey as a results chart

10.4 Discussion

There are limits to the generalisability of the data collected here, for one the target group is not fully represented in this study, there are more students and more individuals who are familiar with disability than the general population doing this work. A number of participants self selected their participation due to their interest and willingness to learn about disability. There is also a possible learning effect of doing the task more then once. This could be tested by doing the first phase two times and discarding the first but that kind of test is out of scope.

10.4.1 RQ3a: How to evaluate a disability toolkit?

The toolkit was assessed and evaluated using the above study. The goal of the toolkit is to facilitate nuanced conversations about disability. The requirements are listed in chapter 7 and the focus group study is a way of testing this goal.

Given that the toolkit wants to intervene in the space of conversation, I found it logical to evaluate it in conversation. In the future I would stay in the space of conversation. If someone doesn't understand what disability actually is, they will fall into the many conversational pitfalls or tropes of understanding. In conversation it goes wrong, to evaluate in any other form would be intervening in a space where the problem did not first occur.

Additionally, evaluating written answers rather than conversations would have only given me a snapshot of a persons understanding and reasoning. Written answers also allow the participant to edit their words, whereas I wanted to capture their less filtered meanings. Group sessions were chosen because solo endeavours lack the generative friction[3]that I find important in the discussions surrounding disability.

Even though I would stay in the space of conversation, I would change how I go about it. I wanted to capture the conversations in the participants' individual notes and my own note-taking during the session. This did not fully capture the conversation as it was difficult to keep track of all its parts and to fully record the meaning of each participant. Using a form of shared externalisation of the conversation would have probably been beneficial, e.g. using sticky-notes, shared whiteboards, stickers, etc. to have the participants externalise and visualise their opinions. Adding recording methods, for instance audio recordings or adding a separate note-taker, would have helped to better capture the rest of the conversations. It also would have made my prompting the conversation as a facilitator during the session and the analysis afterwards easier. Important to note though is that these are stigmatised conversations, and participants may not feel comfortable expressing themselves fully knowing their responses

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[3] language adopted from [15]

are being audio recorded. The extent of this influence needs to be studied further. Therefore, depending on the resources available, preference would go to a note-taker.

10.4.2 RQ3b: How critical are people about existing technologies when asked to analyze from the perspective of disability before exposure to the toolkit vs afterward?

The written answers and the increased nuance of the dialogues of the participants point towards people being more critical after exposure to the toolkit. The participants more accurately identified issues and potential implications of products after the toolkit and after the discussion that the toolkit facilitated, as presented in section 10.2.2. The level of criticalness people have towards existing technologies starts with their baseline understanding of disability. When this baseline understanding is high the toolkit lets them become more precise about their critical reflections and also facilitates a shared language and to share meaning to that language. If participants prior exposure of disability is lower, then it helps facilitate critical reflections on not only what they know but what they do not know and why. Overall, the toolkit does address these two groups although in different ways given the variety of knowledge levels interacting with the toolkit.

10.4.3 Final Card Set

The final card set has had changes to implement some feedback from the evaluation sessions and increase the usability. The primary addition was to move the navigation from a set of cards to a booklet so that all the overarching information is found quickly and easily. additional facilitators information has been added along with providing more usage structure. The cards have been edited, adding bolding for important information and editing spelling and grammar errors throughout the toolkit. This version of the card set does have the limitations of not having these changes tested however time does not permit an additional version of testing the cosmetic features that have changed. Additional testing would have been preferable for the new mechanics and this shortcoming is understood. The final toolkit can be seen in A.16.

Chapter 11

Conclusion and Reflection

This chapter concludes on the thesis and reflects on what has been done and learned in the course of this process. The research research questions will also be re-caped leading up to the main research question.

11.1 Research Question summary

11.1.1 RQ1a

What are the current models, practices around, and definitions of disability that non-expert designers and technologists hold?

In the literature I identified eleven models relevant to how people view and understand disability: Moral, Medical, social, mismatch, superpower, Identity, human rights, cultural, charity and economic models. These models attempt to give an explanation on why disability happens and how we as a society need to treat it. However, I found that in practice non disability expert designers and technologists do not actually hold to the models as defined in literature. I have instead identified remixed versions of them, but those versions are different in practice than what the literature describes, such as Disability as a socially situated difference vs social model, disability as a technical difference vs medical model, disability as a technical consideration vs mismatch model. This indicates to me that the current models are not ideal tools for intervention on the current problem. The practices that people are using to intervene in the current problem are finding information via literature, experts or disabled people directly, their methods would be in the form of simulations, implementation of checklists and poor implementation of co-design. The way non disability expert designers and technologists define disability varies and echos the different models, but point towards those echoed constructions of disability that tend to place disability as a non normative medical and social experience.

11.1.2 RQ1b

What are the current models, practices around, and definitions of disability that disability-expert designers, communicators and technologists hold?

In the literature I identified eleven models relevant to how people view and understand disability, but whereas I found echoes of these models reflected in the views and opinions of non disability expert designers and technologists, I did not find these models reflected in the views and opinions of disability-expert designers, communicators and technologists. The practices used by disability experts tend to be around identifying pain points and addressing them through their discipline as well as that designers spend time humanising their disabled users in the eyes of both disabled and non-disabled stakeholders.

11.1.3 RQ2a

What are key features of a disability toolkit?

To design for disability is to address ableism. To achieve this, the key features of a disability toolkit are a mix of reflective tools to identify how a designer's biases and preconceived assumptions (i.e. the effects of ableism) may impact what gets designed, and practical tools to facilitate understandings of what it means to have a disability. These tools should intervene in the earliest possible phases of the design process. In this case reflective tools draw the designer's attention to the way ableism may have shaped their understanding in three toolkit sections: biases, centring disability and foundations. The practical tools in this case offer a way of addressing that understanding in two toolkit sections: access needs and fracturing disability. Other reflective and practical tools surely exist, but no matter their form, the two-stage approach is in my eyes essential. One without the other will always fail; they work best together.

11.1.4 RQ2b

What are possible formats for a disability toolkit?

There are many possible formats for disability toolkits. In this case physical cards were chosen due to their many affordances and tradition within design sensitisation work. Cards make it easier to keep track of information when tackling complex problems, let you sort extraneous information and are primed to work in tandem with meaningful space without forcing it. These characteristics are essential given the wide scope of the task that is designing for disability.

The cards are designed to prompt conversation through the use of questions and statements. I chose questions and statements as a way to explore the task of designing for disability in cognitive and conversational ways. I think it is appropriate to intervene in the space of spoken conversation as dialogues are foundational to design processes, especially at their earliest stages when the outcomes are most malleable. The space of conversation is also where I found ableism to be encoded and solidified. That addressing ableism is a key part of designing for disability further solidifies my belief that this is a good place for intervention.

When presenting the complex subject/experience that is disability, information can quickly become overwhelming and uncomfortable. Our instincts as people is often to simplify and hide the subject. However, CripHCI asks us to lean into the complexity and discomfort instead of trying to cure it to prevent the curing attitude and spirit from translating into the technologies we design, because the way that we design technologies ultimately becomes the way we interact with disabled mind-bodies [15]. This was touched upon in this thesis, but not explored fully. Navigation was explored as an option for guiding people through the complexity without taking away from it, but this was not explicitly tested.

These lessons could prove foundational to other formats of disability design toolkits. These formats can include serious games, films, books, performance, and so on. Presenting the content is not exclusive to a card-set or text-based format.

11.1.5 RQ3a

How to evaluate a disability toolkit?

Since the toolkit is meant to intervene in the conversational spaces of a design process, I tried to replicate these stages as much as possible in the evaluation of the toolkit. Seeing as the subject in question deals with a lot of stigmatisation, biases, cultural differences and sensitive information, people tend to filter their reactions and their words, making potentially relevant information difficult to capture. That is why, in the evaluation, I tried to prime for a safe space by priming my language, remaining as neutral as possible whilst also prompting participants to elaborate on their standpoints, allowing for mistakes and valuing all feedback equally. This was all done to create an environment that is as comfortable and non judgemental as possible. Based on the participants allowing themselves to be vulnerable, for instance by expressing they at times felt uncomfortable with the subject, I think this approach worked to an extent, though probably not completely seeing as the stigmas and biases are deeply ingrained in society.

In order to ground the conversation in design, as well as to give a concrete grounding point to focus on rather than staying in the abstract, I used real-life disability-related products as a point of reference to base the conversations on. These real-life products were presented to a focus group to talk about disability before and after being presented with the toolkit. This allowed me to first get a baseline for the conversations and see how their knowledge and perspectives shifted after their interaction with the toolkit. This method worked well to capture how the participants in their language framed disability. This allowed me to evaluate if a shift occurred to a more practical and realistic understanding of disability, as was my objective.

However, this method only gives a limited impression of how the toolkit may work in real life situations. Firstly, the participants were evaluating products that were not of their own design. This distance makes it easier to take an objective, critical and reflective stand than if one were to reflect on their own designs. Secondly, the participants were open to discuss disability, seeing as they all responded voluntarily to the open call for participants. Thirdly, the discussions only encompass a small part of what a design process normally looks like, seeing as the evaluation was focused on one subject rather than complex webs. This delineated the conversation from how it would usually look. Lastly, due to time constraints participants got to explore only one selected section of the toolkit per focus group. This did not give me a full picture of which parts of the toolkit would be found more useful, only what worked with that individual section.

To evaluate the full potential of the toolkit, I would take the complete toolkit into the real world and test it with designers in their own processes to gain a fuller understanding of what works and doesn't work in practice.

11.1.6 RQ3b

RQ3b: How critical are people about existing technologies when asked to analyze from the perspective of disability before exposure to the toolkit vs afterward?

Individuals were more critical in their analysis and more reflective of the societal impact of designs after exposure to the toolkit whereas before logistical concerns and use case concerns were more prevalent. Each section contributed to this in their own ways.

The foundations section laid the foundation for using a shared language by all participants and opened up the floor to talk about disability. The fracturing disability and biases sections contributed to creating more nuanced understandings around disability by asking questions about people's assumptions, challenging them to be critical in their thinking and laying emphasis on using spectrums rather than black and white criteria. Furthermore, these sections along with the section centring disability asked for a disability-first perspective that exposes the effects on social, personal and practical levels to dive beyond the surface level of understanding disability. The access needs section helped the participants to move their reasoning about people's wants, needs and actions from the hypothetical into the real world by providing them with concrete examples of possible design considerations. The centring disability section helped participants to talk about disability as a perspective and an experience by mapping it on to their own lived experiences (work, school, home, etc.). All of the above sections contributed to creating a shared language and turned theoretical points into practical perspectives and design considerations. These build knowledge that contribute to better understanding disabled people, humanising them in the process.

During the evaluation it became apparent that each group had a different starting point when it came to their knowledge of disability. This effected the kinds of improvement that was seen regarding their critical reflection. As the toolkit is now, it does not adapt to different starting points of participants' understanding of disability. This means that not all improvements were to the same level and possibly not to their full potential. How to account for this and implement it in the toolkit would need further study.

11.1.7 Main Research question

How to inform designers and technologists about disability and problems with accessibility?

When informing designers and technologists about disability and problems with accessibility it is important to set aside a space and time for conversations and to facilitate these conversations in a way that promotes reflexivity as well as provides practical interventions.

In this case a toolkit that works in the early stages of the design process was developed to provide scaffolding and to guide the conversation. The scaffolding works in two broad phases. The first phase being the identification of problems through tools like reflexivity, questioning assumptions and questions. The second phase aims to fill those newly identified knowledge gaps through practical tools around understanding disability as well as finding where additional information is needed.

In this toolkit that was done through five sections. The first section is that of foundations which provides a base understanding and helps individuals to start mapping the problem space. This section predominantly presents factual information as well as global concepts that are needed when designing for disability. This section aims to be a starting point so it does not fully explore all possibilities of topics covered and may be repetitive for those with existing disability related knowledge. The second tool, that of access needs, describes different logistical concerns related to how people operate in the world and under what parameters they can get done what they need to do. The section biases explores how different assumptions manifest its biases and the effects that they have. This is a tool that asks people to reflect on how their assumptions may be producing unintended outcomes or the different ways that ableism affects what gets built. Centring disability highlights perspectives of disabled people in a way that gives texture and importance to the often underrepresented and underdiscussed experience that is disability. The section of fracturing disability complicates people's notions of disability and can direct people to finding knowledge that they might be missing and help guide them towards a more practical understanding of disability.

All the sections provide a shared language around disability as well as facilitate a space to talk about and explore the perspectives on disability that individuals within a team or design process might have. By making assumptions concrete there is an opportunity to correct and question them. In this particular piece of work the format of a card set was chosen because of familiarity within the state-of-the-art (for example card sets are common in both the design process and conversational spaces). Although the format of a card set is chosen here, multiple different formats of intervention may prove useful for informing designers and technologists about disability and problems with accessibility as long as there is the identification of existing flaws in approach and an effort to provide tools to addressing those flaws.

This toolkit reflects the state-of-the-art in that it uses common formats and intervenes on many of the commonplaces that a toolkit about designing for disability would intervene on and it takes a further disability informed perspective. This perspective is supported and cultivated through the literature review and instils seeing disability through disability, not from non disabled perspectives. It takes a normalising perspective on disability that frames disability as a common and normal occurrence instead of an exception or an “extreme”. It recognises and accepts the discomfort that is addressing disability and ableism instead of ignoring or circumventing the issue. Therefore it takes the lessons learned in the literature, specifically those from disability studies, and conveys it in a form that is familiar to designers and technologists.

However, in taking a format that is familiar to the Sate-of-the-art, it fails to embody two key insights that I gained from studying various sources of literature and interacting with various people during the expert interviews and focus groups. 1) It does not fully parcel information based on an individual’s place in their disability knowledge journey which may mean that the toolkit intervenes in ways that are not maximally useful. 2) It places one view as expert, the toolkit does invoke some access to authority by being the facilitator of the conversation, but disability is inherently nontransferable and there is no one right approach or method to designing for disability which the toolkit may give the illusion that there is. Unfortunately, these shortcomings only became visible towards the end of this research and were therefore not rectified. It would be good to take these into account in follow-up or similar studies.

In summary designers and technologists can be informed about disability and problems with accessibility through a toolkit that takes a two-part perspective. The first part being the identification of assumptions, biases, ableism and how they may be encoded in what we are doing. The second part being practical ways of approaching and developing knowledge about disability.

11.2 Contributions

11.2.1 Theoretical

Within Crip HCI there is a push to re-imagine technologies from the perspective, wants and needs of disabled people. There is the call to use our knowledge as researchers to reflect on, produce and enact our situated knowledge [17]. There is also a call to just assume that disabled people will be involved, to facilitate natural interaction for, and to welcome disabled people and their existence [16] [13] [5] [14].

These are both questions aimed at reevaluating standard ideas of epistemology. Within spaces of technology people's imaginations shape what gets made. These imaginations are then brought into the real world through methods of Science, but the imagination of what we should do is ultimately a reflection of people's values and hopes for the future. This means that to reduce the ableist outcomes of technology we must intervene at the beginning, in the human space of feeling and understanding.

The theoretical contributions are predominantly that I have mapped a problem space and used my perspective to identify the issues from a disability first angle. If we are to have disabled people be involved in the conversations and process of designing technologies that interface with disability, which is an idea supported within CripHCI and wider disability spaces, We need to understand why and how those conversations are currently failing us. There is a lack of understanding around what ableism is and how it creeps its way into our assumptions and ways of generating knowledge. This work may also provide a framework or lessons learned in how to talk about and identify one's positionality, evolution of reflections and how they guided the rest of the research process. This is something that may help us to understand the way our understandings evolve and who we are as people in that. Positionality is difficult in part because it feels very vulnerable and to place one's values clearly for others to see and potentially scrutinise is difficult as it overrides the model of objectivity and disconnection from one's work. If I am clear about the underlying reasons as to why I have done things, then individuals who are interacting with the work moving forward can understand where things came from and why I did what I did. The clearest example of this is Chapter 6. Chapter 6 was not part of my original research plans but throughout the process I kept making decisions based on what I had seen in the past, so in Chapter 6 I added my lived experience as an additional layer of validation because I had recognised several patterns and themes in from own experiences. This helped me understand things that other people talked about in their experiences in the literature. It helped me value my own perspective and to re-frame what was important, namely people and the experiences of disabled people within design. The way I have done the description of my lived experiences and positionality may serve as a 'how to' or 'what not to'-guide for others.

11.2.2 Practical

The practical contributions I have made are in the problem that I am trying to tackle: the complicated and sometimes uncomfortable conversations that need to be had in this space can be difficult. This work was in part born out of my experiences of a not having conversations on disability facilitated in a way that was sensitive to the disabled people in the room and this toolkit offers a structure for conversations moving forward both in an academic classroom sense but also in an industrial setting. I have also built some form of shared language, via the toolkit, in a space where language is so important and changes so much. The way it contributes to the wider field of Crip HCI is that it takes one of the questions that is used to prompt generative friction [15]. With in CripHCI there is often the question of how can disabled people re-imagine this technology and I have done how can a disabled person re-imagine these conversations, what needs to be included, and how do things need to be framed in order to give space for disability insight but also not fall into the pitfalls of epistemological violence that is often encountered by disabled people trying to enact “nothing about us without us”.

Often the reflection of the underlying ‘why’ happens at the end, in a place where it can feel like an attack or disheartened the designer on ever intervening in the space of disability and that loss of will means that people do not design for disability explicitly because it is too difficult and it goes wrong so often. By intervening at an early stage, and in a way that can be used at anytime, I hope to let the enthusiasm passion and energy of individuals designing for disability lead to better outcomes.

11.3 My Reflections

At the beginning of this process, I was naive to the complexity of disability. In the early stages I wanted to design a checklist, a quality assurance framework or a definitive tool that could tell me if something was good or bad. I wanted to be able to make a judgement call on something in relation to disability. However now I see this does not the right goal. It presupposed so many things about disability.

In the early steps of this process, I wanted a definition that would solve all the problems with the existing definitions. I did not end up being able to do that, not because it was outside of my capacity but, because it was the wrong goal. I wanted to make disability easier to digest, more bite sized. In this process I have identified that disability is not just one thing and designing for disability cannot just be one approach. Having only one approach can act as constraining, Disability is an experience that often means approaching tasks in a way that is different so to apply a solutionism attitude is its self a method that will not lead to my goal, there is no one way, there is no prefect [17].

Disability and developing for disability is like a big knot of hundreds ropes on a table. We want to untie the knot, to straighten it out and be able to arrange all the ropes, organise them by colour and size but the knot is too big, to tightly wound. The knot has ropes that are the realities disability and debility, social understanding of disability, our colloquial dialogues around disability, medical understanding of a variety of human conditions, technologies, policies, perspectives, stories, dialogues, hope, and compassion. The knot is continuously been tightened, loosened, un-knotted and re-knotted when we intervene in the space of disability. There are things that tighten the knot that we do not see as making the knot harder to untie even though they do. There are many well-intentioned people working on this knot but they often (inadvertently) end up tighten it. When we monoliths disability we tighten the knot, when we try to "solve" disability we tighten the knot, when we do not facilitates inter-disability solutions and perspectives, pitting and ranking disabilities against each other we tightens the knot, when we refused to say the word disability we tighten the knot. All of these are done with good intentions but pulling at ropes without understanding where they are come from and where they are going to means you end up tightening the knot.

This thesis has been a lot of mapping the knot, seeing where the ropes go and trying to find the ends and making the ends longer (Hopefully not by pulling on them but by following them back to the middle and unweaving as we go). There are some ropes that are now good handles for tackling the knot: these are a collective language around biases, the access needs written out clearly agnostic of any one disability but mapped across disabilities and non-disability, Fracturing disability to let us map the different colours of the ropes, and centring disability lets us look at the knot from another angle. Collective understanding starts with collective language and shared experience this toolkit aims to do that. There are many sections of the knot that are still tightly wound in ways that are difficult to see.

11.3.1 Mapping Disability

I have done something in this work that I wish to now reflect on more deeply, since it is situated in not only my approach to the work but also in the wider landscape. I would like to do this by highlighting something I have specifically not done: classifying disability based on ‘severity’, ‘economic impact’, or other distinct data categories.

Avoiding this is done with an explicit purpose. The tools that do these types of classification do it with often eugenic outcomes or underpinnings. There are scales/questionnaire that do this like the QALY toolkit and I feel they do more harm then good when reducing people to numbers and labels of ‘mild’, ‘moderate’ and ‘severe’. There is a human instinct to want to attach worth to the labels, creating a hierarchy wherein resources are allocated and worth of effort is assigned. This hierarchy deems some human lives more important than others, which can have dire consequences. One notable example of this is illustrated by learning disabled people (using the UK language of the source) unlawfully having ‘do not resuscitate’ orders placed on them without their consent following the second wave Covid-outbreak, without clear indications on whether these people would be effected worse by the virus than people without learning disabilities [90] [91]. Another example comes from Iceland, where almost all pregnancies where Down syndrome is detected are terminated, despite the fact that “Many people born with Down syndrome can live full, healthy lives, with an average lifespan of around 60 years” [92] [93]. These examples illustrate that when we focus on severity, diagnostic markers are valued over someones potential.

I see a need for tools to discuss disability, but there needs to be a balance in making sure that these tools do not create hierarchy in disability, classifying disability by its decentralisation from the norm, whether that hierarchy is who should be privileged in access to resources or be the priority of research. We need ways of understanding differences.

In this thesis, I have parcelled and classified disability without introducing hierarchy. I have done this in two ways: the broad original classification at the start (mind, body, sensory, etc. see:4.1) and the spectra that are in the fracturing disability section. Because I did not classify disability in terms of good and bad, I tried to minimise the inclination to exploit/use or correct/eliminate (others') disability.

By not making differences rankable in both severity and desirability, we do not preemptively limit what we could learn. This is not only in disability but also in other communities that are increasingly being addressed through social and technological advancements. I feel we can and should strive to remake our current classification systems into a more equitable and just reflection of the people we are attempting to describe.

11.3.2 Making it easier for disabled people to be involved

Another goal of mine in this thesis is to make it just a little bit easier for disabled people to exist. Oftentimes people's first conversations around disability when "confronted" with the disabled person is horrible. This idea, has been a goal of mine since before this thesis began but now has for me the language of Epistemic Violence thou work like [14], my focus however has not been on the "experts" as I hope that more people will take up this work. People say things in gut reactions that they would most likely not say if they had been given time and space to think but conversations move quickly and those conversations can be uncomfortable for both parties. I hope that the toolkit can mean people have first conversations that are not directed at a disabled person. Those first messy regurgitation's of bias and story-lines around disability might happen in a space where there is less opportunity for pain. These conversations prevent disabled people from feeling safe and valued in the world and that fact means that we cannot benefit from their depth and breadth of expertise. We cannot benefit from their humanity and their possibility because they do not feel safe being in the world as themselves.

11.3.3 Goal on Conversations

In the introduction I talked about this tool and thesis being part of a wider goal, a wider direction of work. that work being predominantly about “ making it easier for disabled people to shape their own lives. Making it easier to respect the autonomy of disabled people, to amplify Disabled voices (however they may communicate). To safely be Disabled.”. One of the ways this goal has its need highlighted is through the conversations we have around disability. These conversations are often uncomfortable for both disabled people and non disabled people. They have a circular logic because there is no concrete points of intervention and there are often misconceptions about disabled people what they want to do and what spaces they occupy. There are also pinpoints around the language we do and do not use. The toolkit does provide concrete points of intervention and begins to highlight many of the misconceptions. I can not know for certain how other people feel in these conversations but I have witnessed less discomfort and have seen language be shaped and the assumptions be questioned.

11.4 Limitations

11.4.1 Wider context of problem space

The problems that I am trying to solve with the toolkit are wider then what any one project can address. Abelism and its effects are built into many of the systems that technology is built on. There are many people working in this space of making the world easier for disabled people to live in but the work is wide reaching and is still being uncovered. Any work that interfaces with any kind of bias has to simultaneously address the effects of that bias, highlight the historical effects of that bias so that the group that has been artificially discounted can the highlight what is missed. I believe this work has started but it is nowhere near done. Communicating the lived realities and design possibilities for disability is already a massive task that cannot fully be realised with this toolkit because disability is still stigmatised and discounted as a valuable part of life.

11.4.2 Scope of data collection

The people who participated in the research activities are not necessarily fully representative of the people, perspectives and opinions the toolkit would want to address. This is because talking about inherently stigmatised issues and sometimes discussions about disability are perceived as confrontational. Ideally the data of the survey and focus groups would have been done in a space and place where my reputation could not influence it but that is out of scope. I believe the expert interviews, contextual observation, state-of-the-art and literature review benefited from my perspective, but the survey and focus groups could have“cleaner” more representative outcomes if I were not part of collecting that data.

11.4.3 Lab set up and application

Due to the way the work was conducted there is a limit to the generalizability of the outcomes. There is also a limited scope to the data that was collected from the participants. Further explorations of the work it would be interesting to explore not only in field setting (by intervening in the space of a design team) but also an analysis of how the conversations occur with no toolkit used and an existing design toolkit, to compare my intervention to the alternatives available. This could be done in addition to the future work

11.5 Future Work

Future work that could be completed in relationship to this toolkit is the testing and analysis of the mechanics of the toolkit. There could also be additions of visual elements like icons that convey the access needs and biases, more examples on the fracturing disabilities and artwork for the centring disabilities. Further study is also needed to see how the toolkit works in different practises.

The toolkit could also be adopted to different contexts specifically more specific contents. The toolkit right now is agnostic of any one use case scenario and although this makes it generally applicable to many use case scenarios there is advantages from presenting specific information based on a context. Two contacts come to mind.

11.5.1 Medical spaces

The first one the space of medical systems. For this it would be important to look at the specific problems, values and methodologies that exist within medicalised spaces and systems. This particular example comes to mind because it is often a space in which disabled people spend quite a bit of time and where the harms of bad design and ableism can have truly profound impacts, including on people's lives. For this context the ideas of pathologising, normative functioning expectations, medical trauma, medical ableism, independence vs interdependence and the place and role for desensitisation, would all be useful as well as additions of specific support strategies like communication methods (follow up documents) and a disability centred analysis of medical systems like the role of patient "compliance" or "non compliance" and concepts like administrative burden. The work of Mia Mingus may proved a starting point for this.

11.5.2 Educational spaces

The second space that would makes sense to design a specific toolkit for is that of the educational setting. Education is often identified as an equalising factor and tool to reduce societal inequalities. There are many laws and structures specifically around the accessibility of education but practical execution is still lacking. Specific ideas that would need to be explored in an educational version of the toolkit would be presentations of gate-keeping by institutions, normative expectations on the presentations of different disorders, the implications and roles of policies, concepts like double exceptional, "spiky profiles", and the realities of later diagnoses. The concept of administrative burden would also be important to explore in an educational version of the toolkit.

The medical setting and the educational setting would both be very useful specialisations of the toolkit that would most likely involve adding to the foundation section, the centring disability section and possibly with the addition of whole other sections.

11.5.3 Cultural contexts

This toolkit is built within a context and has been developed for that context, as identified in 4.5.13,the way each culture sees disability effects how it is seen, treated and what we have learned from disability. I do not wish to present the notion that the west is the best or the worst in regards to disability, I have after-all been given the help I need to get to this point, simply that different context require different approaches and that there are may be lessons that we can learn from other cultures.

11.5.4 Access improvements

One concept that came up and that is frequently discussed in the space of disabilities is the accessibility of the information and that disabled people deserve the right to access information about disability (and themselves). Within disability there is often a gatekeeping function around knowledge and a hierarchy of what makes a“good” disability or disabled person. This is ultimately detrimental to the goals of this work. In solidarity with all the different kinds of disabled people there are it would be incredibly beneficial to translate the toolkit to truly plain English (or is the plain language version of whatever region the toolkit is being used in). Plain English is deceptively complicated and the work of making this toolkit in plain English was out of scope and beyond my capacities. However it would be fundamental improvement, the toolkit also aims to make the working between disabled and non disabled people easier by developing shared language. Translating the insights, perspectives and experiences of disabled people into a concrete context begins to facilitate communication. Translating those insights into language that does not disadvantage or artificially remove individuals with less language capacity would be incredibly beneficial as there are insights and perspectives that exists in those people that or sometimes difficult to explore due to mismatched language expectations.

As always disabled people must be centred in what comes next, any toolkit or educational tool about disability will benefit from the input of disabled people. Their inputs, thoughts, perspectives and ways of framing are integral and non-negotiable. The work of developing for disability has always been pushed by disabled people but has not always been given the chance to be shaped by them.

11.5.5 Data and how it “Sees” Disability

Out of this work it has come to my attention that the models effect our definitions, that in turn effect the date we collect and have access to (and how we collect it). This is impacting how we intervene and interface with disability in technology. It may be useful to use the models and the identifications of biases used in this work and applying it to how we collect data. Disability resists definition, still we often attempt to understand it and quantify it using data methodologies. With these data collections and analysis we encode the biases in not only their outcomes but also the solutions and interventions that come out of the data that is collected. To illustrate, the data that is collected with a social model of disability as its definition will create interventions that produce social model outcomes and values social model values. Which may not fully address the needs of disabled people. This can mean that interventions do not intervene in spaces and places that are appropriate and instead only intervene in ways reducing these social presentation of disability, not actual harm or pain experienced by disabled people whose data is being collected.

11.6 Conclusion

In conclusion to this thesis, above is work describing not only how our current approach to technology and its intersections with disability is flawed but also an identification that the underlying dialogues and mechanisms we have to understand disability or contributing to the problem of not building technology to its full potential. A toolkit has been made to facilitate the conversations that underpinned development in a way that is hopefully more conducive and nuanced around disability. This toolkit is a steppingstone in a direction of more humane technology and many more steppingstones are needed to achieve that goal.

Appendix A

Appendix

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A.1 Principles as collected in Literature review

Principle	**Definition key points**	**alternative names for principle**	**source**
Empowering	Empowering design ensures products center on the value they provide to people over the revenue it can generate. [23]		[23]
Finite	Finite design maximizes the overall quality of time spent by bounding the experience and prioritizing meaningful and relevant content. [23]		[23]
Inclusive	Inclusive design is a methodology that enables and draws on the full range of human diversity. [23] As individuals spread out from the hypothetical average, the needs of individuals that are outliers, or at the margins, become ever more diverse. Most individuals stray from the average in some facet of their needs or goals. This means that a mass solution does not work well. [24]	Recognize Diversity and Uniqueness [24]	[23]
Resilient	Resilient design focuses on the well-being of the most vulnerable and anticipates the potential for abuse. [23]		[23]
Respectful	Respectful design prioritizes people's time, attention and overall digital well-being. [23]		[23]

Thoughtful	Thoughtful design uses friction to prevent abuse, protect privacy, and steer people towards healthier digital habits. [23]		[23]
Transparent	Transparent design is clear about intentions, honest in actions and free of dark patterns. [23]		[23]
Seek out points of exclusion.	”Proactively seek out points of exclusion, and use them to generate new ideas and highlight opportunities to create new solutions. Understanding exactly how and why people are excluded can help us establish concrete steps towards being more inclusive.” [62]. Designing for inclusively not only opens up our products and services to more people, it also reflects how people really are. All humans grow and adapt to the world around them and we want our designs to reflect that.” [20]	Recognize exclusion [20]	[62] [20]
Identify situational challenges	Exclusion can occur on a situational basis. Consider the context in which your user is interacting with the product and design the experience to be accessible in these daily moments of exclusion. [62]	Consider situation [61]	[62]
Solve for one, extend to many	”Everyone has abilities, and limits to those abilities. Designing for people with permanent disabilities actually results in designs that benefit people universally. Constraints are a beautiful thing.” [20]		[20]

Recognize personal biases	Involve people from different communities throughout the design process. Not only will users show us what they need, they will help us look beyond our own abilities and biases when creating products. [62]		[62]
Learn from diversity	Human beings are the real experts in adapting to diversity. Inclusive design puts people in the center from the very start of the process, and those fresh, diverse perspectives are the key to true insight. [20]		[20]
Offer different ways to engage	Offer people different ways to participate in an experience. With different options, users can choose the method that best serves them in their unique circumstances. [62]	Provide comparable experience [61] Offer choice [61]	[62]
Extend the solution to everyone	Designing a solution for one user group can benefit a much broader audience. [62]		[62]
Be consistent	Use familiar conventions and apply them consistently.Familiar interfaces borrow from well-established patterns. These should be used consistently within the interface to reinforce their meaning and purpose. This should be applied to functionality, behavior, editorial, and presentation. You should say the same things in the same way and users should be able to do the same things in the same way. [61]	Respect conventions [94]	[61]

Give control	Ensure people are in control. People should be able to access and interact with content in their preferred way. [61]		[61]
Prioritise content	Help users focus on core tasks, features, and information by prioritising them within the content and layout. [61]	Enforce simplicity (in reference to interfaces) [94]	[61] [94]
Add value	Consider the value of features and how they improve the experience for different users. [61]		[61]
Inclusive Process and Tools	Inclusive design teams should be as diverse as possible and include individuals who have a lived experience of the users the designs are intended for. This also respects the edict “nothing about us without us” without relegating people with disabilities to the role of subjects of research or token participants in design exercises. [24] Want to know what makes for a truly useful and meaningful service? Ask the people who use and deliver them. [25]	Created with the people who use and deliver them [25]	[24] [25]
Broader Beneficial Impact.	It is the responsibility of inclusive designers to be aware of the context and broader impact of any design and strive to effect a beneficial impact beyond the intended beneficiary of the design. [24]		[24]

Prototyped and tested for usability	Gathering feedback early on helps mitigate risk and makes an idea more resilient in the end. [25]		[25]
Accessible to all	Lowering the barriers to entry helps everyone take advantage of opportunities and resources meant for them. [25]		[25]
Equitably distributed	Public resources are more fairly delivered when they reach the people who need them most. [25]		[25]
Rigorously tested and evaluated for impact and effectiveness	Continuously improving performance based on client needs and feedback and carefully assessing what works leads to better outcomes for residents. [25]		[25]
Involve code early	Web interfaces are made of code. If you're not working with code, you're not working on the interface. That's not to say there's anything wrong with sketching or paper prototyping — in fact, I recommend paper prototyping in my book on inclusive design. Just work with code as soon as you can, and think about code even before that. Maintain a pattern library of coded solutions and omit any solutions that don't adhere to basic accessibility guidelines. [94]		[94]

Don’t be exact	“Perfection is the enemy of good”. But the pursuit of perfection isn’t just to be avoided because nothing ever gets finished. Exacting design also makes things inflexible and brittle. If your design depends on elements retaining precise coordinates, they’ll break easily when your users start adjusting font settings or zooming. Choose not to position elements exactly or give them fixed, “magic number” dimensions. Make less decisions in the interface so your users can make more decisions for it. [94]		[94]
Start with user needs	Service design starts with identifying user needs. If you don’t know what the user needs are, you won’t build the right thing. Do research, analyse data, talk to users. Don’t make assumptions. Have empathy for users, and remember that what they ask for isn’t always what they need. [19]		[19]

Do less	Government should only do what only government can do. If we've found a way of doing something that works, we should make it reusable and shareable instead of reinventing the wheel every time. This means building platforms and registers others can build upon, providing resources (like APIs) that others can use, and linking to the work of others. We should concentrate on the irreducible core. [19]		[19]
Design with data	In most cases, we can learn from real world behaviour by looking at how existing services are used. Let data drive decision-making, not hunches or guesswork. Keep doing that after taking your service live, prototyping and testing with users then iterating in response. Analytics should be built-in, always on and easy to read. They're an essential tool [19]		[19]
Do the hard work to make it simple	Making something look simple is easy. Making something simple to use is much harder - especially when the underlying systems are complex - but that's what we should be doing. Don't take "It's always been that way" for an answer. It's usually more and harder work to make things simple, but it's the right thing to do. [19]		[19]

Iterate. Then iterate again	The best way to build good services is to start small and iterate wildly. Release minimum viable products early, test them with actual users, move from alpha to beta to live adding features, deleting things that don't work and making refinements based on feedback. Iteration reduces risk. It makes big failures unlikely and turns small failures into lessons. If a prototype isn't working, don't be afraid to scrap it and start again. [19]		[19]
This is for everyone	Accessible design is good design. Everything we build should be as inclusive, legible and readable as possible. If we have to sacrifice elegance - so be it. We're building for needs, not audiences. We're designing for the whole country, not just the ones who are used to using the web. The people who most need our services are often the people who find them hardest to use. Let's think about those people from the start. [19]		[19]
Understand context	We're not designing for a screen, we're designing for people. We need to think hard about the context in which they're using our services. Are they in a library? Are they on a phone? Are they only really familiar with Facebook? Have they never used the web before? [19]		[19]

Build digital services, not websites	A service is something that helps people to do something. Our job is to uncover user needs, and build the service that meets those needs. Of course much of that will be pages on the web, but we're not here to build websites. The digital world has to connect to the real world, so we have to think about all aspects of a service, and make sure they add up to something that meets user needs. [19]		[19]
Be consistent, not uniform	We should use the same language and the same design patterns wherever possible. This helps people get familiar with our services, but when this isn't possible we should make sure our approach is consistent. This isn't a straitjacket or a rule book. Every circumstance is different. When we find patterns that work we should share them, and talk about why we use them. But that shouldn't stop us from improving or changing them in the future when we find better ways of doing things or the needs of users change. [19]		[19]

Make things open: it makes things better	We should share what we're doing whenever we can. With colleagues, with users, with the world. Share code, share designs, share ideas, share intentions, share failures. The more eyes there are on a service the better it gets - howlers are spotted, better alternatives are pointed out, the bar is raised. Much of what we're doing is only possible because of open source code and the generosity of the web design community. We should pay that back. [19]		[19]
Perceivable	Information and user interface components must be presentable to users in ways they can perceive. [37]		[37]
Operable	User interface components and navigation must be operable. This means that users must be able to operate the interface (the interface cannot require interaction that a user cannot perform) [37]		[37]
Understandable	Information and the operation of user interface must be understandable. This means that users must be able to understand the information as well as the operation of the user interface (the content or operation cannot be beyond their understanding) [37]		[37]

Robust	Content must be robust enough that it can be interpreted reliably by a wide variety of user agents, including assistive technologies. This means that users must be able to access the content as technologies advance (as technologies and user agents evolve, the content should remain accessible) [37]		[37]

A.2 Edited Principles of Design

Principle	**Synthesized Description**	**Contributing Sources**
Inclusive Process	in order to design for all the possible users of a product or service, we have to start with inclusive processes. inclusive processes center an individual and meets their needs in a way that respects them, this start with inclusive tools, recruitment and language. Understanding who is normally executed from discussions and why (what biases are there) is a start. This also means that diverse team allow the fulfilment of ”nothing about us with out us”	[23],Inclusive design [23] Recognize Diversity and Uniqueness [24] Transparent [23],Inclusive Process and Tools [24] Inclusive design [25], Created with the people who use and deliver them [25],Prototyped and tested for usability [25]
Human Diversity	when we build we make for humans, and human are diverse in their ways of being,and doing. The context of a user shapes how they interact with your solution and that shapes how they view and use it. Because of this the impact can be different and some groups may have solutions that benefit others but are not commonly uses by thous communities. This has a long legacy in tech as many modalities have been pioneered by Disabled People.	Extend the solution to everyone [62], Solve for one, extend to many [20], Learn from diversity [20],Broader Beneficial Impact [24], Understand context [19],This is for everyone [19], Understand context [19]

Build for Adaptability	it is unlikely that you can easily address all the possible needs of all people, one way of mitigating this is too build in handholds for adaptation and build in a safe breaking. Questions that can help you understand how to build for adaptability are what is truly essential, what are other ways to do this? are there paths build for when the main one is unavailable.	Resilient [23], Provide comparable experience [61] Offer choice [61], Offer different ways to engage [62], Add value [61],Operable [37],Make things open: it makes things better [19],Perceivable [37], Build digital services, not websites [19],Equitably distributed [25] Constancy [94],Be consistent [61] Be consistent, not uniform [19],Robust [37],Operable [37]
Build Good	This is the principle you are most like familiar with, the idea of building clean,safe and efficient solutions. Increasingly this also involves environmentally sound considerations and considerations for the life cycle of a solution.	Finite [23], Respectful [23]Prioritise content [61],Enforce simplicity (in reference to interfaces) [94], Constancy [94],Be consistent [61] Be consistent, not uniform [19],Robust [37],Operable [37],Rigorously tested and evaluated for impact and effectiveness [25] Involve code early [94], Start with user needs [19],Don’t be exact [94], Do the hard work to make it simple [19]

Accessibility	making your product usable with a variety of assistive technologies, and with the commonly understood methods used by Disabled People. In some contexts this also refers to financial access (cost), logistical access (availability), and other kinds of access. All kinds of access compound to determine the accessibility of a solution but without key pillars of access there is no accessibility.	Empowering [23],Give control [61],Ensure people are in control [61]Accessible to all [25]
Look for problems	think about how the solution can brake, or where problems can arises in emergencies. The world beyond development is wide and use and mis-use can shape adoption of a solution.	Thoughtful [23], Recognize exclusion [20],Seek out points of exclusion. [62], Consider situation [61], Identify situational challenges [62], Recognize personal biases [62]

leftover: designing with data, do less. Do less [19] Design with data [19]

A.3 Table of Access Needs

Class	**Conditions**	**Needs**	**Tools**
Visual	Blind, low vision, other kinds of visual impairment and conditions that temporary result in visual impairment or are exacerbated by visual input like migraines	Not all people have the same access to visual information, when conveying information visually, alternatives need to be provided and not use for text but for images and diagrams too. This also means making digital information accessible to screen reader and where possible provide materials with optical character recognition	large print, alternative format, tactic markers, high contrast, Braille, Alt text and Camel case.
Print	Blind and low vision, Learning Disabilities, Intellectual disability[1], Second languages and issues with literacy	Some people will have trouble reading or understanding text information, information will need to be conveyed in another manner.	alternative format documents, audio copies of books or articles, plain language and when possible opportunely for clarification.

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[1] This thesis uses the north American/EU language around intellectual and learning disability. That a intellectual disability is classified by impairment in cognitive functioning and skills and an IQ below 70, in the UK this is referred to as a Learning Disability, where in the rest of the west a learning disability is classified as a difficulty in relating to the processing of information and according to the DSM-5 must have a IQ above 90 (although IQ is in and of its self a deeply flawed marker, it is what is used in the literature).

Sound	Deaf/HOH, APD, Sensory issues, busy spaces	A lot of information is convened via sound and spoken language, make sure that this information is also conveyed in other ways like closed captions, signs that tell the same info, there are also considerations to be made around alarm fatigue and over saturation auditory stimuli, when designing alarm think about priority level and how you translate to visual cues, if information is essential to safety it must be conveyed in other ways (look at visual fire alarms as an example).	captions, sign language interpreters, and visual alarms.
Gross motor	paralysis, amputation, a variety of illnesses	Some people are not able to move their arms, and/or legs to the full range of motion that others can, this can make movement difficult or dangerous, think about not only people using assertive equipment but also thou who can not lift heavy object or do to injury can not lift arms higher then their shoulder.	ramps, larger buttons, elevators, proximity sensors, plug ins for alternative input methods like keyboards and mice, tools are the appropriate height for users (kids, shorter people, wheelchair users, people who can not lift above the shoulders)

Fine motor	Conditions with motor component like Parkinson's, Arthritis, limbs differences	many activities require small movement (like punching keys, handwriting, sewing) this can be compacted for some people and in some contexts, also some may be able to physically able to do an action, but it may result in pain.	option to adapt tools and processes, note takers for filling forms, adapted tools, allow people to use their own electronics, when possible, forms ahead of time, help with fastenings or adapted fastening.
Energy	many illnesses, injures and other conditions like ME/CFS, post surgical recovery period, sleep deprivation duo to insomnia or young kids at home, mental illness	energy both cognitive and physical can be difficult for some, some people have less energy to begin with and others may find task more draining then most, making sure people can conserve or pace their energy means that they can complete tasks safely and with less errors.	minimize the number of steps that need to be done in a row, give accurate time predictions, allow for prep work, minimize standing in lines, offer alternative formats that may make it possible for a person to engage with the work at their own pace and on their own time.
Space for Supports	variety	some people will need extra room to manoeuvre or have support tools, people, and animals.	space designated with options in mind, room to manoeuvre wheelchairs, strollers, service animals.

Competition	ESL, intellectual disabilities, cognitive impairment, APD, neurodivergents, brain fog, post viral syndrome	some people have difficulty understandings the meaning of text, processes and what is required of them in a given place or process	plain language, offering examples, listing steps in points, use formatting well, and a simple question asking process.
Memory	Cognitive impairment, ageing	memory, both working, short and long term can all be impaired in a variety of condition, this can lead to mistakes made, frustration and extra long times to complete a task.	way to verify what info has been given in the past, good signage, check lists, system memory
Attention	Cognitive impairment, neurodiversity like ADHD, situational impairments	not all people using a product will be able to give the same amount of attention to the task, this can be do to internal (focus, neurodiveristy, lack of rest or distraction) or external factors (noise in the environment, responsibilities or distractions)	limit extraneous information, movement (like advertisements) on web pages where text needs to be read is not recommended, good formatting of information.

Privacy	all people deserve a certain amount of privacy to make mistakes and process their part of the task	Disabled People often have their Right to privacy disrespected and the can under mind an individual's enjoyment or ability to get thou a process. Disabled People often have their privacy disregard in when they enter public spaces, and the medical privacy is often more sensitive than non-Disabled People. Make sure that your situation fits the cultural and legal needs of the person.	Statement on what will happen with a person's information in plain language, the opportunity to address errors in a space that private.
Time	Cognitive impairment, ageing, a variety of physical, and non-physical disabilities and impairments both permanent and temporary	time and how we use it can be beneficial and, in some cases incredibly frustrating, thinking about how and when you use timeouts and other time dependent features can increase the utility of a design	where appropriate and possible avoid precise timing essential activities.

A.4 Survey on non-expert perceptions of Disability

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Questionnaire on perceptions of Disability

DESCRIPTION: The following survey is on the topic of disability and aims to gather information about how technologists and designers view and understand disability. You will fill out a short survey consisting of scaled questions and open questions.

TIME INVOLVEMENT: Your participation will take approximately 15-20 minutes.

RISKS AND BENEFITS: There is the potential to be uncomfortable with the questions asked, however you can answer only what you are comfortable with answering. We cannot and do not guarantee or promise that you will receive any benefits from this study.

REQUIREMENTS TO PARTICIPATE: You must be 18 years or older to participate.

PARTICIPANT'S RIGHTS: please understand your participation is voluntary and you have the right to withdraw your consent or discontinue participation at any time without giving any reasons. You have the right to refuse to answer particular questions. You have the right to withdraw consent (within 24 hours) for your data to be used for the research.

The results of this research study will be presented in the final thesis of Laure Tolsma. Your identity will not be made known in written materials resulting from the study.

- All your data will be made anonymous at the earliest possible stage.
- Quotes may be used in the thesis and presentation of the thesis

Thank You in advance,
Laure Tolsma

* Required

Consent and Introduction

1. I have read and understood the study information dated [DD/MM/YYYY], or it has been read to me. I have been able to ask questions about the study and my questions have been answered to my satisfaction. *

   ○ Yes

   ○ No

2. I consent voluntarily to be a participant in this study and understand that I can refuse to answer questions and I can withdraw from the study at any time, without having to give a reason. *

   ○ Yes

   ○ No

3. I understand that taking part in the study involves answering a number of questions considering disability, and the questions are both open and scale based. *

   ○ Yes

   ○ No

4. I understand that taking part in the study involves the following risks: That I may feel uncomfortable with the questions asked *

   ○ Yes

   ○ No

5. I understand that information I provide will be used for the Ms thesis of Laure Tolsma *

○ Yes

○ No

6. I understand that personal information collected about me that can identify me, such as [e.g. my name or where I live], will not be shared beyond the study team. *

○ Yes

○ No

7. I agree that my information can be quoted (anonymously) in research outputs *

○ Yes

○ No

Study contact details for further information: Laure Tolsma, l.d.tolsma@student.utwente.nl

If you have questions about your rights as a research participant, or wish to obtain information, ask questions, or discuss any concerns about this study with someone other than the researcher(s), please contact the Secretary of the Ethics Committee Information & Computer Science: ethicscommittee-CIS@utwente.nl

Demographic information

8. At the time of this survey I am

○ 18 - 25

○ 26- 30

○ 31-35

○ Option 4

Scaled Questions

This section will ask you about disability and your feelings about it?

9. Question

	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
Disability is a test	○	○	○	○	○
Disability is a struggle	○	○	○	○	○
Disability is a medical issue	○	○	○	○	○
Disability is a social problem	○	○	○	○	○
Disability is a minority identity	○	○	○	○	○
Disabled People should be the concern of the government	○	○	○	○	○
Disabled People should be the concern of the charitable Organizations	○	○	○	○	○
Disabled People should be the concern of the employers	○	○	○	○	○

10. Question

	Always	Often	Sometimes	Seldom	Never
I feel inspired when I see Disabled people	○	○	○	○	○
I feel uncomfortable around Disabled People	○	○	○	○	○
I feel that Disabled People have their human rights sufficiently protected	○	○	○	○	○
I feel like I know how to interact with a Disabled People when I meet them	○	○	○	○	○

Open questions

11. What is your definition of disability?

12. When you are asked to design something that you are told a disabled user will use what is your approach?

Thank You for participating in this survey!

If you have any you want to say the box is open below for that

13. Suggestions, comments, queries

A.5 Thematic analysis non-expert definitions

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How do you define disability?

Cognitive, physical or other aspects affecting the way in which a person navigates the world.

A physical or mental difference in how one person interacts with the world versus the societal standard of the location they live.

I myself have a disability so I tend to define it as "A different set of tools and/or concerns for day to day life". It's not so much an identity, burden, or anything else, it's just one thing to consider you know? A person in a wheelchair is living their life, that just so happens to include a wheelchair.

It's the impairment of one or more mental or physical traits to the level that it is considered as higher than normal.

Inability/trouble interacting with things that able bodied people have no issue using

when one or more physical or mental capabilities are restricted

Lack of ability to do certain things that are considered normal by the majority of people, because of either physical or mental deviations of an average person's body and mind

Personally, I think it is a spectrum on a physical level and/or a mental level. People who are disabled are (in my opinion) people who cannot physically/mentally perform everything that most bodies/brains are designed for, and therefore cannot 'naturally' participate in activities most people can. It can involve people that are unable to walk around 'naturally', people that can only move in wheelchairs, or people that are (partially) deaf. It could also involve people that have suffered from mild to severe brain damage, or people that for instance have Down syndrome.

disability is something that impacts how a person experiences the world around them. it often diverges from what is societally or medically defined as typical/normal.

Disability to me means any degree of a debilitating condition which hinder or prevent a person's ability to do certain things that others can.

Unable to do what typical/average people can do either metnally or physically.

Disability is a condition that affects one to function at a standard level of the "norm" that can limit their ability to perform physical or mental tasks.

Not being physically or mentally able to live through the day like an able-bodied person. Needing more help from other people or tools (such as a weelchair or braille).

Impairment to perform a task that is considered "normal" to human beings

A condition that makes it more difficult to activities or interact with the world

A.6 Thematic analysis non-expert approach

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what is your approach?

As a ux researcher i first check the literature and familiarize myself with the disability, what kind of issues they encounter, what kind of solutions they seek, how they would like to be treated (e.g. sometimes a different vocabulary is necessary). Finally, I go to the potential user and gather requirements, test solutions with them.

if it is a specialized product for a specific disability i would likely go to a center where i can speak to many people with various levels of the disability in order to understand what specific needs have to be met. as i likely do not have the disability i am designing for, i believe i would need to closely work with the people that have it. otherwise too many important aspects of the tool may be missed. consulting existing recourses and guidelines may also provide a starting point, but i would not rely on them.

I guess it depends on the medium I am designing in. Since I usually do strictly digital, I'd say verifying accessibility standards (ie colour palette, font size, visual noise, alt text, etc.) at every step. However, I can't say I've ever had to be "told" a disabled user will be interacting with something I design? Maybe this is because in this current wave of design education we've been told plenty of times to make our work accessible, but idk I think everyone can benefit from making thing accessible, it's never a thing I've been I've been forced to do.

Do interviews with the disabled user or observe the disabled user in the user context to get to know the user. Depends on the context what method is used

Co-designed would perhaps work best, if it is for a specific user. Interview the person or their caretaker and ask for their day-to-day struggles and how a (specific) problem could be resolved. Also observe the tools that are already their. When designing for more than one disabled person, interview more.

Honestly it's a pretty wide range so my approach would be broad access then getting rid of friction points. An accessible chair is often better to those with mobility concerns, aging etc, but also the majority of people having a day they're a little sore. Neurological perspectives are harder to design around, as certain trends in a demographic may not or even negatively apply? When in doubt I try to ask people or use previously gathered data from the group in question on common concerns.

I first begin by understanding the specific disability as much as I can, either by speaking with intended users or from secondary sources like online studies.

For physical disabilities, I will try to replicate it during the usability testing process as closely as I can, such as oiling up my hands, binding my arms, blindfolding myself, etc.

For other types of disabilities, I will try to work closely with the intended users for frequent user testing sessions to make sure I'm sufficiently catering to them with my designs.

This all depends on the disability. I would first research the disability, and find out about what the most common disadvantages, misconceptions, advantages, or struggles are. After that I would search for literature on the disability. If it is possible, I would like to interview someone who is disabled and see how they view their disability, focus on the cons and the pros. If I were to design for them I would also ask them to perhaps co-design, since I feel like some people might not see their disability as something that hinders them that much. (But this depends on the disability of course.)

Find research or tips to get to know the target audience, then meet them in person and tlak to help about their experience and incroporate them in the product development phase

For colour impairment, I use patterns to identify different colours. Especially when it comes to tables and graphs. There are plugins that show how these images look like for example with different colour blindness. I would then test the graph to see the visibility and effectiveness. In most cases, there would need to be alt text associated with the images with verbal percentages to explain the graph.

First, I'll try to sympathize and come up with several solutions I think they would benefit from. After I'll talk with people that have that disability if available, else, people who know more about that disability. I'll approach them first with as little own input as I can as not to bias them towards a solution that is inspired by a novice in the specific disability and after cross reference their ideas with mine and their opinion about that. Just continue with a standard co-design approach, I think. Unless the problem is trivial. Then I'll probably just use my own plan and maybe ask for conformation from an expert.

Approach this user, involve them throughout the process of developing the intervention

In web design, usually just complying with AODA. Nothing much beyond that

Personally haven't, but would actively seek out those in that community who I might engage with so I could design with them rather than for them.

I try to include disable people on the design process so they can stir the process to make sure the final product or service is accesible to them. I struggle however to think how I would include people with certain mental disabilities as I believe this process can be violent or uncomfortable for them. I would not know how to tackle design for people with ptsd for example.

A.7 Information brochure- Expert Interviews and Activity

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Information brochure- Interviews and Activity – Disability in technology

Friday, November 11th, 2022

DESCRIPTION: You are invited to participate in a conversation about disability and your approach in how you build/design for it. You have been chosen because you have expertise in a particular disability or condition or because of your work in disability in a policy perspective.

This is part of a research study investigating how people design for the phenomena of disability. The interview will consist of a number of questions followed by an activity where you will be presented with a number of definitions of disability and asked to give your opinion on them.

The questions are about your background in designing for disability, your approach and how you communicate about your target. The conversation will only be recorded by notes taken on paper by the researcher and in no other way captured. In the case of a request by the participant or if public health requires it a digital interview can take place in order to guarantee covid safe environments.

TIME INVOLVEMENT: Your participation will take approximately 45 minutes.

RISKS AND BENEFITS: There is the potential to be uncomfortable with the questions asked because disability is an often-stigmatized topic in society, however you can answer only what you are comfortable with answering.

If you want to skip or stop at any time you can do so without having to give an explanation. If you want to take a break that can also be done at any time. I cannot and do not guarantee or promise that you will receive any benefits from this study.

REQUIREMENTS TO PARTICIPATE: You must be 18 years or older to participate. This is an expert interview, the goal is to talk to people working in spaces around disability, this can be in a design, development, implementation or policy perspective.

PARTICIPANT'S RIGHTS: please understand your participation is voluntary and you have the right to withdraw your consent or discontinue participation at any time without giving any reasons. You have the right to refuse to answer particular questions. You have the right to withdraw consent (within 24 hours) for your data to be used for the research.

The results of this research study will be presented in the thesis and thesis personation of Laure Tolsma. Your identity will not be made known in materials resulting from the study.

- All your data will be made anonymous at the earliest possible stage.
- Your paper copy of the interview will be stored securely.
- Quotes may be used in the thesis and presentation of Laure Tolsma thesis
- Your raw data will be deleted once the graduation project is done. The results of the thematic analyse will be in the presentation and thesis. Thematic analysis is when the interviews are compared and coded over all the available interviews to see patterns and themes
- If you choose, you will be listed in the acknowledgement section under experts interviewed (see the consent section)
- All identifiable data from the interviews will be removed as soon as possible.
- The consent forms will be stored securely and separately from the interviews.

ACCESSIBILITY STATEMENT: If you need or would benefit from accommodation please contact Laure Tolsma. The activity involves a conversation in English. We will also be viewing text on printed paper so if you need an alternative format that can be provided. If you feel you might benefit from reading the questions and definitions before the interview, let Laure know and they will be provided.

If additional information is useful to you do not hesitate to ask.

CONTACT INFORMATION:

Questions: If you have any questions, concerns or complaints about this research, its procedures, risks and benefits, contact the main responsible researcher, Laure Tolsma via email at l.d.tolsma@student.utwente.nl or +31 6 286 99401 or the main supervisor Dr. M. Birna van Riemsdijk : m.b.vanriemsdijk@utwente.nl

Independent Contact: If you are not satisfied with how this study is being conducted, or if you have any concerns, complaints, or general questions about the research or your rights as a participant, please contact the Secretary of the Ethics Committee Computer & Information Science: ethicscommittee-cis@utwente.nl

Appointment Contact: If you have made an appointment and need to change it or want additional information, please contact Laure Tolsma, l.d.tolsma@student.utwente.nl or +31 6 286 99401

Consent form

Friday, November 11th, 2022

Please tick the boxes that apply:

	Yes	**No**
I have been informed in a manner which is clear to me about the nature and method of the study as described in the information brochure “interviews and activity – Disability in technology”. My questions have been answered to my satisfaction.	[ ]☐	[ ]
I agree of my own free will to participate in this study, and understand that I can refuse to answer questions and that I can withdraw from the study at any time, without having to give a reason.	[ ]	[ ]
I give permission for paper notes to be made and used for analysis.	[ ]	[ ]
I give permission for quotes to be included in the thesis and thesis presentation.	[ ]	[ ]

I want my participation to be [ ] anonymous, or [ ] I want to be credited as to my contributions to the research. If you want to be credited please fill in how you want to be referred to here:

____

____

__________________________	____________________	_________
Participant name [printed]	Signature	Date

The extra copy of this consent form is for you to keep.

If you have any complaints about this research, please direct them to the Secretary of the Ethics Committee Information & Computer Science: ethicscommittee-cis@utwente.nl

If you have any questions, concerns or complaints about this research, its procedures, risks and benefits, you may contact the main responsible researcher, Laure Tolsma via email at l.d.tolsma@student.utwente.nl or +31 6 286 99401 .
I have provided an explanation of the research and, to the best of my ability, ensured that the participant understands to what they are freely consenting. I declare myself willing to answer to the best of my ability any questions which may still arise about the research.

__________________________	____________________	_________
Researcher name [printed]	Signature	Date

A.8 Capture Template for Expert Interviews and Activity

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Capture Template for interviews and activity – Disability in technology.

--- **Starting check list**--

- ☐ Information brochure given and reviewed
- ☐ Consent read and signed by interviewer and participant
- ☐ Participant id logged

---**Part 1**---

Question 1: How do you describe or define disability?

Question 2: In what context is your connection to disability? (Do you work with Disabled People? Design for Disability?) if a particular disability, what kind?

Question 3: What kind of language do you use and why?

Question 4: When you are designing what are approaches you use to understand how to build for your target group?

Question 5: When working with collaborators how do you approach discussions around disability/ your target audience?

---**Part 2** ---

Definition 1: ‘A disability is any condition of the body or mind (impairment) that makes it more difficult for the person with the condition to do certain activities (activity limitation) and interact with the world around them (participation restrictions)’

Definition 2: ‘Disability is a way of being that is different then the common understanding of the standard. This difference can be in approaches to human activity's and requires tools and processes to adapted to people’s changing and evolving needs.’

Definition 3: 'Persons with disabilities include those who have long-term 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'

*Participants were given the definitions printed in large fonts on a separate piece of paper along with different colored pens for the annotation. *

A.9 Cards Version 1

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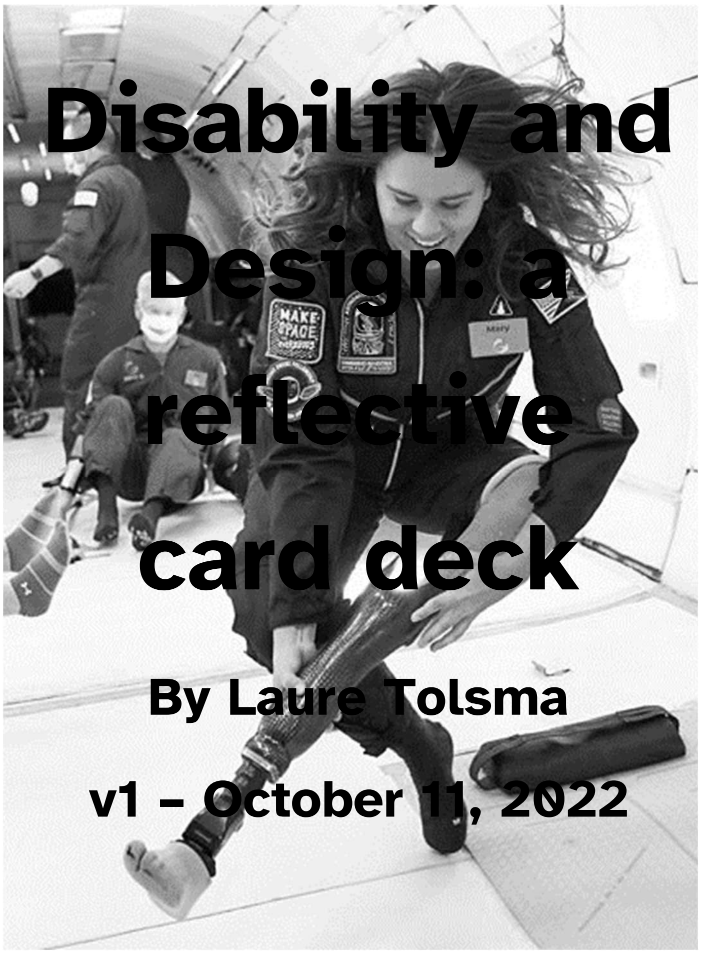

Disability and Design: a reflective card deck

By Laure Tolsma

v1 – October 11, 2022

#1 Welcome v1

Welcome! This card set is to help you explore how to build with disability as a critical lens. Increasingly we are all asked to design more human products and comply with different laws without actually having a deep understanding of disability. This card set will help you explore disability and learn how to practically apply this new knowledge to whatever you're working on. The cards come with an explanation and questions to help you assess the interaction between your project and Disability. Not all cards will be usefull to all projects so use what makes sense for you, your team and your project.

?: Are you ready to get started?

#2 What is Disability? v1

'Disability is a way of being that is different than the common understanding of the standard. This difference can be in approaches to human activities and requires tools and processes to adapted to people's changing and evolving needs.'

This tool kit frames disability not as a lack of ability, but instead as a deficit in a particular ability, this can be as simple as the ability to see the color green or as complicated as the ability to breath without help. When we understand and use more precise abilities we can see all the other abilities and handholds of interaction between a person and the project we are building.

?: What definitions of disability have you heard?

?: How do different definitions shape how we build for disability?

#3 Technology and Disability v1

Technology and disability are interconnected. Disabled people have pioneered many of the technologies we use today and they can offer a perspective on how best to make humane technologies. Many of the tools and interfaces we used today were pioneered by disability communities including texting and shorthand by deaf communities. Audiobooks from the blind and visually impaired communities. When we use the perspective of disability, we can think about what we want to achieve more efficiently and in different ways.

?: What other technologies do you think have origins in disability?

#4 Language v1

Language and how we talk about a topic is important. Words shape our interactions with each other and can signal respect or disrespect. Disabled people and people with the disability are both respectful terms that don't hide what a person is experiencing. In conversations around disability there are euphemisms that although well-intentioned they can make it difficult to be all on the same page. Phrases like “people with an exceptionality”, “special needs”, and “special people” should not be used if disability can be used. But it is also a good idea to match and respect the language people already use.

?: What language have you used in the past and who did you mean when you used it?

?: If you speak a second language, what is “disability” directly translated? How does that make you feel?

#5 Disability Dongles v1

Disability dongles is a term coined by Liz Jackson and Alex Haagaard, they call it “A well-intended elegant, yet useless solution to a problem we never knew we had…” with this they mean that good intentions alone will not build equitable or just solutions. Too often the insights and perspective of disability are disregarded and this results in products and systems that don’t solve but exacerbate the problems they aim to address.

?: How can you include Disabled People the space, to critic the design, without placing limitations or qualifications on their option?

?: Does your project build on or work with AT, practices and accommodations?

?: If developed for a specific disability does it work with multiple disability's?

#6 Who do we design for? v1

Who we think we are designing for shapes what gets developed, often we have personas or target users but without articular and well-rounded templates for disability and how it effects how people use and benefit from a project.

?: Are the groups or community that you want to design for more closely? Why?

?: Is there power balance in your outreach methods?

#7 Disability Pride v1

Disability is a complicated identity, it is marked in part by pain and struggle but also by care, adaption and unique experiences. A person can accept their disability, love the way it shapes them and actively hope that no one else experiences it. A quote by Emily Ladau distils this resilience, joy and perspective. “There is nothing that needs to be changed about my state of being. There is nothing I want to change. I am a whole human being whose body moves forward through life in turns of the wheel, and my reality is not for anyone else to decide."

?:What are the dialogs you have around disability?

?: How do you view disabilities that can not be solved?

#8 Invisible vs Viable v1

Not all disabilities can be seen from the outside, some are signaled by assistive technology, unique features, limb differences, distinct mannerism or ways of moving but not all are. Some have none of the markers listed, some disabilities are from birth, others are acquired by illness, injury or appear later in life. Some of the most prevalent deficits or features are not visible like pain and fatigue.

?: How does your project identify or support people who ask for additional support?

?: When does a need become a disability?

#9 Dis-hist and Technology v1

Lots of the technologies we use today are where developed from the perspective of Disability. If you frame disability as needing support with certain activities or in given environment it makes sense that disability has fueled many technologies as the needs of disabled people are explicit and often ask for new ways of solving problems. Often technologies (for better or worse) are first applied to Disabled People, and even when that is explicate understood the attitudes can be paternalistic or with normative aims

?: Does your technology support Disabled People with what they want to do or make it easier for a system to manage them?

?: How visible is disability and its contributions?

#10 Dis-future v1

How we see the future shapes what we imagine is possible. If we think technology will eliminate disability, we will build inaccessible tools. If with think technology will enable disabled people, will we build that technology and systems to work with that technology and disabled ppl. As medicine gets better at keeping people alive, we will have more (not less) disabled ppl working, play and living in the systems we build. Our collective definition of disability may change but humans will keep being wonderfully diverse and in need of care and connection.

?: Does your future speculation include diversity and disabled ppl?

?: Does the media you consume show human diversity?

#11 Empathy v1

In this kind of work we are often asked to have Empathy. And this can be an incredible tool but true Empathy is time consuming and requires space and energy. It can be overwhelming to feel what others feel or even a fraction of that. It can also give us a false understanding, misunderstanding or pity. We don’t always have to understand or feel the same but we do have to listen.

?: Do you have the time to give the conversations the respect they deserve?

?: is the emotional labor evenly divided and properly compensated?

?: are you asking for vulnerability in order to build empathy?

#12 Intersectionality v1

The intersections (overlaps) between different Identities and how the world sees them shapes how a person experiences an environment, system or product. They may mitigate vulnerabilities or exacerbate them in seen and unseen ways.

?: What are the costs, where are they beared and where can they be beared with the lowest ill effect?

?: Are there intersections that are more vulnerable in your project?

#13 Spectrums v1

Most if not all disabilities exist on spectrums. Spectrums of severity, needs, and skills. These spectrums often change over a personal life time and for some on shorter team scales. That also means that what one person with a particular disability or condition needs or presents is what that person needs and does not necessarily what all people with that condition need.

?: What spectrums do you exist on?

?: What spectrums do you know?

#14 Laws v1

There are in most countries laws in place with the goal of increasing the accessibility of public service and spaces to disabled people. These laws shape what can be brought to market and gives Disabled people an opportunity to address in accessibility thou the law. The laws are based on best practices so they are closer to bare minimums then gold standard and in the spaces of emerging technologies they may provide little guidance.

?: What are the laws in your region?

?: Are there best practices outside of the laws that can guide you?

?: Are the laws in your industry new and what can they be missing?

#15 Data and AI v1

Data and AI are increasingly used to make decisions, shape technology and classify people. They encode bias in a from that may be harder to uncover and cause harm to people (especially from marginalized groups).

?: What are the possible harms of mis-classification or mis-identification?

?: How can errors be flagged and corrected?
?: Who can report errors?

?: What bias are being built in to your data sets or algorithms?

#16 Access to public space v1

Access to public space is for most people a given, we assume that when we enter a library, a shop, a museum or a school that that environment will be safe and accessible to us. However, if your access needs are not meet you may feel unwelcome, you may have to limit your time in that space or not be able to participate in public life fully. When we build inaccessible environments or systems, we limit the spaces that disabled people occupy, thus limiting the spaces we think they belong in. This can limit the number of disabled people we see, making us think that disabled people don't exist or belong in thus spaces, and so a cycle of exclusion builds till we underestimate the ubiquity of disability.

?: How are you making sure to not undermine Disabled peoples access to public space?

#17 Stigma v1

The stigma around disability makes us underestimate how normal and common disability is. It also makes addressing our needs and the needs of others difficult, since there are no honest conversations about what is needed and what is possible. Language and how we feel about language can be confusing and can complicate conversation.

?: What words are you using in currently dialogs?

?: Are the conversations you are having about disability clear, appropriate and approachable?

#18 Assistive technology (AT) v1

Assistive technology (AT) is any item, piece of equipment, software program, or product system that is used to increase, maintain, or improve the functional capabilities of persons with disabilities. Both hi and low tech these tools are important to the functioning and safely of disabled people. Examples are hearing aids, wheel chairs, AAC, glasses, screen readers, headphones, support braces,

?: How does your project interactive with different kinds of AT?

?: How can you support peoples use of their AT?

#19 Acess vs Accessibility v1

When people go to use a tool, object or system there are 2 ways it can fail them before they even get started. One is a lack of access and the other is that it is inaccessible. Theses 2 are often confused but acess is more about a lack of practical “hand holds” for use, ie that the tool does not meet the skills they have available. The other is a failure in expectations, that the people who built the project are not expecting certain kinds of people to use the thing they built. For a project to be truly accessible both need to be meet.

?: Are your users descriptions normative?

?: Who are you expecting to not be using your product? Why?

#20Vulnerability vsSusceptibility v1

Often in conversations about disability and other potentially vulnerable groups there's the idea of vulnerability but not an understanding of susceptibility. There are certain factors could that make people more susceptible to certain kinds of Harms and these cannot be changed only mitigated. We have conversations about vulnerability we don't often understand or highlight what is unchangeable and what we make. We cannot change an individual susceptibility to a particular harm but we can change their vulnerability by avoiding exposing them to that harm and building systems that don't expose them to that harm.

?: What are some variabilities and Susceptibility in your project?

?: How can you mitigate them and be aware before they do damage?

#21 What are Access Needs? v1

We all have access needs. Access needs are what you need to safely and comfortably complete tasks in a given environment. They can look like adequate lighting, written materials in your language or stairs to get into building. Disabled peoples access needs are the same but for their brains and their bodies. The following cards will give concrete examples of possible different kinds of access needs, the tools we can use to address people's access needs and examples of conditions where these access needs are more prevalent.

?: What access needs are relevant for your project?

?: What are your acess needs?

?: How can the tools listed on each card be adapted to fit your project and the acess need?

#22 Visual Acess Needs v1

Not all people have the same access to visual information, when conveying information visually, alternatives need to be provided. Not only for text but for images and diagrams too. This also means making digital information accessible to screen reader and
where possible provide materials with optical character recognition.

Tools: large print, alternative format, tactic markers, high contrast, Braille, Alt text, in-depth disruptions of products/product images and dark mode.

Conditions: Blind, low vision, other kinds of visual impairment and conditions that temporary result in visual impairment or are exacerbated by visual input like migraines.

#23 Print Acess Needs v1

Some people will have trouble reading or understanding text information. Information will need to be conveyed in another manner. This is especially true when safely, legal or other important information is being conveyed. This is like visual acess needs but some people have more specific needs around text.

Tools: alternative format documents, audio copies of books or articles, plain language and when possible opportunely for clarification, Came Case.

Conditions: Blind and low vision, Learning Disabilities, Intellectual disability, Second languages and issues with literacy.

#24 Sound Acess Needs v1

A lot of information is convened via sound and spoken language, make sure that this information is also conveyed in other ways like closed captions, signs that tell the same info, there are also considerations to be made around alarm fatigue and over saturation of auditory stimuli. When designing alarms think about priority level and how you translate to visual cues, if information is essential to safety, it must be conveyed in other ways (look at visual fire alarms as an example).

Tools: captions, sign language interpreters, vibration alarms, and visual alarms

Conditions: Deaf/HOH, APD, Sensory issues, busy spaces.

#25 Gross motor Acess Needs v1

Some people are not able to move their arms, and/or legs to the full range of motion that others can, this can make movement difficult or dangerous, think about not only people using assertive equipment but also, thou who cannot lift heavy object or due to injury cannot lift arms higher than their shoulder.

Tools: ramps, larger buttons, elevators, proximity sensors, plug ins for alternative input methods like keyboards and mice, tools are the appropriate height for users (kids, shorter people, wheelchair users, people who can’t lift above the shoulders).

Conditions: paralysis, amputation, a variety of illnesses, broken limbs, cerebral palsies.

#26 Dexterity and grip strength Acess Needs v1

Many activities require small movement (like punching keys, long hand writing, sewing) this can be compacted for some people and in some contexts, also some may be able to physically able to do an action but it may result in pain.

Tools: option to adapt tools and processes, note takers for filling forms, adapted tools, allow people to use their own electronics when possible, forms ahead of time, help with fastenings or adapted fastening.

Conditions: Conditions with motor component like Parkinson's, Arthritis, limbs differences.

#27 Energy Acess Needs v1

Energy both cognitive and physical can be difficult for some, some people have less energy to begin with and others may find task more draining then most, making sure people can conserve or pace their energy means that they can complete tasks safely and with less errors.

Tools: minimize the number of steps that need to be done in a row, give accurate time predictions, allow for prep work, minimize standing in lines, offer alternative formats that may make it possible for a person to engage with the work at their own pace and on their own time.

Conditions: many illnesses, injures and other conditions like ME/CFS, post-surgical recovery period, sleep loss duo to insomnia or young kids at home, mental illness.

#28 Space for Supports Needs v1

Some people will need extra room to maneuver or have support tools, people and animals. Give them that space.

Tools: space designated with options in mind, room to maneuver wheelchairs, strollers, and service animals.

Conditions: new parents, wheelchairs users, mobility aid uses.

#29Comprehension Acess Needs v1

Some people have difficulty understandings the meaning of text, and processing what is required of them in a given place or process.

Tools: plain language, offering examples, listing steps in points, use formatting well, and a simple question asking process.

Conditions: ESL, intellectual disabilities, cognitive impairment, APD, neurodivergent, brain fog, post viral syndrome.

#30 Attention Acess Needs v1

Not all people using a product will be able to give the same amount of attention to the task, this can be due to internal (focus, neurodiversity, lack of rest, or distraction) or external factors (noise in the environment, responsibilities or distractions)

Tools: Plan language, limit extraneous information, limit movement (like advertisements) on web pages where text needs to be read, good formatting of information.

Conditions: Cognitive impairment, neurodiversity like ADHD, situational impairments

#31 Privacy Needs v1

Disabled People often have their Right to privacy disrespected and this can undermine an individual’s enjoyment or safety. Disabled People often have their privacy disregard when they enter public spaces and the medical privacy is often more sensitive then non-Disabled People. Make sure that your situation fits the cultural and legal needs of the persons. Privacy also serves a protective function from discrimination which Disabled People are often at heighten risk for.

Tools: Statement on what will happen with a person’s information in plain language, the opportunity to address errors in a space that private, proper cybersecurity.

Conditions: All people deserve a certain amount of privacy to make mistakes and process their part of the task.

#34 Time Needs v1

Time and how we use it can be beneficial and, in some cases, incredibly frustrating. Thinking about how and when you use timeouts and other time dependent features can increase the utility of a design. There is also opportunity that comes from structuring time asynchronously, this means that people who have fluctuating time and energy available can still benefit form your project.

Tools: Where appropriate and possible avoid precise timing essential activities. For games an accessibility menu where people can change how they play the game is a common solution

Conditions: Cognitive impairment, ageing, a variety of physical, and non-physical disabilities and impairments both permanent and temporary.

#35 Sensory needs v1

A person's sensory needs are often tied to their neurology. These needs are tied to the environment that that person is in and are related to the senses (sight, sound, smell, taste, texture) and when the sensory needs are not meet the results are overstimulation, under-stimulation.

Tools: allowing for personal adaptations like headphones, sunglasses and AT. If you are going to require mandatory uniforms or other personal level equipment, make sure it meets the users' needs or can be adapted, sensory experiences that are neutral and non-taxing (think of all the senses)

Conditions: ASD, other neurodiversity's, migraines

#36 Principles v1

Principles are a common tool in design, they help us to understand our shared values and help guild designs and projects. The following cards outline possible principles inspired by universal design. They center disability and aim to reflect our human needs with the aim of humanin technologies.

#37 Inclusive Process v1

In order to design for all the possible users of a product or service, we have to start with inclusive processes. Inclusive processes center an individual and meets their needs in a way that respects them, this starts with inclusive tools, recruitment and language. Understanding who is normally executed from discussions and why (what biases are there) is a start. This also means that diverse team allow the fulfilment of "nothing about us without us"

?: How can we highlight disabled voices?

?: What does representation look like to you?

?: Are peoples acess needs meet in your interactions with them?

#38 Human Diversity v1

When we build, we make for humans, and human are diverse in their ways of being, and doing. The context of a user shapes how they interact with your solution and that shapes how they view and use it. The users, end use, and context will be different for each person who interacts with your project.

?: How can we respect the diversity of human using?

#39 Build for Adaptability v1

It is unlikely that you can easily address all the possible needs of all people, one way of mitigating this is to build in handholds for adaptation and build in a safe breaking. Questions that can help you understand how to build for adaptability are what is truly essential, what are other ways to do this? are there paths build for when the main one is unavailable.

?: How does it brack?

?: what are possible critical errors?

?: how appropriable is it?

#40 Build Good v1

This is the principle you are most like familiar with, the idea of building clean, safe and efficient solutions. Increasingly this also involves environmentally sound considerations and considerations for the life cycle of a solution. A consideration that is relevent for disability is that of breaking and end of use, learing new tools can be more difficult for disabled people and if that product is essential then you need to make sure it fails safely too.

?: What does the end of life cycle look like?

?:Can it be safely broken, and adapted?

#41 Accessibility v1

Making your product usable with a variety of assistive technologies, and with the commonly understood methods used by Disabled People. In some contexts, this also refers to financial access (cost), logistical access (availability), and other kinds of access. All kinds of access compound to determine the accessibility of a solution but without key pillars of access there is no accessibility.

?: How does this work with AT?

?: What are the costs both running and starting?

#42 Look for problems v1

Think about how the solution can break, or where problems can arise in emergencies. The world beyond development is wide and use and mis-use can shape adoption of a solution.

?: How can you minimize misuse without placing more burden on vulnerable users?

#43 Biases v1

Biases are built in to the tools and methods we use every day but being aware of them can help us combat them. There are many bias that are not listed like race (racism), gender (sexism and misogyny), gender expression (heteronormativity), age (ageism), access to financial resources, sexual orientation, religion, immigration status, and national origin. Instead, the cards talk about bias that in part make up ableism (discrimination in favor of non-disabled people and against disabled people), so that you can keep an eye out for them, bias come from our society and are often not an active refection of the values we hold, having bias do not make us bad people, designers or technologist, they however do shape what we make so awareness can be a tool in building more humane.

#44 Normative bias v1

Normative bias is based on an assumption that the default body is that of a non-disabled white young adult cisgendered heterosexual man. This means that disabled people, women, racialized communities, the elderly and anyone who's being or characteristics fall outside of that assumed normal are often not built and designed for. This bias is also prevalent in data and non-human decisions.

?: What are the assumptions you are making about who will use the project?

?:How many perspectives are at the table, are all voices given space to talk and be critical?

#45 Rarity bias v1

Rarity bias is the idea that disabled people simply aren't that common. This is part of a long legacy of many factors, to name a few, a lack of representation in media, the effects of access to public space, and that many disabilities have no visual markers. This is often exacerbated by ableism and the other listed bias limiting the interaction between disabled and non-disabled people in schools, workplaces and public space.

?: What percentage of your users are you expecting to be disabled? Are your numbers in line with the percentage of disabled people in your region or country?

#46 Gratefulness bias v1

This bias comes from a place of paternalism, it is an assumption that disabled people should be grateful for the care and health that they get and that anything is better than nothing. it clouds our ability to be critical of the things we built in relationship to disability and lead to disability dongles.

?:How can you make sure that disabled voices are heard and respected? Even the Critics?

#47 Infantilization bias v1

Infantilization bias places disabled people any submissive position it devalues their perspectives and insight, their intelligence their capabilities and their capacities. It manifests when people use baby talk to grown adult disabled people and these are often considered insulting.

?: What are the assumptions are you making about an individual's capacity?

?: How can you avoid overriding disabled persons decisions?

#48 Exploitation Inspiration bias 1

Exploitation inspiration is a phenomenon where disabled people are used simply as a tool instead of being full human beings. Their successes and failures are situated simply as examples to non-disabled people. This bias is incredibly prevalent in the media we consume and shows up in phrases like “at least you are not disabled” and “if they can do it you can too” the bias is often removes the agency and nuance of disabled people and their lives and experiences.

?: Are you showing disabled people fully or are you using their images and stories to further your agenda?

#49 Models v1

The way we see disability is shaped by many factors, your first experience with disability, your past interactions, the media you consume and social, cultural and religious factors. Often, we have storyline about disability, what it means, how it happens and how we need to interact with it that are different for everyone. They shape our reactions and interactions and when they mismatch with the models that others have it can make it difficult to work together on problem solving. Sometimes the models we have do not match with the values we hold which can make it hard to talk about the issues. In the next few cards some common models will be described. This is to help you identify the model you hold but not to dictate the one you use. They all have pros and cons.

#50 Religious model v1

This Model see disability as an act of God. Either a punishment or a lesson to that person or their family/community. This means that disabled people's lives are often seen as a pity or inspiration.

?: How does this model interact with medicine ?

#51 Medical model v1

The medical model sees disability as a flaw in the human body to be cured or given a life as "normal" possible. This situates disability as something a doctor sees and not as a human experience, this can make it hard to find ways to support disability outside of medical intervention.

?: Do you need a medical diagnostics? Why?

?: Do you listen to medical institutions over disabled people?

#52 Social model v1

This model situates disability as an issue in how society treats disabled people. It sees disability as a limitation on people thou there social and physical environment. This works well for sensory, physical and visible disabilities but less well for chronic illness, painful conditions and invisible illnesses. This model allows for there to be a world in where disabilities can be accommodated in to no longer being an "issue" for that Disabled Person. It is commonly used in spaces like laws, schools/educational mandates and policy.

?: What is the role of social accommodation in your project? What are the limits and costs to that approach?

#53 Mismatch model v1

This is a model developed for design and designers. It situates disability as a mismatch between a personas body and the environment. This model can be especially usefull when talking about temporary disabilities. However, this model leads to a definition of disability that can be solved via an intervention, it lives in a space were solving in implied and this definition does not identify of offer a handle to tackle disability's that are not "solvable".

?: What can technology and design "solve" and what is beyond its reach?

#54 Superpower model v1

The superpower model of disability looks at disability as a super power, it's the model we most often seen in advertainment and film. It frames disability not for disabled people but for non-disabled people. This also frame disability as something that one can be good at and as an inspiration. As a side effect it makes it almost impossible for Disabled People to be ordinary members of society, it sets standers that are "superhuman" and eliminates space for nuance. This model is also often criticized to be damaging to a disabled persons social and personal development

?: What are possible side effects of requiring exemptional for participation?

#56 Human Rights model v1

The model views disability inclusion and care as a human right. Like the social model it frames disability as a social phenomenon. It places independence as a key goal and legal structures as a path to that goal. It identifies sources of oppression and can be useful when combined with other lens or models. The model is foundational in the policy spaces such as The United Nations Convention on the with Disabilities as the foundation for many countries approaches to disability and the law.

?: Do the laws we have right now provide enough information or do you need another model to help you design?

#58 Charity model v1

This model places the care of Disabled People as a charitable option, this can make it hard to advocate for business cases and makes it sound optional. It also often has paternalistic side effects, as well as being pity, it is Othering and limits the agency and autonomy of Disabled People. It is widely regarded as a deeply ablest model and is linked to eugenics by promoting the lives of Disabled People as lesser then non-disabled People. This model is not positively reserved by disability rights community's and limits the business case for disability.

?: What happens to Disabled People when things get hard?

?: Does this model intersect with the rarity bias?

#59 Economic model v1

This model frames disability as a defect in economic productivity. This model can make the cost and benefit of accessible or universal design look only economical. Although there are cost to both disability and inaccessibility, they are often hidden in ways that are not easily added to a spread sheet. Since a majority of development and products are coming out of entity's that have an economic obligation it is import to not under estimate the effects of this model on the perceptions of disability.

?: Does capitalism often guide us to the best for all people outcomes?

#60 Other models v1

The models discussed above are predominantly western in origin but disability exists in every cultural on earth. The role of community vs individually manifests differently in different cultures and this, in turn, has implications for the treatment of disability and the role of community. Given the interpersonal nature of disability it is important to remember that different cultures and languages have different approaches and that they may provide insights as to how to think about disability and how it works within our systems and what we build.

?: What other models might be useful to you?

?: How can you define your own model?

Ways to use the cards v1

The cards can be used in many ways, cards 1-20 can be used without a use context to ground and start conversations about disability or for self-study.

Cards 21 to 32 can be used with a project to see if common acess needs are being met, picking up 2 acess needs you can then get a feel for the interaction between multiple disability and a project.

Cards 36 to 42 can help you develop your own principals.
And cards 43 to 48 can help highlight possible bias that may be encoded solutions or tools you are already familiar with.

Cards 49 to 60 are few of the models (storylines) we have around disability, its role and its impacts.

Tips v1

Defaults need to be accessible customizations don’t.

Play to the strengths you have, use the acess holds that already exist to help you fill the acess gaps you find.

Practical solutions promote adoption, lower cost and avoid disability dongles.

Law suits are expensive and implementing wide spread changes after production will always be more costly then employing a critical perspective early on.

Thank You v1

The font used in the card set is Atkinson Hyperlegible by the Braille Institute.

If you want to add you own cards to your deck the card size is that of A6 so folding a A4 page in quarts allows you to easily add your own.

This card set is part of the Ms thesis of Laure Tolsma, feel free to contact her for more information and resources.

A.10 Cards Version 2

Print out begins on next page.

Disability and Design: an exploration card deck

Disability and Design: an exploration card deck

Welcome! This card set is to help you explore how to build with disability as a critical lens. Increasingly we are all asked to design more human products and comply with different laws without actually having a deep understanding of disability. This card set will help you explore disability and learn how to practically apply this new knowledge to whatever you're working on. The cards come with an explanation and questions to help you assess the interaction between your project and Disability. Not all cards will be usefull to all projects so use what makes sense for you, your team and your project.

?: Are you ready to get started?

Naming the discomfort

Disability and ableism are everywhere, but often in an unnamed ways, it can be uncomfortable to talk about disability. And this is for lots of reasons, stigma, the fear of saying something wrong, identifying weakness and asking help. So many reason that can make it hard and that’s ok, to do the work of making your outcomes less ableist takes time, energy and will involve mistakes. It can be hard to look back on mistakes and talk about them with honestly. Its ok to be uncomfortable, or uneasily since this is a kind of work that most of us do not do often. Be patient with yourself and your team and know that its ok to step back and take a moment.

Foundations | 1

What is Disability?

This tool kit frames disability not as a lack of ability, but instead as a deficit in a particular ability, this can be as simple as the ability to see the color green or as complicated as the ability to breath without help. When we understand and use more precise abilities, we can see all the other abilities and handholds of interaction between a person and the project we are building. But what is disability? The next 3 card split it in to 3 parts, the social, the mind body and how it is enacted.

?: What definitions of disability have you heard?

?: How do different definitions shape how we build for disability?

Foundations | 2

Disability as a (social) phenomena

When we look at disability as a phenomena (both socially and politically) we can see that to be disabled means way that you are expected to act in the world and a way that the world interacts with you. This understanding of disability is framed by interpersonal relationship, expectations and social connotations around limits and worth. Someone can be more limited by the perception of their disability then their own mind body, another can be more limited by their mind body then is understood by their community or environments. There are social and politic expectations that sometimes overlap with the mind-bodies of Disabled people and times where there is a deep mismatch.

?: What are the expectations you see others having for disabled people?

The mind-body in disability

Outside of social interactions and the political we can also see disability as a way of being, this lens can tell us more about how we practically design for disability but the phenomena tells us what it means to design for disability. Individual mind-bodies are what is disabled, they are the lens that we need to look at systems and tools from. Mind-bodies and their experiences overlap but cannot be transferred. They can show us the practical adaptations that are needed and give us a logistical understanding of how a condition manifests in a given environment. Any thing that a body can do it can fail to do or need help doing.

What does it mean to be disabled?

To be the labeled or understood as disabled can give normative and ablest assumptions about not what only that person is capable of but what that person should be doing. There is often a bias towards cure regardless of the cost, the efficacy or the possibility of that cure. There are assumptions about what kinds of spaces disabled people are allowed to be in, what kinds of jobs they have, what kinds of needs they have, and what kinds of wants that they have. Many different models can actually be harmful because they make assumptions that aren't always true and sometimes those assumptions limit what disabled people get to do safely.

What disability can tell us about technology

Technology and disability are interconnected. Disabled people have pioneered many of the technologies we use today and they can offer a perspective on how best to make technologies. Many tools and interfaces were pioneered including texting and shorthand by deaf communities and Audiobooks from blind and visually impaired communities. When we use the perspective of disability, we can think about what we want to achieve in different ways. If you frame disability as needing support with certain activities or in given environment it makes sense that disability has fueled many technologies as the needs of disabled people are explicit and often ask for new ways of solving problems. Often technologies (for better or worse) are first applied to Disabled People, and even when that is explicitly understood the attitudes biased

?: What other technologies do you think have origins in disability? **?:** Does your technology support Disabled People with what they want to do or make it easier for a system to manage them? **?:** How visible is disability and its contributions?

Variety within disability and how it shapes our language

Language and how we talk about a topic is important. Words shape our interactions with each other and can signal respect or disrespect. Disabled people and people with disabilities are both respectful terms that don't hide what a person is experiencing. In conversations around disability there are euphemisms that, although well-intentioned, can make it difficult to be all on the same page. Phrases like “people with an exceptionality”, “special needs”, and “special people” should not be used if disability can be used. But it is also a good idea to match and respect the language people already use.

?: What language have you used in the past and who did you mean when you used it?

?: If you speak a second language, what is “disability” directly translated? How does that make you feel?

Disabled people and people with the disability. The language of curative possibility

1 of the questions is which is better disabled people or people with disabilities. One invokes a kind of curative possibility the other less so, disabled people insinuates that the disability well not go away and that it is part of who that person is now. people with disabilities separates the person from their disability. and depending on the experience of the individual one is going to be preferred. Some people have a history with trying to be “cured” and this can bring back painful memory which can change how disabled person feels about an interaction and especially when we're trying to build spaces of dialogue this can put us back more than it can put us forward.

Disability Dongles

Disability dongles is a term coined by Liz Jackson and Alex Haagaard, they call it “A well-intended elegant, yet useless solution to a problem we never knew we had...” with this they mean that good intentions alone will not build equitable or just solutions. Too often the insights and perspective of disability are disregarded and this results in products and systems that don’t solve but exacerbate the problems they aim to address.

?: How can you include Disabled People the space, to critic the design, without placing limitations or qualifications on their option?

?: Does your project build on or work with AT, practices and accommodations?

?: If developed for a specific disability does it work with multiple disability's?

Who do we design for?

Who we think we are designing for shapes what gets developed, often we have personas or target users but without articular and well-rounded templates for disability and how it effects how people use and benefit from a project.

?: Are the groups or community that you want to design for more closely? Why?

?: Is there power balance in your outreach methods?

Disability Pride

Disability is a complicated identity, it is marked in part by pain and struggle but also by care, adaption and unique experiences. A person can accept their disability, love the way it shapes them and actively hope that no one else experiences it. A quote by Emily Ladau distils this resilience, joy and perspective. “There is nothing that needs to be changed about my state of being. There is nothing I want to change. I am a whole human being whose body moves forward through life in turns of the wheel, and my reality is not for anyone else to decide." Although disability may often be marked by pain it also deeply full of joy and possibility. Disability pride is often in opposition to people who so deeply devalue disabled lives that they are often the targets of pity and eugenics.

?:What are the dialogs you have seen around disability?

?: How do you view disabilities that cannot be solved or cured?

Invisible vs Visible

Not all disabilities can be seen from the outside, some are signaled by assistive technology, unique features, limb differences, distinct mannerism or ways of moving but not all are. Some have none of the markers listed, some disabilities are from birth, others are acquired by illness, injury or appear later in life. Some of the most prevalent deficits or features are not visible like pain and fatigue.

?: How does your project identify or support people who ask for additional support?

?: When does a need become a disability?

?: Does your identification model privilege some disabilities over others?

Dis-future

How we see the future shapes what we imagine is possible. If we think technology will eliminate disability, we will build inaccessible tools. If with think technology will enable disabled people to live and thus there will be more, not less, disabled people, we will we build that technology and systems to work with disabled people. As medicine gets better at keeping people alive, we will have more (not less) disabled people working, play and living in the systems we build. Our collective definition of disability may change but humans will keep being wonderfully diverse and in need of care and connection.

?: Does your future speculation include diversity and disabled people?

?: Does the media you consume show human diversity?

Empathy

In this kind of work we are often asked to have Empathy. And this can be an incredible tool but true Empathy is time consuming and requires space and energy. It can be overwhelming to feel what others feel or even a fraction of that. It can also give us a false understanding, misunderstanding or pity. We don’t always have to understand or feel the same but we do have to listen.

?: Do you have the time to give the conversations the respect they deserve?

?: Is the emotional labor evenly divided and properly compensated?

?: Are you asking for vulnerability in order to build empathy?

Intersectionality

The intersections (overlaps) between different Identities and how the world sees them shapes how a person experiences an environment, system or product. They may mitigate vulnerabilities or exacerbate them in seen and unseen ways. We often talk about vulnerable people, marginalized and those at risk with out understanding why they are politically situated like that. We also do not often understand the steps we need to take to address there are unequal risk for discrimination

?: What are the costs, where are they beared and where can they be beared with the lowest ill effect?

?: Are there intersections that are more vulnerable in your project?

Spectrums

Most, if not all, disabilities exist on spectrums. Spectrums of severity, needs, and skills. These spectrums often change over a personal life time, and for some, on shorter team scales. That also means that what one person with a particular disability or condition needs or presents as is what that one person needs and does not necessarily what all people with that condition need.

?: What spectrums do you exist on?

?: What spectrums do you know?

Laws

In most countries laws in place with the goal of increasing the accessibility of public service and spaces to disabled people. These laws shape what can be brought to market and gives Disabled people an opportunity to address inaccessibility thou the law. The laws are based on best practices and evolving understanding so they are closer to bare minimums then gold standard and in the spaces of emerging technologies they may provide little guidance.

?: What are the laws in your region?

?: Are there best practices outside of the laws that can guide you?

?: Are the laws in your industry new and what can they be missing?

Data and AI

Data and AI are increasingly used to make decisions, shape technology and classify people. They encode bias in a from that may be harder to uncover and cause harm to people (especially from marginalized groups).

?: What are the possible harms of mis-classification or mis-identification?

?: How can errors be flagged and corrected? **?:** Who can report errors?

?: What bias are being built in to your data sets or algorithms?

Access to public space

Access to public space is for most people a given, we assume that when we enter a library, a shop, a museum or a school that that environment will be safe and accessible to us. However, if your access needs are not meet you may feel unwelcome, you may have to limit your time in that space or not be able to participate in public life fully. When we build inaccessible environments or systems, we limit the spaces that disabled people occupy, thus limiting the spaces we think they belong in. This can limit the number of disabled people we see, making us think that disabled people don't exist or belong in thus spaces, and so a cycle of exclusion builds till we underestimate the ubiquity of disability.

?: How are you making sure to not undermine Disabled peoples access to public space?

Stigma

The stigma around disability makes us underestimate how normal and common disability is. It also makes addressing our needs and the needs of others difficult, since there are no honest conversations about what is needed and what is possible. Language and how we feel about language can be confusing and can complicate conversation.

?: What words are you using in currently dialogs?

?: Are the conversations you are having about disability clear, appropriate and approachable?

Assistive technology (AT)

Assistive technology (AT) is any item, piece of equipment, software program, or product system that is used to increase, maintain, or improve the functional capabilities of persons with disabilities. Both hi and low tech these tools are important to the functioning and safely of disabled people. Examples are hearing aids, wheel chairs, AAC, glasses, screen readers, headphones, support braces, and other tools both medical and non-medical in origin.

?: How does your project interactive with different kinds of AT?

?: How can you support peoples use of their AT?

Acess vs Accessibility

When people go to use a tool, object or system there are 2 ways it can fail them before they even get started. One is a lack of access and the other is that it is inaccessible. Theses 2 are often confused but acess is more about a lack of practical "hand holds" for use, ie that the tool does not meet the skills they have available. The other is a failure in expectations, that the people who built the project are not expecting certain kinds of people to use the thing they built. For a project to be truly accessible both need to be meet.

?: Are your users descriptions normative?

?: Who are you expecting to not be using your product? Why?

Vulnerability vs Susceptibility

Often in conversations about disability and other potentially vulnerable groups there's the idea of vulnerability but not an understanding of susceptibility. There are certain factors could that make people more susceptible to certain kinds of Harms and these cannot be changed only mitigated. We have conversations about vulnerability we don't often understand or highlight what is unchangeable and what we make. We cannot change an individual susceptibility to a particular harm but we can change their vulnerability by avoiding exposing them to that harm and building systems that don't expose them to that harm.

?: What are some vulnerability and susceptibility in your project?

?: How can you mitigate them and be aware before they do damage?

Tips

Defaults need to be accessible, customizations don’t.

Play to the strengths you have, use the acess holds that already exist to help you fill the acess gaps you find.

Practical solutions promote adoption, lower cost and avoid disability dongles.

Law suits are expensive and implementing wide spread changes after production will always be more costly then employing a critical perspective early on.

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What are Access Needs?

We all have access needs. Access needs are what you need to safely and comfortably complete tasks in a given environment. They can look like adequate lighting, written materials in your language or stairs to get into building. Disabled peoples access needs are the same but for their brains and their bodies. The following cards will give concrete examples of possible different kinds of access needs, the tools we can use to address people's access needs and examples of conditions where these access needs are more prevalent (but anyone can have any mix of acess needs).

?: What access needs are relevant for your project?
?: What are your acess needs?
?: How can the tools listed on each card be adapted to fit your project and the acess need?

Visual Acess Needs

Not all people have the same access to visual information, when conveying information visually, alternatives need to be provided. Not only for text but for images and diagrams too. This also means making digital information accessible to screen reader and where possible provide materials with optical character recognition.

Tools: large print, alternative format, tactic markers, high contrast, Braille, Alt text, in-depth descriptions of products/product images and dark mode. Proper HTML.

Conditions: Blind, low vision, other kinds of visual impairment and conditions that temporary result in visual impairment or are exacerbated by visual input like migraines.

Print Acess Needs

Some people will have trouble reading or understanding text information. Information will need to be conveyed in another manner. This is especially true when safely, legal or other important information is being conveyed. This is like visual acess needs but some people have more specific needs around text (like they are able to interpret images but not text).

Tools: alternative format documents, audio copies of books or articles, plain language and when possible, opportunely for clarification, Came Case.

Conditions: Blind and low vision, Learning Disabilities, Intellectual disabilities, Second languages, young participants, and issues with literacy.

Sound Acess Needs

A lot of information is convened via sound and spoken language. Make sure that this information is also conveyed in other ways like closed captions and, signs that tell the same info. There are also considerations to be made around alarm fatigue and over saturation of auditory stimuli. When designing alarms think about priority level and how you translate to visual cues. If information is essential to safety, it must be conveyed in other ways (look at visual fire alarms as an example).

Tools: captions, sign language interpreters, vibration alarms, and visual alarms. announcement display boards.

Conditions: Deaf/HOH, APD, Sensory issues, busy spaces.

Gross motor Acess Needs

Some people are not able to move their arms, and/or legs to the full range of motion that others can, this can make movement difficult or dangerous, think about not only people using assertive equipment but also, thou who cannot lift heavy object or due to injury cannot lift arms higher than their shoulder.

Tools: ramps, larger buttons, elevators, proximity sensors, plug ins for alternative input methods like keyboards and mice, tools are the appropriate height for users (kids, shorter people, wheelchair users, people who can't lift their arms above the shoulders).

Conditions: paralysis, amputation, a variety of illnesses, broken limbs, cerebral palsies and physical injuries like sprains.

Dexterity and grip strength Acess

Many activities require small movement (like punching keys, long hand writing, sewing, using a smart phone). This can be complicated for some people and in some contexts, also some may be able to physically able to do an action but it may result in pain.

Tools: option to adapt tools and processes, note takers for filling forms, adapted tools, allow people to use their own electronics, forms ahead of time, help with fastenings or adapted fastening.

Conditions: Conditions with motor component like Parkinson's, Arthritis, and limbs differences.

Energy Acess Needs

Energy, both cognitive and physical, can be difficult for some. Some people have less energy to begin with and others may find task more draining then most. Making sure people can conserve or pace their energy means that they can complete tasks safely and with less errors.

Tools: minimize the number of steps that need to be done in a row, give accurate time predictions, allow for prep work, minimize standing in lines, offer alternative formats that may make it possible for a person to engage with the work at their own pace and on their own time.

Conditions: many illnesses, injures and other conditions like ME/CFS, post-surgical recovery period, sleep loss duo to insomnia or young kids at home, mental illness.

Space for Supports Needs

Some people will need extra room to maneuver or have support tools, people and animals. Give them that space.

Tools: space designated with options in mind, room to maneuver wheelchairs, strollers, and service animals.

Conditions: new parents, wheelchairs users, mobility aid uses.

Comprehension Acess Needs

Some people have difficulty understandings the meaning of text or spoken instructions, and processing what is required of them in a given place or process.

Tools: plain language, offering examples, listing steps in points, use formatting well, providing information ahead of an interaction or task and a simple question asking process.

Conditions: ESL, intellectual disabilities, cognitive impairment, APD, neurodivergent, brain fog, post viral syndrome.

Attention Access Needs

Not all people using a product will be able to give the same amount of attention to the task. This can be due to internal (focus, neurodiversity, lack of rest, or distraction) or external factors (noise in the environment, responsibilities or distractions)

Tools: Plain language, limit extraneous information, limit movement (like advertisements) on web pages where text needs to be read, good formatting of information.

Conditions: Cognitive impairment, neurodiversity like ADHD, situational impairments like medications, pain or illness.

Privacy Needs

Disabled People often have their Right to privacy disrespected and this can undermine an individual's enjoyment or safety. Disabled People often have their privacy disregard when they enter public spaces and the medical privacy is often more sensitive then non-Disabled People. Make sure that your situation fits the cultural and legal needs of the persons. Privacy also serves a protective function from discrimination which Disabled People are often at heighten risk for.

Tools: Statement on what will happen with a person's information in plain language, the opportunity to address errors in a space that private, access statements that promote information balance, proper cybersecurity.

Conditions: All people deserve a certain amount of privacy to make mistakes and process their part of the task.

Time Needs

Time and how we use it can be beneficial and, in some cases, incredibly frustrating. Thinking about how and when you use timeouts and other time dependent features can increase the utility of a design. There is also opportunity that comes from structuring time asynchronously, this means that people who have fluctuating time and energy available can still benefit from your project.

Tools: Where appropriate and possible avoid precise timing essential activities. For games an accessibility menu where people can change how they play the game is a common solution. Most important information first and the option to skip and come back later to information or tasks.

Conditions: Cognitive impairment, ageing, a variety of physical, and non-physical disabilities and impairments both permanent and temporary.

Sensory needs

A person's sensory needs are often tied to their neurology. These needs are tied to the environment that that person is in and are related to the senses (sight, sound, smell, taste, texture) and when the sensory needs are not meet the results are overstimulation or under-stimulation. With sense-based disabilities the person often experiences that sense difference which may make the sensory experience different.

Tools: allowing for personal adaptations like headphones, sunglasses and AT. If you are going to require mandatory uniforms or other personal level equipment, make sure it meets the users' needs or can be adapted. Sensory experiences that are neutral and non-taxing (think of all the senses). Keep physical spaces in good working order and when an issue is identified fix it even if it is technically "not broken"

Conditions: ASD, other neurodiversity's, migraines, sensory disabilities like Deaf/HOH, low vis.

Temperature Access Needs

All people need to be at a safe environmental temperature. Many conditions may narrow this safe and comfortable temperature range. There are also concerns about the younger and older people. For the most part theirs needs are addressed in most situations but as the climate changes, hotter and colder weather will be more common. It is important to plan for non-only people but equipment and tools.

Tools: Looking for inspiration in places that more routinely experience the kinds of temperatures you are looking to plan for can be useful as those locations have already adapted to that temperature. These tools might also include planning different kinds of activities or using different kinds of tools under different temps. Recognizing that people do not always perform as expected under stress.

Conditions: A variety disabilities, individuals on antidepressants can have trouble regulating body temperatures and those who cannot advocate for their own environmental comfort might need extra support.

Biases

Biases are built in to the tools and methods we use every day but being aware of them can help us combat them. There are many biases that are not listed like race (racism), gender (sexism and misogyny), gender expression (heteronormativity), age (ageism), access to financial resources, sexual orientation, religion, immigration status, and national origin. Instead, the cards talk about bias that in part make up ableism (discrimination in favor of non-disabled people and against disabled people), so that you can keep an eye out for them. Bias come from our society and are often not an active refection of the values we hold. Having bias do not make us bad people, designers or technologist, they however do shape what we make so awareness can be a tool in building more humane.

Normative bias

Normative bias is based on an assumption that the default body is that of a non-disabled white young adult cisgendered heterosexual man. This means that disabled people, women, racialized communities, the elderly and anyone who’s being or characteristics fall outside of that assumed normal are often not built and designed for. This bias is also prevalent in data and non-human decisions. This bias is not only in how people are (or are supposed to be) but also what they want (or what they are supposed to want), and how they want to achieve it.

?: What are the assumptions you are making about who will use the project?

?:How many perspectives are at the table, are all voices given space to talk and be critical?

Rarity bias

Rarity bias is the idea that disabled people simply aren’t that common. This is part of a long legacy of many factors, to name a few, a lack of representation in media, the effects of a lack of access to public space, and that many disabilities have no visual markers. This is often exacerbated by ableism and the other listed bias limiting the interaction between disabled and non-disabled people in schools, workplaces and public space.

?: What percentage of your users are you expecting to be disabled? Are your numbers in line with the percentage of disabled people in your region or country?

Gratefulness bias

This bias comes from a place of paternalism, it is an assumption that disabled people should be grateful for the care and health that they get and that anything is better than nothing. It clouds our ability to be critical of the things we built in relationship to disability and lead to disability dongles.

?:How can you make sure that disabled voices are heard and respected? Even the critical ones?

Infantilization bias

Infantilization bias places disabled people in a submissive position, to those who are less disabled. It devalues their perspectives and insight, their intelligence, their capabilities and their capacities. It manifests when people use baby talk to adult disabled, or only asking the option of support people and these are often considered insulting.

?: What are the assumptions are you making about an individual's capacity?

?: How can you avoid overriding disabled persons decisions?

Exploitation Inspiration

Exploitation inspiration is a phenomenon where disabled people are used simply as a tool for inspiration instead of being full human beings. Their successes and failures are situated simply as examples to non-disabled people. This bias is incredibly prevalent in the media we consume and shows up in phrases like “at least you are not disabled” and “if they can do it, you can too”. The bias is often removing the agency and nuance of disabled people and their lives and experiences.

?: Are you showing disabled people fully or are you using their images and stories to further your agenda or improve your image?

Visibility Bias

This bias is one that links a disabilities impact on a person to the disabilities visibility. It shapes the only valid disabled people as presenting in a particular way and shapes the access to care people have. There are many disabilities that have no visual markers (like use of equipment, distinct mannerisms or differences in how the body looks). There are also many disabilities that are not easily seen from medical perspectives like on a blood test, MRI or other test. This is especially true for differential diagnosis, neurological conditions, psychiatric conditions, neurodevelopmental conditions. There are also many conditions which are difficult to diagnose and many conditions for diagnostics are incredibly expensive, but that does not mean that that person is not in need of support or adaptation.

?: what are the possible side effects of requiring people to have visible or diagnosed differences?

Siloed Bias

People often assume that if a disability is severe enough then they will be taken care of in an isolated setting and that very few people in the general public experience disability. This bias comes up from a variety of sources it is part of the legacy of institutionalization and part of the reason that there's still a push for community support for disabled people. In different institutions this comes up in different ways and many institutions consider themselves too important, prestigious, or academic to adapt to the needs of disabled people. But if they want to have an impact, support their clients and staff they need to adapt and assume that anyone interacting with them may be disabled.

?: What are the factors that may be limiting how welcome, safe and a part of your system Disabled people feel?

Models

The way we see disability is shaped by many factors. Your first experience with disability, your past interactions, the media you consume, and social, cultural and religious factors. Often, we have storyline about disability, what it means, how it happens and how we need to interact with it, this can be different for everyone. They shape our reactions and interactions, and the bias we may hold. when our models mismatch the models that others have it can make it difficult to work together on problem solving. Sometimes the models we have do not match with the values we hold which can make it hard to talk about or hard to find clarity. In the next few cards some common models will be described. This is to help you identify the model you hold but not to dictate the one you use. They all have pros and cons and there are question that can help you examine the model that you hold.

Religious model

This Model see disability as an act of God or as a result of morals failings. Either a punishment or a lesson to that person or their family/community. This means that disabled people's lives are often seen as a pity or inspiration. This model is also seen in the media we consume (even when we think there is no religious connection) in the many story lines where a disabled person acts as a guide or "wise-old-man".

?: How does this model interact with medicine and the medical model?

?: What kinds of intervention or care does this model promote?

Medical model

The medical model sees disability as a flaw in the human body to be cured or given a life as "normal" possible. This situates disability as something a doctor sees (via test, scans and observation) and not as a human experience. This approach can give us a deeper understanding of the biology of a condition but it can also make it hard to find ways to support disability outside of medical intervention.

?: Do you need a medical diagnostics to provide care? Why or why not?

?: Do you listen to medical institutions over disabled people? What are the pros and cons of this approach?

Social model

This model situates disability as an issue in how society treats disabled people. It sees disability as a limitation on people thou their social and physical environment. This works well for sensory, physical and visible disabilities but less well for chronic illness, painful conditions and invisible illnesses. This model allows for there to be a world in where disabilities can be accommodated in to no longer being an "issue" for that Disabled Person. It is commonly used in spaces like laws, schools/educational mandates and policy.

?: What is the role of social accommodation in your project? What are the limits and costs to that approach?

?: What is the relationship between visibility and access to care?

Mismatch model

This is a model developed for design and designers. It situates disability as a mismatch between a personas body and the environment. This model can be especially usefull when talking about temporary disabilities. However, this model leads to a definition of disability that can be solved via an intervention, it lives in a space were solving is implied and this definition does not identify of offer a handle to tackle disability's that are not "solvable".

?: What can technology and design “solve” and what is beyond its reach?

?: What tools are within reach for this model?

Superpower model

The superpower model of disability looks at disability as a super power, it’s the model we most often seen in advertainment and film. It frames disability not for disabled people but for non-disabled people. This also frame disability as something that one can be good at and as an inspiration. As a side effect it makes it almost impossible for Disabled People to be ordinary members of society, it sets standers that are "superhuman" and eliminates space for nuance. This model is also often criticized to be damaging to a disabled persons social and personal development.

?: What are possible side effects of requiring exemptional for participation?

?: how will this model inform what you build?

Human Rights model

The Human rights model views inclusion and care as a human right of all, including Disabled people. Like the social model it frames disability as a social phenomenon. It places independence as a key goal and legal structures as a path to that goal. It identifies sources of oppression and can be useful when combined with other models. The model is foundational in the policy spaces such as The United Nations Convention on the with Disabilities and acts as the foundation for many countries approaches to disability and the law.

?: Do the laws we have right now provide enough information or do you need another model to help you design?

Charity model

This model places the care of Disabled People as a charitable option, this can make it hard to advocate for business cases and makes it appear as optional. It also often has paternalistic side effects, as well as being pitying, it is Othering and limits the agency and autonomy of Disabled People. It is widely regarded as a deeply ablest model and is linked to eugenics by promoting the lives of Disabled People as lesser then non-disabled People. This model is not positively reserved by disability rights community's and limits the business case for disability. It also implies that disabled people are not capable of derecting their own care, and that non-disabaled people are the only ones capable.

?: What happens to Disabled People when things get hard (economically) under this model?

?: Does this model intersect with the rarity bias?

Economic model

This model frames disability as a defect in economic productivity. This model can make the cost and benefit of accessible or universal design look only economical. Although there are cost to both disability and inaccessibility, they are often hidden in ways that are not easily added to a spread sheet. Since a majority of development and products are coming out of entity's that have an economic obligation it is import to not under estimate the effects of this model on the perceptions of disability. This model also shapes many governments approach to benefits and supports.

?: Does capitalism often guide us to the best for all people outcomes?

Other models

The models discussed above are predominantly western in origin but disability exists in every cultural on earth. The role of community vs individually manifests differently in different cultures and this, in turn, has implications for the treatment of disability/disabled people and the role of community. Given the interpersonal nature of disability it is important to remember that different cultures and languages have different approaches and that they may provide insights as to how to think about disability, how it works within our systems and what we build.

?: What other models might be useful to you?

?: How can you define your own model?

Principles

Principles are a common tool in design, they help us to understand our shared values and help guild designs and projects. The following cards outline possible principles inspired by universal design. They center disability and aim to reflect our human needs with the aim of humanin technologies.

Principles | 1

Inclusive Process

In order to design for all the possible users of a product or service, we have to start with inclusive processes. Inclusive processes center an individual and meets their needs in a way that respects them, this starts with inclusive tools, recruitment and language. Understanding who is normally executed from discussions and why (what biases are there) is a start. This also means that diverse team allow the fulfilment of "nothing about us without us"

?: How can we highlight disabled voices?

?: What does representation look like to you?

?: Are peoples acess needs meet in your interactions with them?

Principles | 2

Human Diversity

When we build, we make for humans, and human are diverse in their ways of being, and doing. The context of a user shapes how they interact with your solution and that shapes how they view and use it. The users, end use, and context will be different for each person who interacts with your project.

?: How can we respect the diversity of human using your product or system?

Principles | 3

Build for Adaptability

It is unlikely that you can easily address all the possible needs of all people, one way of mitigating possible harms is to build in handholds for adaptation and build in a safe breaking. Questions that can help you understand how to build for adaptability are what is truly essential, what are other ways to do this? are there paths build for when the main one is unavailable?

?: How does it breakdown or fail?

?: What are possible critical errors?

?: How appropriable is it?

Principles | 4

Build Good

This is the principle you are most like familiar with, the idea of building clean, safe and efficient solutions. Increasingly this also involves environmentally sound considerations and considerations for the life cycle of a solution. A consideration that is relevent for disability is that of breaking and end of use. Learning new tools can be more difficult for disabled people and if that product is essential then you need to make sure it fails safely too.

?: What does the end of life cycle look like?

?:Can it be safely broken, and adapted?

Accessibility

Making your product usable with a variety of assistive technologies, and with the commonly understood methods used by Disabled People. In some contexts, this also refers to financial access (cost), logistical access (availability), and other kinds of access. All kinds of access compound to determine the accessibility of a solution but without key pillars of access there is no accessibility.

?: How does this work with existing assistive technology?

?: What are the costs, both running and starting?

Look for problems

Think about how the solution can break, or where problems can arise in emergencies. The world beyond development is wide and use and mis-use can shape adoption of a solution.

?: How can you minimize misuse without placing more burden on vulnerable users?

Tools

The tools on the fallowing cards are to help you practically apply some of the lessons learned in the rest of the card set, they practically show case how we can act past the biases that are listed and will hopefully prime you to learn from disability and the perspective of disabled people that you will work with.

Tool 2 is meant to be done prior to codesign activities or outreach activities to help balance the power dynamics between participants and designers and avoid pitfalls that are common in interaction.

Tool 3 can help you fracture and deepen your understanding of how individuals experience their own mind bodies and environments this also might help highlight interactions and intersections between different disabilities and give a deeper understanding of how to the approach the task of designing. different kinds of disabilities require different kinds of interventions so matching them and understanding what you're working with can help.

Tool 4 can be used at any point in the design process to help you uncover where your access handholds already are. different kinds of handholds can he expanded on or serve as handholds for further kinds of design interventions or AT.

Accessibility statement

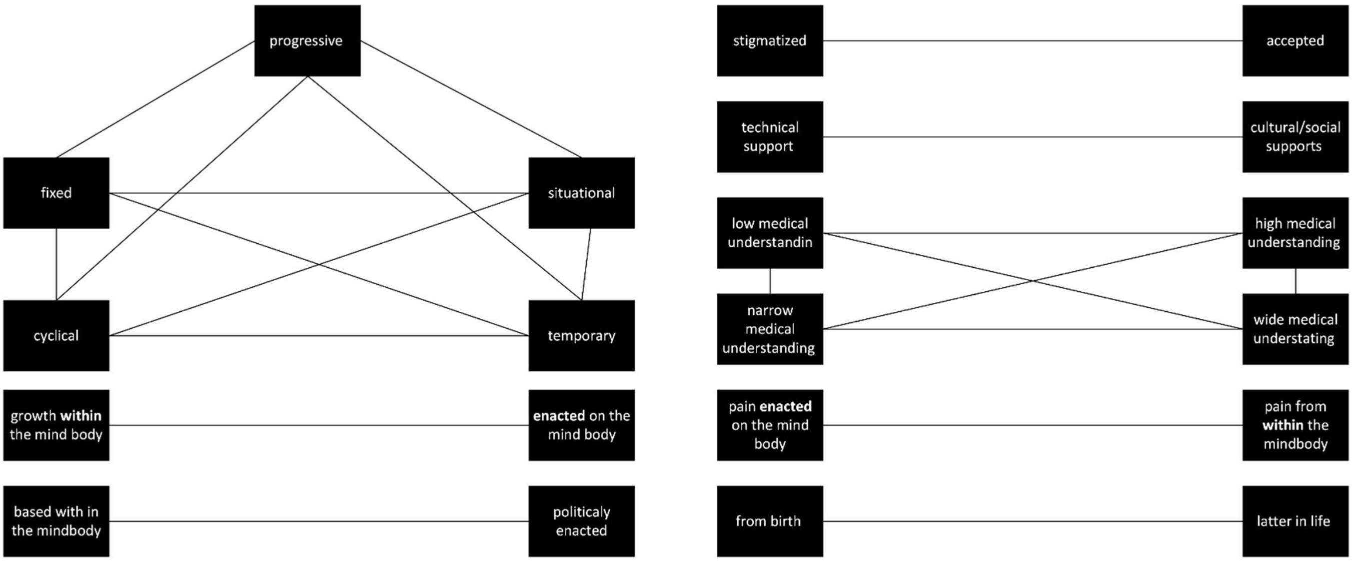
One of the tools we can use to make sure that disabled people can safely work with us when we are doing design related activities is that of accessibility statements. An accessibility statement is a sentence or paragraph that lists what a person will be able to expect when they are interacting with you or your product. It lists the capacities, tools or processes that people will need to fully interact with your Interaction so that they can get a better picture of where they might need accommodations to improve their access. It shifts the responsibility from the participant to the provider for explaining what is to be expected. it lets the participants keep their privacy but still allows interactions to be adapted to individuals.

> For this tool kit the accessibility statement would be something like: you will read a paper card set printed in black on white paper. The font is readable to normal vision. You will be asked to talk about the content of the cards with peers and some activities many involve writing.

By making the statement with details it allows people to ask for their preferred methods. Like someone with visual access needs may ask for it printed extra-large, or in Braille. Someone with attention needs may ask for a preview copy so they can get used to it. Some one may ask to have a copy in openDyslexic. And there are many other ways of adapting that they know that you have not though of yet.

Fracturing Disability

Disability is often described as a monolithic identity. When it is split, it is in to diagnostic categories that narrow the experience to the of a medical lens. That does not always work and allow for target groups selection (it is very easy to dismiss a patient population). That’s why looking at the other ways grouping and categorizing disability may help you understand disability from a experience based perspective. Shared experiences and solutions can be mapped across disabilities and non-disability. Below are several different scales we can use to describe disability that are not medical and center the disabled person in their own experience. For this activity you will need a specific disabled person although it can be adapted to personas.



Find you access advantage

Take something you love work with often or find interesting and map out it's possible access meets and access points. if we take Twitter for an example it has a high degree of temporal access, it's use of short pieces of textual information that are then sorted in a way that lets people get up to date quickly means that you don't actually have to spend a lot of time to understand what is happening in your given Twitter community. this kind of access is built into its DNA because it promotes short easy to digest pieces of information and individuals can pick it up and put it down at anytime without consequences.

but your access advantage could be in the structure of the information the form of the product or other features. Sometimes these are affordances but we can also build on individual access handholds to provide additional access. like in the example above because there was temporal access through print access it is easier to expand access using at like screen readers and promote other forms of access like alt text or plain language.

A.11 Information brochure for focus group

Print out begins on next page.

Focus group – Disability in technology- Information brochure

DESCRIPTION: You are invited to participate to participate in a focus group about a tool kit for understanding disability and its interaction in design and technology. This is part of a research study investigating how people define and understand the phenomena of disability. The focus group will consist of a spot the issue game at the beginning and the end and an exploration of the tool kit. The conversation will only be recorded by notes taken by the researcher and in no other way captured. You will also be asked to fill out a demographic sheet that will anonymously be analyzed. At the end there will be a closing survey. In the case of request by the participant (or if public health requires it) digital focus groups can take place in order to guarantee a covid safe environments.

SETUP OF THE FOCUS GROUP: The groups 2-4 people in size, who responded to the same outreach methods as you. There will be a game collaborative played with the group, you will first be given a chance to come up with your answers and then your group will discuss the answer together. The goal is to see if the card set helps you have grounded discussion and come to new conclusions as a result. The game involves viewing a short video about a product (related to disability, built Enviromint, technologies and furniture) and you will be tasked with identifying possible issues, things done well and anything else that stands out to you. You will write this on the given sheet.
TIME INVOLVEMENT: Your participation will take approximately 2 hours.

RISKS AND BENEFITS: There is possible discomfort involved in this study due to the nature of the topic. The card set you are being asked to reflect on covers topics like bias, disability and possibly your past experiences. I**f you want to skip or stop at any time you can do so without having to give an explanation.** If you want to take a break that can also be done at any time. We cannot and do not guarantee or promise that you will receive any benefits from this study.

REQUIREMENTS TO PARTICIPATE: You must be 18 years or older to participate.

PARTICIPANT'S RIGHTS: please understand your participation is voluntary and you have the right to withdraw your consent or discontinue participation at any time without giving any reasons. You have the right to refuse to answer particular questions. You have the right to withdraw consent (within 24 hours) for your data connected to demographics, it will not be possible to remove your contributions from the larger group notes and observations.

The results of this research study will be presented in the thesis and thesis personation of Laure Tolsma. Your identity will not be made known in materials resulting from the study.

- All your data will be made anonymous at the earliest possible stage.
- Your paper copy of the game answers and demographic sheet will be stored securely.
- Quotes may be used in the thesis and presentation of Laure Tolsma thesis.
- Your raw data will be deleted once the graduation project is done. The results of the thematic analyse will be in the presentation and thesis. Thematic analysis is when the focus groups, and game answers are compared and coded over all the available focus groups to see patterns and themes.
- The exit survey will be used to improve and evaluate the tool kit.

ACCESSIBILITY STATEMENT: If you need or would benefit from accommodation please contact Laure Tolsma. The activities involves reading, writing and talking in English and interaction with a physical set of cards and other people. We will also be viewing images on a projector so if you need an alternative format that can be provided. If additional information is useful to you do not hastate to ask. If you prefer to type answers instead of writing please bring a device to work with or let Laure know ahead of time so one can be provided.

CONTACT INFORMATION:

Questions: If you have any questions, concerns or complaints about this research, its procedures, risks and benefits, contact the main responsible researcher, Laure Tolsma via email at l.d.tolsma@student.utwente.nl or +31 6 286 99401 .

Independent Contact: If you are not satisfied with how this study is being conducted, or if you have any concerns, complaints, or general questions about the research or your rights as a participant, please contact the Secretary of the Ethics Committee Computer & Information Science: ethicscommittee-cis@utwente.nl

Appointment Contact: If you have made an appointment and need to change it or want additional information, please contact Laure Tolsma, l.d.tolsma@student.utwente.nl or +31 6 286 99401

Consent form

Please tick the boxes that apply:

	Yes	**No**
I have been informed in a manner which is clear to me about the nature and method of the study as described in the information brochure "Focus group – Disability in technology". My questions have been answered to my satisfaction.	[ ]	[ ]
I agree of my own free will to participate in this study, and understand that I can refuse to answer questions and that I can withdraw from the study at any time, without having to give a reason.	[ ]	[ ]
I give permission for paper notes to be made and used for analysis.	[ ]	[ ]
I give permission for demographic used for analysis.	[ ]	[ ]
I give permission for game results used for analysis.	[ ]	[ ]
I give permission for quotes to be included in the thesis and thesis presentation (Fully anonymous).	[ ]	[ ]

__________________________ ____________________ _________

Participant name [printed] Signature Date

The extra copy of this consent form is for you to keep.

If you have any complaints about this research, please direct them to the Secretary of the Ethics Committee Information & Computer Science: ethicscommittee-cis@utwente.nl

If you have any questions, concerns or complaints about this research, its procedures, risks and benefits, you may contact the main responsible researcher, Laure Tolsma via email at l.d.tolsma@student.utwente.nl or +31 6 286 99401 .

I have provided an explanation of the research and, to the best of my ability, ensured that the participant understands to what they are freely consenting. I declare myself willing to answer to the best of my ability any questions which may still arise about the research.

__________________________ ____________________ _________

Researcher name [printed] Signature Date

A.12 Demographic sheet and participants fill in sheet for focus group

Print out begins on next page.

Focus group demographic

I am in: [ ] my Bachelors [ ] my Masters [ ] PHD or postdoc [ ] Industry [ ] Other____________________

I identify as ____ (gender identity)

I am familiar with disability: [ ] yes [ ] no

I am familiar with neurodiversity: [ ] yes [ ] no

I am familiar with chronic illness or medically complexities: [ ] yes [ ] no

I would describe myself as (select all that apply):

[ ] having a design background [ ] having a technical or computer science background [ ] having the social sciences background [ ] having a humanities background

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Slide # ___ | Did you know about this product before today? Yes [ ] No [ ] | R1 [X] R2 [ ]

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Slide # ___ | Did you know about this product before today? Yes [ ] No [ ] | R1 [ ] R2 [X]

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A.13 Script for focus group

Print out begins on next page.

Script for focus group

Materials

- ☐ Paper
- ☐ Consent forms (print)
- ☐ Markers
- ☐ Card set (print +cut)
- ☐ Laptop for slides
- ☐ Dice (to randomly generate participation ID)
- ☐ Demographic form(print)

Introduction (10 min) :

- ☐ Demographic
- ☐ Consent

Intro yourself: hi all my name is Laure and I am here today with you all to test something that I am working on, the thing we will be testing is a card set meant to promote discussions about disability and how it interacts with technology.

When it comes to disability we all have different life experiences and perspectives on disability so keep an open mind and if you want to take a break let me know and we can do that. There are rests planned but your comfort is also important so just let me know.

To do this we are going to play a "game" a bit like spot the difference but this time we are trying to find issue. Explore the card set and then play the game again.

Now I am going to ask you all to go around the room and we can go over names and a small bit about who we are.

I know you read it on the consent but I want to reiterate that if you want to leave or stop or take a brack, you do not need to give a reason why, just let me know and that will be it.

As for what will be captured in the focus group is my paper notes, the marks you make on paper and my mental notes

Any questions?

part 1 (20 min) : game play (see .ppt for example)

so I am going to hand out paper, or you can type on your phone and send it to me,

- roll the dice to see what slide we are working with,
- give 5 min to write down the individual answers
- we come together to think about what the group answer looks like.

part 2 (30 min with 15 min break) so 45 total : the cards

set the card deck on the table and explain the basic format and then allow them to go through the cards on their own time.

if they get stuck, prompt them to read card 1 and then they can look at the cards with the game slide in mind.

Part 3 (20 min) : revisit the game

To assess the effectiveness of the cards the same game slide in mind, the participants will be asked to redo the activity again, both individual and group.

Part 4 (25 min): debrief

- I know that having conversations about disability at times can be uncomfortable, how do you all feel about how that went?
- Are there any cards that you liked or did not like, stand outs, confusion?
- Take home survey

A.14 Game for focus group

Print out begins on next page.

Welcome

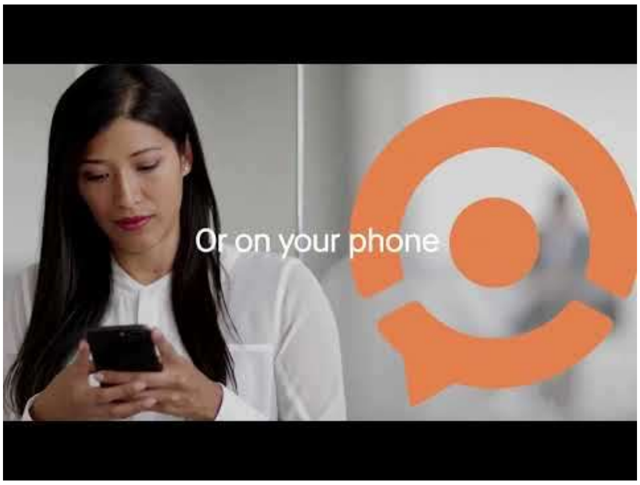
Spot the issue

Game for Building technology with
the Perspective of Disability

How to play

1. On the following slides you will see an Image/video of a product and a short description of the product.
2. Your task is to note different ways that that object, product or feature interact with disability. This can be **issues**, things that are **done well** and other things that stand out, good, bad or don’t know yet.

1 - Audio into captions glasses



- The glasses take audio input and translate it into captions that are projected on the lenses for the users to read.

#2-Stair climbing wheelchair

- This is a power wheelchair that can climb up and down stairs.

#3- Stairs with integrated ramp aka "stramps"

- A set of stairs in a public park leading to a public building.
- The ramp zig-zags from one side of the stairs to the other.

#4- Sign language gloves

- Gloves that interpretive hand movements in to spoken language

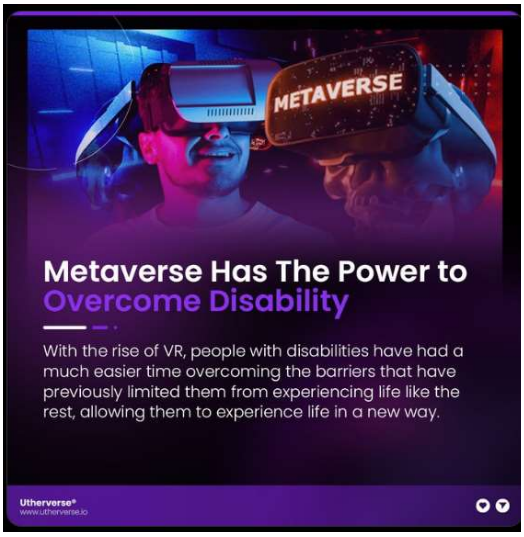
#5- Hearing hair clip

- A hair clip that converts sounds in the wearers Enviromint into vibrations

#6- theater performance caption glasses

https://www.nationaltheatre.org.uk/your-visit/access/caption-glasses

#7- VR and disability press release

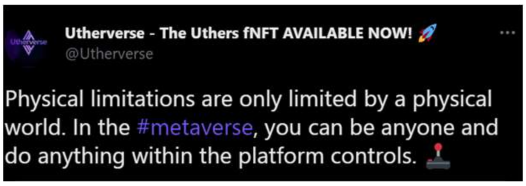


Metaverse Has The Power to Overcome Disability

With the rise of VR, people with disabilities have had a much easier time overcoming the barriers that have previously limited them from experiencing life like the rest, allowing them to experience life in a new way.

Utherverse®
www.utherverse.io

- An advertisement by a VR company talking about how VR will "Overcome Disability"



Utherverse - The Uthers fNFT AVAILABLE NOW! 🚀
@Utherverse

Physical limitations are only limited by a physical world. In the #metaverse, you can be anyone and do anything within the platform controls. 🕹️

#8- Surface Adaptive Kit

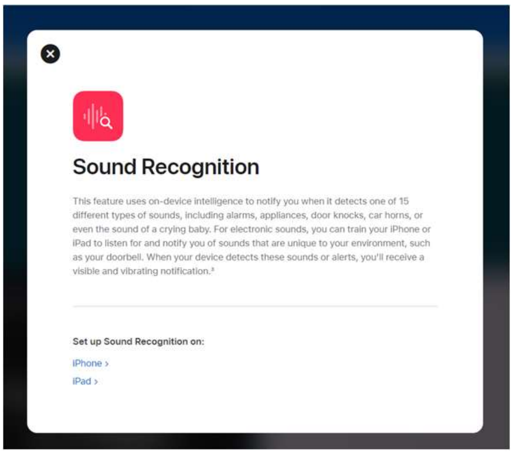
- This set of stickers is designed by Microsoft to allow users to adapt there electronics to their needs.
- The 3d stickers are different colors and have different raised textures
- There is also a pull tab to allow easier pulling of the flap on Microsoft tablet

https://sea.mashable.com/tech/17775/this-sticker-kit-makes-laptops-easier-to-use-for-those-with-disabilities

#9- "ADA" furniture

https://www.fastcompany.com/90771457/pottery-barn-debuts-150-pieces-of-furniture-for-people-with-disabilities

#10- Apple Sound Recognition



Sound Recognition

This feature uses on-device intelligence to notify you when it detects one of 15 different types of sounds, including alarms, appliances, door knocks, car horns, or even the sound of a crying baby. For electronic sounds, you can train your iPhone or iPad to listen for and notify you of sounds that are unique to your environment, such as your doorbell. When your device detects these sounds or alerts, you'll receive a visible and vibrating notification.[3]

Set up Sound Recognition on:

iPhone ›
iPad ›

https://www.apple.com/accessibility/

#11- ThisAbles Ikea

https://thisables.com/en/how-did-it-all-begin/

#12- Tommy Adaptive

https://uk.tommy.com/tommy-adaptive

Toolkit Evaluation survey

A.15 Cards Version 3

Disability and Design: An Exploration Card Deck

Welcome! This card set is to help you explore how to build with Diablility as a critical lens. Increasingly we are all asked to design more human products and comply with different laws without having a deep understanding of disability, accessibility or how they work. The cards are divided into section that you can use at different stages of the design process. Not all cards will be useful to all projects so use what makes sense for you, your team, and your project.

Foundations - 1st section is the foundations section, it will help you get started and learn some of the foundations concepts in the space of designing for disability.

Access needs - 2nd section is a tool that can help you understand what to keep in mind as you build and can also help you find solutions by looking at other disablitys with the same or similar access needs.

Fractruing Disablity - 3rd section is an activity with infomation cards that illustrate some of the concepts that underpin the actitiy. This activity helps you to understand not only the direct ways disabilities differ for each person's experience it but also can help give an indication of the different goals, lens, and perspectives you can employ when building or developing solutions. This can be used in an exploratory phase or along side co-design.

Centering Disablity - 4th section lets us understand what access and accessibility looks like by showing what inaccessibility looks and feels like.

Biases - 5th section can be used as a reflective tool to help you understand how ableist noms may have snuck their way in the underpining of what you are building.

Thank You

The font used in the card set is Atkinson Hyperlegible by the Braille Institute.

Blank cards have been included where they would not increase cost but additional cards can always be added. If you want to add you own cards to your deck the card size is that of A6 so folding a A4 page in quarts allows you to easily add your own.

This card set is part of the Ms thesis of Laure Tolsma, feel free to contact her for more information and resources.

Tips

Defaults need to be accessible, customizations don't.

Practical solutions promote adoption, lower cost and avoid disability dongles.

Law suits are expensive and implementing wide spread changes after production will always be more costly then employing a critical perspective early on.

Foundations

The foundational cards will help you explore some concepts that are common in designing for Disability. It's recommended that you start here: this can serve as a branching off point based on what you and your team find interesting or important. Around 31.1% of the Dutch population is disabled so understanding disability how it works and how to design for it is important not only from an inclusion perspective but also from a business and legal compliance perspectives.

As you look through the following cards think about how they impact not only your process but what you will end up making. Disability is deeply multifaceted and diverse, not everything may be clear in the beginning. Disability is often removed from our daily lives through ableism (Abelism being discrimination against Disabled people in favor of non Disabled people) so it is very natural to be confused or finds this process complicated or difficult. Let us start with the basics!

Naming the discomfort

Disability and ableism are everywhere, but often in unnamed ways. It can be uncomfortable to talk about disability, this is for lots of reasons, stigma, the fear of saying something wrong, identifying weakness and asking help. So many reason that can make it hard and that’s ok. It is worth taking the time and effort to remove abilism from your work. It can be hard to look back on mistakes and talk about them with honestly. Its ok to be uncomfortable, or uneasy since this is a kind of work that most of us do not do often. Be patient with yourself and your team and know that its ok to step back and take a moment.

What is Disability?

This tool kit frames disability not as a lack of ability, but instead as a isuue with particular ability. This can be as simple as the ability to see the color green or as complicated as the ability to breath without help. When we understand and use more precise abilities, we can see all the other abilities and handholds of interaction between a person and the project we are building. But what is disability? Disability can be split in 3 aspects; The mind and body (on card 3), The social phenomena (card 4), and How disability shapes expectations (card 5).

The mind-body in disability

Outside of social and political interactions, we can also see disability as a way of being. This lens can tell us more about how we practically design for disability but the phenomena tells us what it means to design for disability. Individual mind-bodies are what is disabled, they are the lens that we need to look at systems and tools from. Mind-bodies and their experiences overlap but cannot be transferred. They can show us the practical adaptations that are needed and give us a logistical understanding of how a condition manifests in a given environment. Any thing that a body can do it can fail to do or need help doing.

Disability as a (social) phenomena

When we look at disability as a phenomena (both socially and politically) we can see that to be disabled causes differences in how you interact with the world and how it interacts with you. This understanding of disability is framed by interpersonal relationships, expectations, and social connotations around limits and worth. Someone can be more limited by the perception of their disability than their own mind-body, others can be more limited by their mind-body then what is understood by their community or environments. There are social and political expectations that sometimes overlap with the mind-bodies of Disabled people and times where there is a deep mismatch.

?: What are the expectations you see others having for Disabled people?

How disability shapes expectation

To be labeled or understood as disabled can give normative and ablest assumptions about, not only what that person is capable of but, what that person should be doing. There is often a bias towards cure regardless of theoretical cost, efficiency or the possibility of that cure. There are assumptions about what kinds of spaces Disabled people are allowed to be in, what kinds of jobs they have, what kinds of needs they have, and what kinds of wants that they have. Many different ways of thinking about disbality can actually be harmful because they make assumptions that aren't always true and sometimes those assumptions limit what Disabled people get to do safely. So what we expect Disabled people to do shapes what we build accessible.

Dis-future

How we see the future shapes what we imagine is possible. If we think technology will eliminate disability, we will build inaccessible tools. If with think technology will enable Disabled people to live, there will be more, not less, Disabled people, and we will we build that technology and systems to work with Disabled people. As medicine gets better at keeping people alive, we will have more (not less) Disabled people working, playing and living in the systems we build. Our collective definition of disability may change but humans will keep being wonderfully diverse and in need of care and connection.

?: Does your future speculation include diversity and Disabled people?

?: How does the media you consume show human diversity?

What Disability can tell us about technology

Technology and Disability are interconnected. Disabled people have pioneered many of the technologies we use today and they can offer a perspective on how best to make technologies. Many tools and interfaces were pioneered by Disabled people including texting and shorthand by deaf/HOH communities and audiobooks by blind and visually impaired communities. When we use the perspective of disability, we can think about what we want to achieve in different ways. If you frame disability as needing support with certain activities or in given environment it makes sense that disability has fueled many technologies as the needs of Disabled people are explicit and often ask for new ways of solving problems.

?: What other technologies do you think have their origins in disability?

?: Does your technology support Disabled people with what they want to do or make it easier for a system to manage them?

Laws

In most countries, there are laws in place with the goal of increasing the accessibility of public service and spaces to Disabled people. These laws shape what can be brought to market and gives Disabled people an opportunity to address inaccessibility through the law. The laws are based on best practices and evolving understandings so they are closer to bare minimums than gold standard. In the spaces of emerging technologies they may provide little guidance.

?: What are the laws surrounding accessibility in your country?

?: Are there best practices outside of the laws that can guide you?

?: Are the laws in your industry new and what can they be missing/lacking?

Fracturing Disability - A (re)framing activity

Disability is often described as a monolithic identity. When it is split up, it is in to diagnostic categories that narrow our underanding to a medical approach. That does not always work and allows for narrow target groups selection (it is very easy to dismiss a patient population). That is why looking at the other ways grouping and categorizing disability may help you understand disability from a experience based perspective. Shared experiences and solutions can be mapped across disabilities and non-disability. Below are several different scales we can use to describe disability that are not diagnostic and center the Disabled person in their own experience. For this activity you will need a specific Disabled person although it can be adapted to personas.

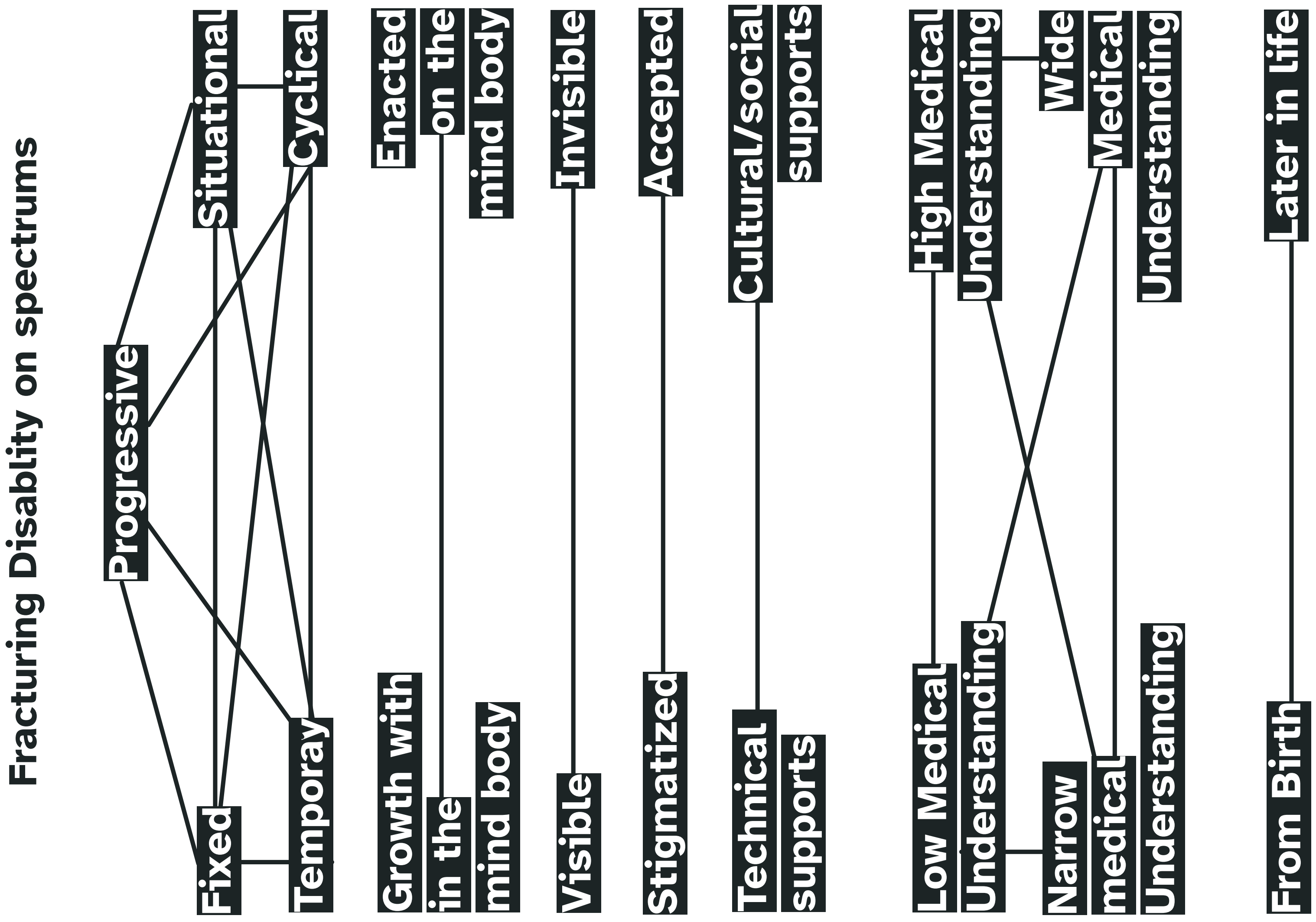
On the following cards some spectrums will be explained along with guidance from what you can learn from this spectrum and the two options at each end.

By mapping a person's experience we can see different ways to intervene and different angles or avenues for design.

The cards can be used with a particular disabled co-designer in mind, as a way of complicating personas, or to better map out a specific disability. The cards after the spectrum map will help explain each spectrum so it may be useful to read them first.

You can use the spectrums by plotting your example or participant on them. This will give you a richer understanding of where to intervene and a more granular understanding of that person's experience and their context.

Fracturing Disability | 0



Spectrums

Most, if not all, disabilities exist on spectrums. Spectrums of severity, needs, and skills. These spectrums often change over a personal lifetime, and for some, on shorter team scales. That also means that what one person with a particular disability or condition needs or presents is what that one person needs and does not necessarily what all people with that condition need.

?: What spectrums do you exist on?

?: What spectrums do you know?

Who do we design for?

Who we think we are designing for shapes what gets developed, often we have personas or target users but without articular and wellfounded templates for their disabilities and how it affects them. How people use and benefit from a projectis shaped by who we think we are designing for.

?: Are the groups or community that you want to design for more closely? Why?

?: Is there power balance in your outreach methods?

Timelines and change

Disabilities can change over time. Disabilities that are fixed and don't change over time can often be adapted to and worked around. Disabilities that are progressive will require different kinds of interventions at different stages and may involve more planning. Disabilities that are situational where possible should avoid that triggering situation and if that's not possible be intervened carefully because skills haven't been set up around that disability and may be experienced with little warning. Cyclical disabilities come and go, ebb and flow, and might need different levels of help at different times, where a person is in that cycle is really for them to determine and they should be supported in the interventions they choose at that moment. Temporary disabilities might need extra help to get something done but it doesn't always make sense to build lots of skill if it's going to go away after a little bit.

Social vs mind body pain

For some disabilities the part that causes pain and difficulty is the political or social expectations around that disability. For others the pain comes from inside of a person's mind body. This can change how we design for things, if an activity causes physical pain we might want to adapt that activity to a person's body or avoid it, if an activity causes emotional pain we might want to remove the stigma around it or highlight a person's possibility in that task.

Invisible vs Visible

Not all disabilities can be seen from the outside. Some are signalled by assistive technology, unique features, limb differences, distinct mannerism or ways of moving but not all are. Some have none of the markers listed. Some disabilities are from birth, and others are acquired by illness, or injury or appear later in life. Some of the most prevalent deficits or features are not visible like pain and fatigue.

?: How does your project identify or support people who ask for additional support?

?: When does a need become a disability?

?: Does your identification model privilege some disabilities over others?

Stigma

The stigma around disability makes us underestimate how normal and common disability is. It also makes addressing ones needs and the needs of others difficult, since there are no honest conversations about what is needed and what is possible. Language and how we feel about language can be confusing and can complicate the conversation. People may be hesitant to ask for help with stigmatized condition, people may be hesitant to provide care or assistance to a person with a stigmatized condition.

?: What words are you using in currently dialogues?

?: Are the conversations you are having about disability clear, appropriate and approachable?

Assistive technology (AT) and Cultural Adaptations

Assistive technology (AT) is any item, piece of equipment, software program, or product system that is used to increase, maintain, or improve the functional capabilities of persons with disabilities. Both high and low tech these tools are important to the functioning and safety of Disabled people. Examples are hearing aids, wheelchairs, Augmentative and Alternative Communication (AAC), screen readers, headphones, support braces, and other tools both medical and non-medical in origin. Cultural adaptations might look like changing when we expect someone to do something and make allowances for adaptations. This can be like grace on time requirements or verbal feedback instead of written feedback. These are very natural adaptations that we all do socially all the time.

?: How does your project interactive with different kinds of AT?

?: How can you support peoples use of their AT?

?: What cultural adaptations are already being used or are available?

Medical understanding

There are many disabilities where science and medicine does not fully understand the underlying mechanisms. There are many disabilities that are commonly misunderstood. There are disabilities that many can name and people sort of understand how they work. There is all sorts of mixes of these elements. Ones understanding of how a disability is understood and whether or not we understand the mechanisms underneath it changes how we design because if science doesn't know the answer it doesn't make sense to intervene on an underlying mechanism. There are common misconceptions about almost every disability that change how people interact with it. All of this is important to remember when designing.

Vulnerability vs Susceptibility

Often in conversations about disability and other potentially vulnerable groups there's the idea of vulnerability but not an understanding of susceptibility. There are certain factors could that make people more susceptible to certain kinds of Harms and these cannot be changed only mitigated. We have conversations about vulnerability we do not often understand or highlight what is unchangeable and what we make. We cannot change an individual susceptibility to a particular harm but we can change their vulnerability by avoiding exposing them to that harm and building systems that don't expose them to that harm.

?: What are some vulnerability and susceptibility in your project?

?: How can you mitigate them and be aware before they do damage?

Time of onset

When in someone's life that they started experiencing their disability changes the kind of support they need, the individual blind from birth has different needs and requirements than someone who is loseing eyesight later in life. The skills they have, are willing to learn, the tools they have access to, and the things they are expected to do are all different.

Intersectionality

The intersections (overlaps) between different identities and how the world sees them shape how a person experiences an environment, system or product. They may mitigate vulnerabilities or exacerbate them in seen and unseen ways. We often talk about vulnerable people, marginalized people and, those at risk without understanding why they are politically situated like that. We also do not often understand the steps we need to take to address there is unequal risk of discrimination.

?: What are the costs, where are they beared and where can they be beared with the lowest ill effect?

?: Are there intersections that are more vulnerable in your project?

Centering Disability

The following section takes insights and concepts from disability studies and translates them to something that is useful and accessible to designers. It takes foundational concepts and perspectives from Disabled people and can help us understand from that perspective.

These cards center some views of Disabled people and can provide critical insight into not only what we built but how we go about building it.

?: How can you include Disabled people the space, critic to the design, without placing limitations or qualifications on their option?
?: Does your project build on or work with AT, practices and accommodations?
?: If developed for a specific disability does it work with multiple disability's?

Forced Intimacy

Forced intimacy is a term coined by Mia Mingus, that distills the way Disabled people are often asked to be vulnerable in order to gain care. It is often under the guise of educating, others curiosity or in order to ensure the resources are going to the right people but it's removes agency and overrides the consent of Disabled people. It is emotionally draining and frustrating and is built in to the very structure of how abelism works.

?: Are you asking for vulnerability in order to build empathy?

Disability Pride

Disability is a complicated identity, it is marked in part by pain and struggle but also by care, adaption and unique experiences. A person can accept their disability, love the way it shapes them and actively hope that no one else experiences it. A quote by Emily Ladau distils this resilience, joy and perspective.
“There is nothing that needs to be changed about my state of being. There is nothing I want to change. I am a whole human being whose body moves forward through life in turns of the wheel, and my reality is not for anyone else to decide."
Although disability may often be marked by pain it also deeply full of joy and possibility. Disability pride is in opposition to people who devalue disabled lives.

?:What are the dialogs you have seen around disability?
?: How do you view disabilities that cannot be solved or cured?

Acess vs Accessibility

When people go to use a tool, object or system there are two ways it can fail them before they even get started. One is a lack of access and the other is that it is inaccessible. Theses 2 are often confused but acess is more about a lack of practical “hand holds” for use, ie that the tool does not meet the skills they have available. The other is a failure in expectations, that the people who built the project are not expecting certain kinds of people to use the thing they built. For a project to be truly accessible both need to be meet.

?: Are your users descriptions normative?

?: Who are you expecting to not be using your product? Why?

Variety within disability and how it shapes our language

Language and how we talk about a topic is important. Words shape our interactions with each other and can signal respect or disrespect. Disabled people, Person experiencing disability and people with disabilities are all respectful terms that don't hide what a person is experiencing. In conversations around disability there are euphemisms that, although well-intentioned, can make it difficult to be all on the same page. Phrases like “people with an exceptionality”, “special needs”, and “special people” should not be used if disability can be used. But it is also a good idea to match and respect the language people already use.

?: What language have you used in the past and who did you mean when you used it?

?: If you speak a second language, what is “disability” directly translated? How does that make you feel?

Disabled people and people with disability. The language of curative possibility

One of the questions is which is ofthen asked is witch is better Disabled people or people with disabilities? One invokes a kind of curative possibility the other less so. Disabled people insinuates that the disability well not go away and that it is part of who that person is now. People with disabilities separates the person from their disability. Depending on the experience of the individual one is going to be preferred. Some people have a history with trying to be “cured” and this can bring back painful memory which can change how a disabled person feels about an interaction and especially when designers are trying to build spaces of dialogue this can put us back more than it can put us forward.

Disability Dongles

Disability dongles is a term coined by Liz Jackson and Alex Haagaard, they call it “A well-intended elegant, yet useless solution to a problem we never knew we had…” with this they mean that good intentions alone will not build equitable or just solutions. Too often the insights and perspective of disability are disregarded and this results in products and systems that don’t solve but exacerbate the problems they aim to address.

?: How can you include Disabled people the space, to critic the design, without placing limitations or qualifications on their option?

?: Does your project build on or work with AT, practices and accommodations?

?: If developed for a specific disability does it work with multiple disability's?

Empathy

In this kind of work we are often asked to have Empathy. This can be an incredible tool but true Empathy is time consuming, requires space and energy. It can be overwhelming to feel what others feel or even a fraction of that. It can also give us a false understanding, misunderstanding or pity. We don't always have to understand or feel the same but we do have to listen.

?: Do you have the time to give the conversations the respect they deserve?

?: Is the emotional labor evenly divided and properly compensated?

Access to public space

Access to public space is for most people a given, we assume that when we enter a library, a shop, a museum or a school that that environment will be safe and accessible to us. However, if your access needs are not meet you may feel unwelcome, you may have to limit your time in that space or not be able to participate in public life fully. When we build inaccessible environments or systems, we limit the spaces that Disabled people occupy, thus limiting the spaces we think they belong in. This can limit the number of Disabled people we see, making us think that Disabled people don't exist or belong in the spaces, and so a cycle of exclusion builds till we underestimate the ubiquity of disability.

?: How are you making sure to not undermine Disabled peoples access to public space?

Find you access advantage - activity

Take something you love work with often or find interesting and map out it's possible access meets and access points. If we take Twitter for an example, it had a high degree of temporal access, it's use of short pieces of textual information that are then sorted in a way that lets people get up to date quickly means that you don't actually have to spend a lot of time to understand what is happening in your given Twitter community. This kind of access is built into its DNA because it promotes short easy to digest pieces of information and individuals can pick it up and put it down at anytime without consequences.

Your access advantage could be in the structure of the information the form of the product or other features. Sometimes these are affordances but we can also build on individual access handholds to provide additional access. like in the example above because there was temporal access through print access it is easier to expand access using at like screen readers and promote other forms of access like alt text.

Centering Disability |

Centering Disability |

Accessibility Statement - activity

An accessibility statement is a sentence or paragraph that lists what a person can expect from an interaction. It lists the capacities, tools or processes that people will need to fully interact with your interaction so that they can ask for accommodation. It shifts the responsibility from the participant to the provider letting the participants keep their privacy and Limit forced intimacy (see CD 1).

For this tool kit the accessibility statement would be something like: you will read a paper card set printed in black on colored paper. The font is readable to normal vision. You will be asked to talk about the content of the cards with peers and some activities many involve writing.

By making the statement with details it allows people to ask for their preferred methods. There are many other ways of adapting that they know that you have not though of yet.

What are Access Needs?

This set of cards can help you explore how different access needs are being addressed or not addressed by your design.

Each access need card has an explanation of the access need, some tools that are commonly used to address that access need which can serve as inspiration, and some conditions that more commonly experienced that access need. We can look to the conditions to see if our concerned group is listed there but we can also look to other conditions with the same access needs to help address access needs that we are missing. Groups that often experience that access need often have creative ways of going about it that disabilities comumity and don't create a normative expectation of how we are supposed to address those access needs. Were at all possible amplifying solutions and methods from other disabled communities can help you address and access need without increasing a normative expectation of how a person is supposed to address that access need.

What are Access Needs?

We all have access needs. Access needs are what you need to safely and comfortably complete tasks in a given environment. They can look like adequate lighting, written materials in your language or stairs to get into building. Disabled peoples access needs are the samething but for their brains and their bodies. The following cards will give concrete examples of possible different kinds of access needs, the tools we can use to address people's access needs and examples of conditions where these access needs are more prevalent (but anyone can have any mix of acess needs). Conditons with same or simmiler access needs may help you find inspiration.

?: What access needs are relevant for your project?
?: What are your acess needs?
?: How can the tools listed on each card be adapted to fit your project and the acess need?

Visual Acess Needs

Not all people have the same access to visual information, when conveying information visually, alternatives need to be provided. Not only for text but for images and diagrams too. This also means making digital information accessible to screen reader and where possible provide materials with optical character recognition.

Tools: large print, alternative format, tactic markers, high contrast, Braille, Alt text, in-depth descriptions of products/ product images and dark mode. Proper HTML.

Conditions: Blind, low vision, other kinds of visual impairment and conditions that temporary result in visual impairment or are exacerbated by visual input like migraines.

Print Acess Needs

Some people will have trouble reading or understanding text information. Information will need to be conveyed in another manner. This is especially true when safely, legal or other important information is being conveyed. This is like visual acess needs but some people have more specific needs around text (ie they are able to interpret images but not text).

Tools: alternative format documents, audio copies of books or articles, plain language and when possible, opportunely for clarification, Came Case.

Conditions: Blind and low vision, Learning Disabilities, Intellectual disabilities, Second languages, young participants, and issues with literacy.

Sound Acess Needs

A lot of information is convened via sound and spoken language. Make sure that this information is also conveyed in other ways like closed captions and, signs that tell the same info. There are also considerations to be made around alarm fatigue and over saturation of auditory stimuli. When designing alarms think about priority level and how you translate to visual cues. If information is essential to safety, it must be conveyed in other ways (look at visual fire alarms as an example).

Tools: captions, sign language interpreters, vibration alarms, and visual alarms. announcement display boards.

Conditions: Deaf/HOH, Auditory processing disorder (APD), Sensory issues, busy spaces.

Gross motor Acess Needs

Some people are not able to move their arms, and/or legs to the full range of motion that others can. This can make movement difficult or dangerous, think about not only people using assistive equipment but also, those who cannot lift heavy object or due to injury cannot lift arms higher than their shoulder.

Tools: ramps, larger buttons, elevators, proximity sensors, plug ins for alternative input methods like keyboards and mice, tools are the appropriate height for users (kids, shorter people, wheelchair users, people who can’t lift their arms above the shoulders).

Conditions: paralysis, amputation, a variety of illnesses, broken limbs, Cerebral palsy and physical injuries like sprains.

Dexterity and grip strength Acess

Many activities require small movement (like punching keys, long hand writing, using a smart phone). This can be complicated for some people and in some contexts, also some may be able to physically able to do an action but it may result in pain.

Tools: option to adapt tools and processes, note takers for filling forms, adapted tools, allow people to use their own electronics, forms ahead of time, help with fastenings or adapted fastening.

Conditions: Conditions with motor component like Parkinson's, Arthritis, and limbs differences.

Energy Acess Needs

Energy, both cognitive and physical, can be difficult for some. Some people have less energy to begin with and others may find task more draining then others.. Making sure people can conserve or pace their energy means that they can complete tasks safely and with less errors.

Tools: minimize the number of steps that need to be done in a row, give accurate time predictions, allow for prep work, minimize standing in lines, offer alternative formats that may make it possible for a person to engage with the work at their own pace and on their own time.

Conditions: many illnesses, injures and other conditions like Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), post-surgical recovery period, sleep loss do to insomnia or young kids at home, mental illness.

Space for Supports Needs

Some people will need extra room to maneuver or have support tools, people and animals. Give them that space.

Tools: space designated with options in mind, room to maneuver wheelchairs, strollers, and service animals.

Conditions: new parents, wheelchairs users, mobility aid uses.

Comprehension Acess Needs

Some people have difficulty understandings the meaning of text or spoken instructions, and processing what is required of them in a given place or process.

Tools: plain language, offering examples, listing steps in points, use formatting well, providing information ahead of an interaction or task and a simple question asking process.

Conditions: Second language learners, intellectual disabilities, cognitive impairment, Auditory processing disorder (APD), neurodivergent, brain fog, post viral syndrome.

Attention Acess Needs

Not all people using a product will be able to give the same amount of attention to the task. This can be due to internal (focus, neurodiversity, lack of rest, or internal distraction) or external factors (noise in the environment, responsibilities or external distractions)

Tools: Plain language, limit extraneous information, limit movement (like advertisements) on web pages where text needs to be read, good formatting of information.

Conditions: Cognitive impairment, neurodiversity like ADHD, situational impairments like medications, pain or illness.

Privacy Needs

Disabled people often have their Right to privacy disrespected and this can undermine an individual's enjoyment or safety. Disabled people often have their privacy disregard when they enter public spaces and medical privacy is often more sensitive then non-Disabled people. Make sure that your situation fits the cultural and legal needs of the persons. Privacy also serves a protective function from discrimination which Disabled people are often at heighten risk for.

Tools: Statement on what will happen with a person's information in plain language, the opportunity to address errors in a space that private, access statements that promote information balance, proper cybersecurity

.

Conditions: All people deserve a certain amount of privacy to make mistakes and process their part of the task.

Time Needs

Time and how we use it can be beneficial and, in some cases, incredibly frustrating. Thinking about how and when you use timeouts and other time dependent features can increase the utility of a design. There is also opportunity that comes from structuring time asynchronously, this means that people who have fluctuating time and energy available can still benefit from your project.

Tools: Where appropriate and possible avoid precise timing essential activities. For games an accessibility menu where people can change how they play the game is a common solution. Most important information first and the option to skip and come back later to information or tasks.

Conditions: Cognitive impairment, ageing, a variety of physical, and non-physical disabilities and impairments both permanent and temporary.

Sensory needs

A person's sensory needs are often tied to their neurology. These needs are tied to the environment that that person is in and are related to the senses (sight, sound, smell, taste, texture) and when the sensory needs are not meet the results are overstimulation or under-stimulation. With sense-based disabilities the person often experiences senses difference which may make the sensory experience different.

Tools: allowing for personal adaptations like headphones, sunglasses and AT. If you are going to require mandatory uniforms or other personal level equipment, make sure it meets the users' needs or can be adapted. Sensory experiences that are neutral and non-taxing (think of all the senses). Keep physical spaces in good working order and when an issue is identified fix it even if it is technically "not broken"

Conditions: ASD, other neurodiversity's, migraines, sensory disabilities like Deaf/HOH, low vision.

Temperature Access Needs

All people need to be at a safe environmental temperature. Many conditions may narrow this safe and comfortable temperature range. There are concerns about younger and older people. For the most part theirs needs are addressed in most situations but as the climate changes, hotter and colder weather will be more common. It is important to plan for non-only people but equipment and tools.

Tools: Looking for inspiration in places that more routinely experience the kinds of temperatures you are looking to plan for can be useful as those locations have already adapted to that temperature. These tools might also include planning different kinds of activities or using different kinds of tools under different temps. Recognizing that people do not always perform as expected under stress.

Conditions: A variety disabilities, individuals on antidepressants can have trouble regulating body temperatures and those who cannot advocate for their own environmental comfort might need extra support.

Biases

Biases are built in to the tools and methods we use every day, but being aware of them can help us combat them. There are many biases that are not listed like race (racism), gender (sexism and misogyny), gender expression (heteronormativity), age (ageism), access to financial resources, sexual orientation, religion, immigration status, and national origin. Instead, the cards talk about bias that in part make up ableism (discrimination in favor of non-Disabled people and against Disabled people), so that you can keep an eye out for them. Bias come from our society and are often not an active refection of the values we hold**. Having bias do not make us bad people, designers or technologist, they however do shape what we make so awareness can be a tool in building more humane.**

In this activity you will be given meny bias, and will be asked to investaget whether or not the bias is presant in your outcome.

Normative bias

Normative bias is based on an assumption that the default body is that of a non-disabled white young adult cisgendered heterosexual man. This means that Disabled people, women, racialized communities, the elderly and anyone who's being or characteristics fall outside of that assumed "normal" are often not built/designed for. This bias is also prevalent in data and non-human decisions. This bias is not only in how people are (or are supposed to be) but also what they want (or what they are supposed to want), and how they want to achieve it.

?: What are the assumptions you are making about who will use the project?

?:How many perspectives are at the table, are all voices given space to talk and be critical?

Rarity bias

Rarity bias is the idea that Disabled people simply aren't that common. This is part of a long legacy of many factors, to name a few, a lack of representation in media, the effects of a lack of access to public space, and that many disabilities have no visual markers. This is often exacerbated by ableism and the other listed bias limiting the interaction between disabled and non-Disabled people in schools, workplaces and public space.

?: What percentage of your users are you expecting to be disabled? Are your numbers in line with the percentage of Disabled people in your region or country?

Gratefulness bias

This bias comes from a place of paternalism, it is an assumption that Disabled people should be grateful for the care and health that they get and that anything is better than nothing. It clouds our ability to be critical of the things we built in relationship to disability and lead to disability dongles.

?:How can you make sure that disabled voices are heard and respected? Even the critical ones?

Infantilization bias

Infantilization (to treat like a child) bias places Disabled people in a submissive position, to those who are less or not disabled. It devalues their perspectives, insight, their intelligence, their capabilities and their capacities. It manifests when people use baby talk to adult disabled, or only asking the option of support people and these are often considered insulting.

?: What are the assumptions are you making about an individual's capacity?

?: How can you avoid overriding disabled persons decisions?

Exploitation Inspiration

Exploitation inspiration is a phenomenon where Disabled people are used simply as a tool for inspiration instead of being full human beings. Their successes and failures are situated simply as examples to non-Disabled people. This bias is incredibly prevalent in the media we consume and shows up in phrases like “at least you are not disabled” and “if they can do it, you can too”. The bias is often removing the agency and nuance of Disabled people, their lives and experiences.

There are also literal examples of exploitation of Disabled people, like below minimum wage workshops and other “feel good” businesses.

?: Are you showing Disabled people fully or are you using their images and stories to further your agenda or improve your image?

Visibility Bias

This bias is one that links a disabilities impact on a person to the disabilities visibility. It shapes the only valid Disabled people as looking a certain way and shapes the access to care people have. There are many disabilities that have no visual markers (like use of equipment, distinct mannerisms or differences in how the body looks). There are also many disabilities that are not easily seen from medical perspectives like on a test. This is especially true for psychiatric conditions, and neurodevelopmental conditions. There are also many conditions which are difficult to diagnose and many conditions for diagnostics are incredibly expensive, but that does not mean that that person is not in need of support or adaptation.

?: What percentage of your users are you expecting to be disabled? Are your numbers in line with the percentage of Disabled people in your region or country?

Siloed Bias

People often assume that if a disability is severe enough then they will be taken care of in an isolated setting and that very few people in the general public experience disability. This bias comes up from a variety of sources it is part of the legacy of institutionalization and part of the reason that there's still a push for community support for Disabled people. In different institutions this comes up in different ways and many institutions consider themselves too important, prestigious, or academic to adapt to the needs of Disabled people. But if they want to have an impact, support their clients and staff they need to adapt and assume that anyone interacting with them may be disabled.

?: What are the factors that may be limiting how welcome, safe and a part of your system Disabled people feel?

Data and AI

Data and AI are increasingly used to make decisions, shape technology and classify people. They encode bias in a from that may be harder to uncover and cause harm to people (especially from marginalized groups). For example hiring algorithms that disproportionately recommend hiring white men over disabled people people of color and women. Hand washing stations with automatic sensors that don't recognize dark skin tones or Censoring automatically generated captioning. Each of these encode the different parts of abelism as a bias where they can be scaled quickly.

?: What are the possible harms of mis-classification or mis-identification?

?: How can errors be flagged and corrected?

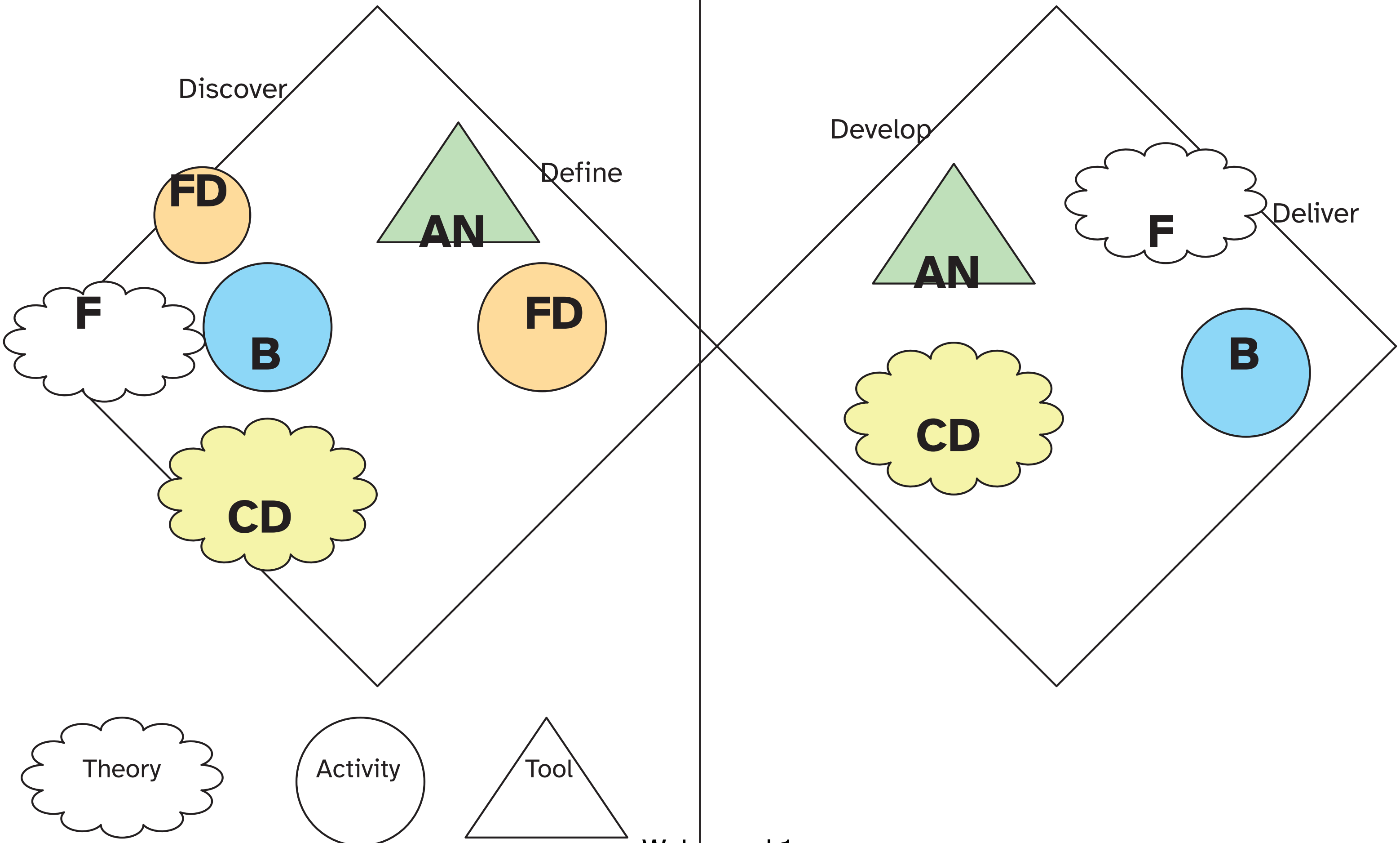
?: Who can report errors?

?: What bias are being built in to your data sets or algorithms?

Curative bias

Curative bias is the assumption that any worthwhile solution or intervention must forever solve all the problems of that disability. It manifests in the instincts of people to “educate” and “teach” instead of just providing assistance as guided by the disabled person. It looks like wanting to ”cure” autism instead of adapting a process to a person. It looks like building wheelchairs that climb stairs instead of adapting the environment to have ramps. It looks like placing compliance requirements around care. It assumes that the disabled person does not have the knowledge they need to know what is best for their body and their brain. It sees Disabled people as something to be fixed.

Cards in the design process



Thank You

The font used in the card set is Atkinson Hyperlegible by the Braille Institute.

Blank cards have been included where they would not increase cost but additional cards can always be added. If you want to add you own cards to your deck the card size is that of A6 so folding a A4 page in quarts allows you to easily add your own.

This card set is part of the Ms thesis of Laure Tolsma, feel free to contact her for more information and resources.

Tips

Defaults need to be accessible, customizations don’t.

Play to the strengths you have, use the acess holds that already exist to help you fill the acess gaps you find.

Practical solutions promote adoption, lower cost and avoid disability dongles.

Law suits are expensive and implementing wide spread changes after production will always be more costly then employing a critical perspective early on.

A.16 Final toolkit

Print out begins on next page.

Foundations

The foundational cards will help you explore some concepts that are common in designing for Disability. It's recommended that you start here: this can serve as a branching off point based on what you and your team find interesting or important. Around 31.1% of the Dutch population is disabled so understanding disability how it works and how to design for it is important not only from an inclusion perspective but also from a business and legal compliance perspectives.

As you look through the following cards think about how they impact not only your process but what you will end up making. Disability is deeply multifaceted and diverse, not everything may be clear in the beginning. **Disability is often removed from our daily lives through ableism (Abelism being discrimination against Disabled people in favor of non Disabled people) so it is very natural to be confused or finds this process complicated or difficult.** Let us start with the basics!

Naming the discomfort

Disability and ableism are everywhere, but often in unnamed ways. **It can be uncomfortable to talk about disability, this is for lots of reasons: stigma, the fear of saying something wrong, identifying weakness and asking help**. So many reason that can make it hard and that's ok. It is worth taking the time and effort to remove abelism from your work. It can be hard to look back on mistakes and talk about them with honestly. Its ok to be uncomfortable, or uneasy since this is a kind of work that most of us do not do often. Be patient with yourself and your team and know that its ok to step back and take a moment.

What is Disability?

This tool kit frames disability not as a lack of ability, but instead as a isuue with a particular ability. This can be as simple as the ability to see the color green or as complicated as the ability to breath without help**. When we understand and use more precise abilities, we can see all the other abilities and handholds of interaction between a person and the project we are building**. But what is disability? Disability can be split in 3 aspects; The mind and body (on Foundations 3), The social phenomena (Foundations 4), and How disability shapes expectations (Foundations 5).

The mind-body in disability

Outside of social and political interactions, we can also see disability as a way of being. This lens can tell us more about how we practically design for disability but the phenomena tells us what it means to design for disability. **Individual mind-bodies are what is disabled, they are the lens that we need to look at systems and tools from. Mind-bodies and their experiences overlap but cannot be transferred.** They can show us the practical adaptations that are needed and give us a logistical understanding of how a condition manifests in a given environment. Any thing that a mindbody can do it can fail to do or need help doing.

Disability as a (social) phenomena

When we look at disability as a phenomena (both socially and politically) we can see that to be disabled causes differences in how you interact with the world and how it interacts with you. This understanding of disability is framed by interpersonal relationships, expectations, and social connotations around limits and worth. **Someone can be more limited by the perception of their disability than their own mind-body, others can be more limited by their mind-body then what is understood by their community or environments**. There are social and political expectations that sometimes overlap with the mind-bodies of Disabled people and times where there is a deep mismatch.

?: What are the expectations you see others having for Disabled people?

How disability shapes expectation

To be labeled or understood as disabled can give normative and ablest assumptions about, not only what that person is capable of but, what that person should be doing. There is often a bias towards cure regardless of theoretical cost, efficiency or the possibility of that cure. **There are assumptions about what kinds of spaces Disabled people are allowed to be in, what kinds of jobs they have, what kinds of needs they have, and what kinds of wants that they have**. Many different ways of thinking about disablity can actually be harmful because they make assumptions that aren't always true and sometimes those assumptions limit what Disabled people get to do safely. So what we expect Disabled people to do shapes what we build accessible.

Dis-future

How we see the future shapes what we imagine is possible. If we think technology will eliminate disability, we will build inaccessible tools. If with think technology will enable Disabled people to live, there will be more, not less, Disabled people, and we will we build that technology and systems to work with Disabled people. **As medicine gets better at keeping people alive, we will have more (not less) Disabled people working, playing and living in the systems we build**. Our collective definition of disability may change but humans will keep being wonderfully diverse and in need of care and connection.

?: Does your future speculation include diversity and Disabled people?

?: How does the media you consume show human diversity?

What Disability can tell us about technology

Technology and Disability are interconnected. Disabled people have pioneered many of the technologies we use today and they can offer a perspective on how best to make technologies. Many tools and interfaces were pioneered by Disabled people including texting and shorthand by deaf/HOH communities and audiobooks by blind and visually impaired communities. When we use the perspective of disability, we can think about what we want to achieve in different ways**. If you frame disability as needing support with certain activities or in given environment it makes sense that disability has fueled many technologies as the needs of Disabled people are explicit and often ask for new ways of solving problems.**

?: What other technologies do you think have their origins in disability?

?: Does your technology support Disabled people with what they want to do or make it easier for a system to manage them?

Laws

In most countries, there are laws in place with the goal of increasing the accessibility of public service and spaces to Disabled people. These laws shape what can be brought to market and gives Disabled people an opportunity to address inaccessibility through the law. The laws are based on best practices and evolving understandings so they are closer to bare minimums than gold standard. In the spaces of emerging technologies they may provide little guidance.

?: What are the laws surrounding accessibility in your country?

?: Are there best practices outside of the laws that can guide you?

?: Are the laws in your industry new and what can they be missing/lacking?

Fracturing Disability - A (re)framing activity

Disability is often described as a monolithic identity. When it is split up, it is in to diagnostic categories that narrow our underanding to a medical approach. That does not always work and allows for narrow target groups selection (it is very easy to dismiss a patient population). That is why looking at the other ways grouping and categorizing disability may help you understand disability from a experience based perspective. Shared experiences and solutions can be mapped across disabilities and non-disability. Below are several different scales we can use to describe disability that are not diagnostic and center the Disabled person in their own experience. For this activity you will need a specific Disabled person although it can be adapted to personas.

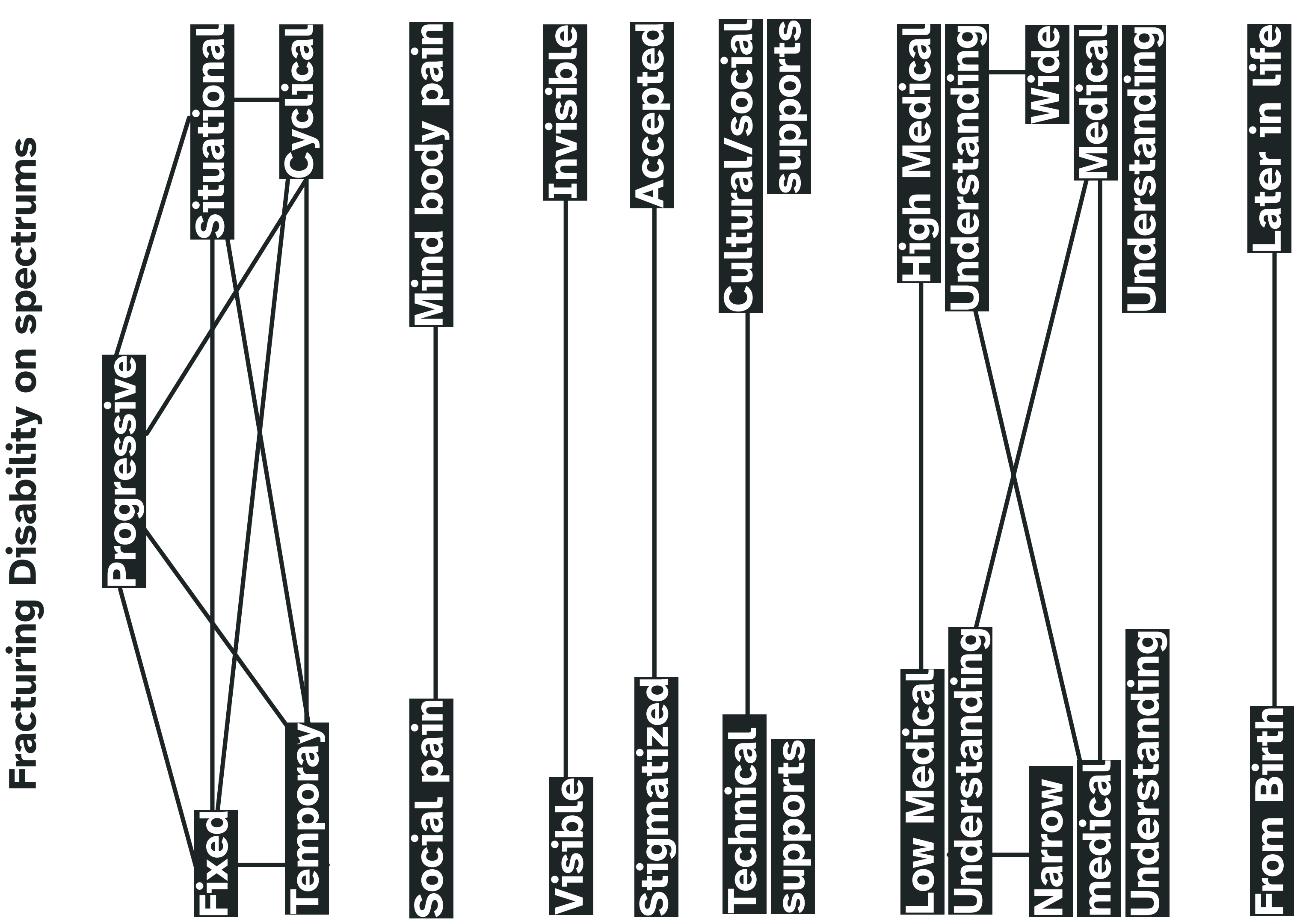
On the following cards some spectrums will be explained along with guidance from what you can learn from this spectrum and the two options at each end.

By mapping a person's experience we can see different ways to intervene and different angles or avenues for design.

The cards can be used with a particular disabled co-designer in mind, as a way of complicating personas, or to better map out a specific disability. The cards after the spectrum map will help explain each spectrum so it may be useful to read them first.

You can use the spectrums by plotting your example or participant on them. This will give you a richer understanding of where to intervene and a more granular understanding of that person's experience and their context.

Fracturing Disability | 0



Spectrums

Most, if not all, disabilities exist on spectrums. Spectrums of severity, needs, and skills. These spectrums often change over a personal lifetime, and for some, on shorter team scales. **That also means that what one person with a particular disability or condition needs or presents is what that one person needs and does not necessarily what all people with that condition need.**

?: What spectrums do you exist on?

?: What spectrums do you know?

Who do we design for?

Who we think we are designing for shapes what gets developed, often we have personas or target users but without articular and wellfounded templates for their disabilities and how it affects them. How people use and benefit from a projectis shaped by who we think we are designing for.

?: Are the groups or community that you want to design for more closely? Why?

?: Is there power balance in your outreach methods?

Timelines and change

Disabilities can change over time. Disabilities that are fixed and don't change over time are often adapted to and worked around. Disabilities that are progressive will require different kinds of interventions at different stages and may involve more planning. Disabilities that are situational where possible should avoid that triggering situation and if that's not possible be intervened carefully because skills haven't been set up around that disability and may be experienced with little warning. Cyclical disabilities come and go, ebb and flow, and might need different levels of help at different times, where a person is in that cycle is really for them to determine and they should be supported in the interventions they choose at that moment. Temporary disabilities might need extra help to get something done but it doesn't always make sense to build lots of skill if it's going to go away after a little bit.

Social vs mind body pain

For some disabilities the part that causes pain and difficulty is the political or social expectations around that disability. For others the pain comes from inside of a person's mind body. This can change how we design for things, if an activity causes physical pain we might want to adapt that activity to a person's body or avoid it, if an activity causes emotional pain we might want to remove the stigma around it or highlight a person's possibility in that task.

Invisible vs Visible

Not all disabilities can be seen from the outside. Some are signalled by assistive technology, unique features, limb differences, distinct mannerism or ways of moving but not all are. Some have none of the markers listed. Some disabilities are from birth, and others are acquired by illness, or injury or appear later in life. **Some of the most prevalent deficits or features are not visible like pain and fatigue.**

?: How does your project identify or support people who ask for additional support?

?: When does a need become a disability?

?: Does your identification model privilege some disabilities over others?

Stigma

The stigma around disability makes us underestimate how normal and common disability is. It also makes addressing ones needs and the needs of others difficult, since there are no honest conversations about what is needed and what is possible. Language and how we feel about language can be confusing and can complicate the conversation. **People may be hesitant to ask for help with stigmatized condition, people may be hesitant to provide care or assistance to a person with a stigmatized condition.**

?: What words are you using in currently dialogues?

?: Are the conversations you are having about disability clear, appropriate and approachable?

Medical understanding

There are many disabilities where science and medicine does not fully understand the underlying mechanisms. There are many disabilities that are commonly misunderstood. There are disabilities that many can name and people sort of understand how they work. There is all sorts of mixes of these elements. Ones understanding of how a disability is understood and whether or not we understand the mechanisms underneath it changes how we design because if science doesn't know the answer it doesn't make sense to intervene on an underlying mechanism. There are common misconceptions about almost every disability that change how people interact with it. All of this is important to remember when designing.

Assistive Technology (AT) and Cultural Adaptations

Assistive technology (AT) is any item, piece of equipment, software program, or product system that is used to increase, maintain, or improve the functional capabilities of persons with disabilities. Both high and low tech these tools are important to the functioning and safety of Disabled people. Examples are hearing aids, wheelchairs, Augmentative and Alternative Communication (AAC), screen readers, headphones, support braces, and other tools both medical and non-medical in origin. Cultural adaptations might look like changing when we expect someone to do something and make allowances for adaptations. This can be like grace on time requirements or verbal feedback instead of written feedback. These are very natural adaptations that we all do socially all the time.

?: How does your project interactive with different kinds of AT?

?: How can you support peoples use of their AT?

?: What cultural adaptations are already being used or are available?

Vulnerability vs Susceptibility

Often in conversations about disability and other potentially vulnerable groups there's the idea of vulnerability but not an understanding of susceptibility. There are certain factors could that make people more susceptible to certain kinds of Harms and these cannot be changed only mitigated. We have conversations about vulnerability we do not often understand or highlight what is unchangeable and what we make. **We cannot change an individual susceptibility to a particular harm but we can change their vulnerability by avoiding exposing them to that harm and building systems that don't expose them to that harm.**

?: What are some vulnerability and susceptibility in your project?

?: How can you mitigate them and be aware before they do damage?

Time of onset

When in someone's life that they started experiencing their disability changes the kind of support they need, the individual blind from birth has different needs and requirements than someone who is loseing eyesight later in life. **The skills they have, are willing to learn, the tools they have access to, and the things they are expected to do are all different.**

Intersectionality

The intersections (overlaps) between different identities and how the world sees them shape how a person experiences an environment, system or product. **They may mitigate vulnerabilities or exacerbate them in seen and unseen ways.** We often talk about vulnerable people, marginalized people and, those at risk without understanding why they are politically situated like that. We also do not often understand the steps we need to take to address there is unequal risk of discrimination.

?: What are the costs, where are they beared and where can they be beared with the lowest ill effect?

?: Are there intersections that are more vulnerable in your project?

Centering Disability

The following section takes insights and concepts from disability studies and translates them to something that is useful and accessible to designers. It takes foundational concepts and perspectives from Disabled people and can help us understand from that perspective.

These cards center some views of Disabled people and can provide critical insight into not only what we built but how we go about building it.

?: How can you include Disabled people the space, critic to the design, without placing limitations or qualifications on their option?
?: Does your project build on or work with AT, practices and accommodations?
?: If developed for a specific disability does it work with multiple disability's?

Forced Intimacy

Forced intimacy is a term coined by Mia Mingus, that distills the way **Disabled people are often asked to be vulnerable in order to gain care.** It is often under the guise of educating, others curiosity or in order to ensure the resources are going to the right people but it **removes agency and overrides the consent of Disabled people.** It is emotionally draining and frustrating and is built in to the very structure of how abelism works.

?: Are you asking for vulnerability in order to build empathy?

Disability Pride

Disability is a complicated identity, it is marked in part by pain and struggle but also by care, adaption and unique experiences. A person can accept their disability, love the way it shapes them and actively hope that no one else experiences it. A quote by Emily Ladau distils this resilience, joy and perspective.

“There is nothing that needs to be changed about my state of being. There is nothing I want to change. I am a whole human being whose body moves forward through life in turns of the wheel, and my reality is not for anyone else to decide." Although disability may often be marked by pain it also deeply full of joy and possibility. Disability pride is in opposition to people who devalue disabled lives.

?:What are the dialog you have seen around disability?
?: How do you view disabilities that cannot be solved or cured?

Acess vs Accessibility

When people go to use a tool, object or system there are two ways it can fail them before they even get started. One is a lack of access and the other is that it is inaccessible. Theses 2 are often confused but acess is more about a lack of practical “hand holds” for use, ie that the tool does not meet the skills they have available. The other is a failure in expectations, that the people who built the project are not expecting certain kinds of people to use the thing they built. For a project to be truly accessible both need to be meet.

?: Are your users descriptions normative?

?: Who are you expecting to not be using your product? Why?

Variety within disability and how it shapes our language

Language and how we talk about a topic is important. Words shape our interactions with each other and can signal respect or disrespect. **Disabled people, Person experiencing disability and people with disabilities are all respectful terms that don't hide what a person is experiencing.** In conversations around disability there are euphemisms that, although well-intentioned, can make it difficult to be all on the same page. Phrases like “people with an exceptionality”, “special needs”, and “special people” should not be used if disability can be used. But it is also a good idea to match and respect the language people already use.

?: What language have you used in the past and who did you mean when you used it?

?: If you speak a second language, what is “disability” directly translated? How does that make you feel?

Disabled people and people with disability. The language of curative possibility

One of the questions is which is ofthen asked is which is better Disabled people or people with disabilities? One invokes a kind of curative possibility the other less so. Disabled people insinuates that the disability well not go away and that it is part of who that person is now. People with disabilities separates the person from their disability. Depending on the experience of the individual one is going to be preferred. Some people have a history with trying to be “cured” and this can bring back painful memory which can change how a disabled person feels about an interaction and especially when designers are trying to build spaces of dialogue this can put us back more than it can put us forward.

Disability Dongles

Disability dongles is a term coined by Liz Jackson and Alex Haagaard, they call it “A well-intended elegant, yet useless solution to a problem we never knew we had…” with this they mean that **good intentions alone will not build equitable or just solutions.** Too often the insights and perspective of disability are disregarded and this results in products and systems that don’t solve but exacerbate the problems they aim to address.

?: How can you include Disabled people the space, to critic the design, without placing limitations or qualifications on their option?

?: Does your project build on or work with AT, practices and accommodations?

?: If developed for a specific disability does it work with multiple disability's?

Empathy

In this kind of work we are often asked to have Empathy. This can be an incredible tool but true Empathy is time consuming, requires space and energy. It can be overwhelming to feel what others feel or even a fraction of that. It can also give us a false understanding, misunderstanding or pity. **We don’t always have to understand or feel the same but we do have to listen.**

?: Do you have the time to give the conversations the respect they deserve?

?: Is the emotional labor evenly divided and properly compensated?

Access to public space

Access to public space is for most people a given, we assume that when we enter a library, a shop, a museum or a school that that environment will be safe and accessible to us. **However, if your access needs are not meet you may feel unwelcome, you may have to limit your time in that space or not be able to participate in public life fully.** When we build inaccessible environments or systems, we limit the spaces that Disabled people occupy, thus limiting the spaces we **think** they belong in. This can limit the number of Disabled people we see, making us think that Disabled people don’t exist or belong in the spaces, and so a cycle of exclusion builds till we underestimate the ubiquity of disability.

?: How are you making sure to not undermine Disabled peoples access to public space?

Find you access advantage - activity

Take something you love work with often or find interesting and map out it's possible access meets and access points. If we take Twitter for an example, it had a high degree of temporal access, it's use of short pieces of textual information that are then sorted in a way that lets people get up to date quickly means that you don't actually have to spend a lot of time to understand what is happening in your given Twitter community. This kind of access is built into its DNA because it promotes short easy to digest pieces of information and individuals can pick it up and put it down at anytime without consequences.

Your access advantage could be in the structure of the information the form of the product or other features. Sometimes these are affordances but we can also build on individual access handholds to provide additional access. like in the example above because there was temporal access through print access it is easier to expand access using at like screen readers and promote other forms of access like alt text.

Accessibility Statement - activity

An accessibility statement is a sentence or paragraph that lists what a person can expect from an interaction. It lists the capacities, tools or processes that people will need to fully interact with your interaction so that they can ask for accommodation. It shifts the responsibility from the participant to the provider letting the participants keep their privacy and Limit forced intimacy (see Centering disbaility 1).

For this tool kit the accessibility statement would be something like: you will read a paper card set printed in black on colored paper. The font is readable to normal vision. You will be asked to talk about the content of the cards with peers and some activities many involve writing.

By making the statement with details it allows people to ask for their preferred methods. There are many other ways of adapting that they know that you have not though of yet.

Access Needs?

This set of cards can help you explore how different access needs are being addressed or not addressed by your design.

Each access need card has an explanation of the access need, **some tools that are commonly used to address that access need which can serve as inspiration, and some conditions that more commonly experienced that access need.** We can look to the conditions to see if our concerned group is listed there but we can also look to other conditions with the same access needs to help address access needs that we are missing. **Groups that often experience that access need often have creative ways of going about it that disabilities comumity and don't create a normative expectation of how we are supposed to address those access needs**. Where at all possible amplifying solutions and methods from other disabled communities can help you address and access need without increasing a normative expectation of how a person is supposed to address that access need.

Access Needs | 0

What are Access Needs?

We all have access needs. Access needs are what you need to safely and comfortably complete tasks in a given environment. They can look like adequate lighting, written materials in your language or stairs to get into building. Disabled peoples access needs are the samething but for their brains and their bodies. The following cards will give concrete examples of possible different kinds of access needs, the tools we can use to address people's access needs and examples of conditions where these access needs are more prevalent (but anyone can have any mix of acess needs). Conditons with same or simmiler access needs may help you find inspiration.

?: What access needs are relevant for your project?
?: What are your access needs?
?: How can the tools listed on each card be adapted to fit your project and the access need?

Access Needs | 1

Visual Access Needs

Not all people have the same access to visual information, when conveying information visually, alternatives need to be provided. Not only for text but for images and diagrams too. This also means making digital information accessible to screen reader and where possible provide materials with optical character recognition.

Tools: large print, alternative format, tactic markers, high contrast, Braille, Alt text, in-depth descriptions of products/ product images and dark mode. Proper HTML. Described Video.

Conditions: Blind, low vision, other kinds of visual impairment and conditions that temporary result in visual impairment or are exacerbated by visual input like migraines.

Access Needs | 2

Print Access Needs

Some people will have trouble reading or understanding text information. Information will need to be conveyed in another manner. This is especially true when safely, legal or other important information is being conveyed. This is like visual acess needs but some people have more specific needs around text (ie they are able to interpret images but not text).

Tools: alternative format documents, audio copies of books or articles, plain language and when possible, opportunely for clarification, Camel Case.

Conditions: Blind and low vision, Learning Disabilities, Intellectual disabilities, Second languages, young participants, and issues with literacy.

Sound Access Needs

A lot of information is convened via sound and spoken language. **Make sure that this information is also conveyed in other ways** like closed captions and, signs that tell the same info. There are also considerations to be made around alarm fatigue and over saturation of auditory stimuli. When designing alarms think about priority level and how you translate to visual cues. If information is essential to safety, it must be conveyed in other ways (look at visual fire alarms as an example).

Tools: captions, sign language interpreters, vibration alarms, and visual alarms. announcement display boards.

Conditions: Deaf/HOH, Auditory processing disorder (APD), Sensory issues, busy spaces.

Gross motor Access Needs

Some people are not able to move their arms, and/or legs to the full range of motion that others can. This can make movement difficult or dangerous, think about not only people using assistive equipment but also, those who cannot lift heavy object or due to injury cannot lift arms higher than their shoulder.

Tools: ramps, larger buttons, elevators, proximity sensors, plug ins for alternative input methods like keyboards and mice, tools are the appropriate height for users (kids, shorter people, wheelchair users, people who can't lift their arms above the shoulders).

Conditions: paralysis, amputation, a variety of illnesses, broken limbs, Cerebral palsy and physical injuries like sprains.

Dexterity and grip strength Access

Many activities require small movement (like punching keys, long hand writing, using a smart phone). This can be complicated for some people and in some contexts, also some may be able to physically able to do an action but it may result in pain.

Tools: option to adapt tools and processes, note takers for filling forms, adapted tools, allow people to use their own electronics, forms ahead of time, help with fastenings or adapted fastening.

Conditions: Conditions with fine motor component like Parkinson's, Arthritis, and limbs differences.

Energy Access Needs

Energy, both cognitive and physical, can be difficult for some. Some people have less energy to begin with and others may find task more draining then others. Making sure people can conserve or pace their energy means that they can complete tasks safely and with less errors.

Tools: minimize the number of steps that need to be done in a row, give accurate time predictions, allow for prep work, minimize standing in lines, offer alternative formats that may make it possible for a person to engage with the work at their own pace and on their own time.

Conditions: many illnesses, injures and other conditions like Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), post-surgical recovery period, sleep loss do to insomnia or young kids at home, mental illness.

Space for Supports Needs

Some people will need extra room to maneuver or have support tools, people and animals. Give them that space.

Tools: space designated with options in mind, room to maneuver wheelchairs, strollers, and service animals.

Conditions: new parents, wheelchairs users, mobility aid uses.

Comprehension Access Needs

Some people have difficulty understandings the **meaning** of text or spoken instructions, and processing what is required of them in a given place or process.

Tools: plain language, offering examples. listing steps in points, use formatting well, providing information ahead of an interaction or task and a simple question asking process.

Conditions: Second language learners, intellectual disabilities, cognitive impairment, Auditory processing disorder (APD), neurodivergent, brain fog, post viral syndrome.

Attention Acess Needs

Not all people using a product will be able to give the same amount of attention to the task. This can be due to internal (focus, neurodiversity, lack of rest, or internal distraction) or external factors (noise in the environment, responsibilities or external distractions)

Tools: Plain language ,reminders as to what has happened limit extraneous information, limit movement (like advertisements) on web pages where text needs to be read, good formatting of information.

Conditions: Cognitive impairment, neurodiversity like ADHD, situational impairments like medications, pain or illness.

Privacy Needs

Disabled people often have their Right to privacy disrespected and this can undermine an individual's enjoyment or safety. **Disabled people often have their privacy disregard when they enter public spaces and medical privacy is often more sensitive then non-Disabled people**. Make sure that your situation fits the cultural and legal needs of the persons. Privacy also serves a protective function from discrimination which Disabled people are often at heighten risk for.

Tools: Statement on what will happen with a person's information in plain language, the opportunity to address errors in a space that private, access statements that promote information balance, proper cybersecurity

.

Conditions: All people deserve a certain amount of privacy to make mistakes and process their part of the task.

Time Needs

Time and how we use it can be beneficial and, in some cases, incredibly frustrating. Thinking about how and when you use timeouts and other time dependent features can increase the utility of a design. There is also opportunity that comes from structuring time asynchronously, this means that people who have fluctuating time and energy available can still benefit from your project.

Tools: Where appropriate and possible avoid precise timing essential activities. For games an accessibility menu where people can change how they play the game is a common solution. Most important information first and the option to skip and come back later to information or tasks.

Conditions: Cognitive impairment, ageing, a variety of physical, and non-physical disabilities and impairments both permanent and temporary.

Sensory needs

A person's sensory needs are often tied to their neurology. These needs are tied to the environment that that person is in and are related to the senses (sight, sound, smell, taste, texture) and when the sensory needs are not meet the results are overstimulation or under-stimulation. With sense-based disabilities the person often experiences senses difference which may make the sensory experience different.

Tools: allowing for personal adaptations like headphones, sunglasses and AT. If you are going to require mandatory uniforms or other personal level equipment, make sure it meets the users' needs or can be adapted. Sensory experiences that are neutral and non-taxing (think of all the senses). Keep physical spaces in good working order and when an issue is identified fix it even if it is technically "not broken"

Conditions: ASD, other neurodiversity's, migraines, sensory disabilities like Deaf/HOH, low vision.

Temperature Access Needs

All people need to be at a safe environmental temperature. Many conditions may narrow this safe and comfortable temperature range. There are concerns about younger and older people. For the most part theirs needs are addressed in most situations but as the climate changes, hotter and colder weather will be more common. It is important to plan for non-only people but equipment and tools.

Tools: Looking for inspiration in places that more routinely experience the kinds of temperatures you are looking to plan for can be useful as those locations have already adapted to that temperature. These tools might also include planning different kinds of activities or using different kinds of tools under different temps. Recognizing that people do not always perform as expected under stress.

Conditions: A variety disabilities, individuals on antidepressants can have trouble regulating body temperatures and those who cannot advocate for their own environmental comfort might need extra support.

Biases

Biases are built in to the tools and methods we use every day, but being aware of them can help us combat them. There are many biases that are not listed like race (racism), gender (sexism and misogyny), gender expression (heteronormativity), age (ageism), access to financial resources, sexual orientation, religion, immigration status, and national origin. Instead, the cards talk about bias that in part make up ableism (discrimination in favor of non-Disabled people and against Disabled people), so that you can keep an eye out for them. Bias come from our society and are often not an active refection of the values we hold**. Having bias do not make us bad people, designers or technologist, they however do shape what we make so awareness can be a tool in building more humane.**

In this activity you will be given many bias, and will be asked to investaget whether or not the bias is presant in your outcome.

Normative bias

Normative bias is based on an assumption that the **default body is that of a non-disabled white young adult cisgendered heterosexual man.** This means that Disabled people, women, racialized communities, the elderly and anyone who's being or characteristics fall outside of that assumed "normal" are often not built/designed for. This bias is also prevalent in data and non-human decisions. **This bias is not only in how people are (or are supposed to be) but also what they want (or what they are supposed to want), and how they want to achieve it.**

?: What are the assumptions you are making about who will use the project?

?:How many perspectives are at the table, are all voices given space to talk and be critical?

Rarity bias

Rarity bias is the idea that Disabled people simply are not that common. This is part of a long legacy of many factors, to name a few, a lack of representation in media, the effects of a lack of access to public space, and that many disabilities have no visual markers. This is often exacerbated by ableism and the other listed bias limiting the interaction between disabled and non-Disabled people in schools, workplaces and public space.

?: What percentage of your users are you expecting to be disabled? Are your numbers in line with the percentage of Disabled people in your region or country?

Gratefulness bias

This bias comes from a place of paternalism, it is an **assumption that Disabled people should be grateful for the care** and health that they get and that anything is better than nothing. It clouds our ability to be critical of the things we built in relationship to disability and lead to disability dongles.

?:How can you make sure that disabled voices are heard and respected? Even the critical ones?

Infantilization bias

Infantilization (to treat like a child) bias places Disabled people in a submissive position, to those who are less or not disabled. It devalues their perspectives, insight, their intelligence, their capabilities and their capacities. It manifests when people use child-like talk to adult disabled, or only asking the option of support people and these are often considered insulting.

?: What are the assumptions are you making about an individual's capacity?

?: How can you avoid overriding disabled persons decisions?

Exploitation Inspiration

Exploitation inspiration is a phenomenon where **Disabled people are used simply as a tool for inspiration instead of being full human beings. Their successes and failures are situated simply as examples to non-Disabled people.** This bias is incredibly prevalent in the media we consume and shows up in phrases like “at least you are not disabled” and “if they can do it, you can too”. The bias is often removing the agency and nuance of Disabled people, their lives and experiences.

There are also literal examples of exploitation of Disabled people, like below minimum wage workshops and other “feel good” businesses.

?: Are you showing Disabled people fully or are you using their images and stories to further your agenda or improve your image?

Visibility Bias

This bias is one that **links a disabilities impact on a person to the disabilities visibility.** It shapes the only valid Disabled people as looking a certain way and shapes the access to care people have. There are many disabilities that have no visual markers (like use of equipment, distinct mannerisms or differences in how the body looks). There are also many disabilities that are not easily seen from medical perspectives like on a test. This is especially true for psychiatric conditions, and neurodevelopmental conditions. There are also many conditions which are difficult to diagnose and many conditions for diagnostics are incredibly expensive, but that does not mean that that person is not in need of support or adaptation.

?: What percentage of your users are you expecting to be disabled? Are your numbers in line with the percentage of Disabled people in your region or country?

Siloed Bias

People often assume that **if a disability is severe enough then they will be taken care of in an isolated setting** and that very few people in the general public experience disability. This bias comes up from a variety of sources it is part of the legacy of institutionalization and part of the reason that there's still a push for community support for Disabled people. In different institutions this comes up in different ways and many institutions consider themselves too important, prestigious, or academic to adapt to the needs of Disabled people. But if they want to have an impact, support their clients and staff they need to adapt and assume that anyone interacting with them may be disabled.

?: What are the factors that may be limiting how welcome, safe and a part of your system Disabled people feel?

Data and AI

Data and AI are increasingly used to make decisions, shape technology and classify people. They encode bias in a from that may be harder to uncover and cause harm to people (especially from marginalized groups). For example hiring algorithms that disproportionately recommend hiring white men over disabled people people of color, and women. Hand washing stations with automatic sensors that don't recognize dark skin tones or Censoring in automatically generated captioning. Each of these **encode the different parts of abelism as a bias where they can be scaled quickly.**

?: What are the possible harms of mis-classification or mis-identification?

?: How can errors be flagged and corrected?

?: Who can report errors?

?: What bias are being built in to your data sets or algorithms?

Curative bias

Curative bias is the assumption that **any worthwhile solution or intervention must forever solve all the problems of that disability**. It manifests in the instincts of people to “educate” and “teach” instead of just providing assistance as guided by the disabled person. It looks like wanting to ”cure” autism instead of adapting a process/situation to a person. It looks like building wheelchairs that climb stairs instead of adapting the environment to have ramps. It looks like placing compliance requirements around care. It assumes that the disabled person does not have the knowledge they need to know what is best for their body and their brain. It sees Disabled people as something to be fixed.

A.16.1 Companion Booklet for final toolkit

Print out begins on next page.

Disability and Design

An Exploration toolkit

By Laure Tolsma

The font used in the toolkit is Atkinson Hyperlegible by the Braille Institute.

Blank cards have been included where they would not increase cost but additional cards can always be added. If you want to add you own cards to your deck the card size is that of A6, folding a A4 page in quarts allows you to easily add your own.

This card set is part of the Ms thesis of Laure Tolsma, feel free to contact her for more information and resources.

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Welcome!

This card set is to help you explore how to build with Diablility as a critical lens. Increasingly we are all asked to design more human products and comply with different laws without having a deep understanding of disability, accessibility or how they work. The cards are divided into section that you can use at different stages of the design process. Not all cards will be useful to all projects so use what makes sense for you, your team, and your project.

Foundations - 1st section is the foundations section, it will help you get started and learn some of the foundations concepts in the space of designing for disability.

Access needs - 2nd section is a tool that can help you understand what to keep in mind as you build and can also help you find solutions by looking at other disablitys with the same or similar access needs.

Fractruing Disablity - 3rd section is an activity with infomation cards that illustrate some of the concepts that underpin the actitiy. This activity helps you to understand not only the direct ways disabilities differ for each person's experience it but also can help give an indication of the different goals, lens, and perspectives you can employ when building or developing solutions. This can be used in an exploratory phase or along side co-design.

Centering Disablity - 4th section lets us understand what access and accessibility looks like by showing what inaccessibility looks and feels like.

Biases - 5th section can be used as a reflective tool to help you understand how ableist noms may have snuck their way in the underpining of what you are building.

Tips

Defaults need to be accessible, customizations don’t.

Practical solutions promote adoption, lower cost and avoid disability dongles.

Law suits are expensive and implementing wide spread changes after production will always be more costly then employing a critical perspective early on.

Notes for facilitators

The tool kit is large in both size and scope, therefor it is recommended that you pace the number of cards you put in front of people at a time, there will also be cards that aren't necessarily relevant to you and your situation so doing a quick pre sort may help.

There are many different ways of exploring the toolkit in a group and different sections can be applied in different ways. The cards are color-coded so that you can easily pull out the sections you need and it is easiest to use with a big table that lets you arrange the cards as you see fit. The backs of the cards are blank so you can flip them over and “deactivate” them.

In exploring the toolkit there are many ways to do so, some groups go conveyor belt style where they look at a card and move it on to the next person. other groups will hold up a card, look at and discuss that card in relationship to the product or problem space they are working in. some groups get different colored markers that they mark on the cards and they can keep track of which cards they have seen by keeping track of what color their marker is. don't be afraid to add additional support tools to explore the toolkit. this might be a timer to limit the amount of time you spend on each card, this might be giving the card set to your participants ahead of time so they can look through it and get comfortable with it. this might be sticking them on a whiteboard or wall near information that they correspond to. card set is made of paper so that you can easily move and manipulate it.

Design phases and the toolkit

Exploring

During the exploratory phase you are trying to gather as much knowledge and information about what you need to build and what it needs to account for for this it may be useful to explore the **Foundations**, **Access Needs** and **Fracturing Disability**. **Centering Disability** and reflecting on what **Biases** already exist in the space you are attempting to design in is also useful. **Access Needs** can help you understand what things you will have to account for in your solution. **Fracturing Disability** can help you get a nuanced perspective on target groups. **Centering Disability** provides foundational insights from disability studies and the **Biases** can be used to analyze existing attitudes methods and policies in the space that you're designing for.

Narowing

During the narrowing phase you have to sort through a lot of information to see what's really important. Here **Facturing Disability** can help you see more clearly angles of approach and places for intervention.

Building and testing

For the building and testing phases **Access Needs** can be used as a pre testing tool. **Biases** can be used to reflect on what you've built. the reflection all cards could be useful foundations can present issues that you need to make sure you've addressed access needs can be a way of reflecting on whether or not you've met the access needs and what access needs need to be met in the future fracturing disability can be used in reverse you could map your solution to where it falls on the spectrums giving you a more nuanced understanding of what your solution can and cannot do and the biases can be used to see if any have made it into what you've built.

Reflection

For reflection all cards could be useful. **Foundations** can present issues that you need to make sure you've addressed. **Access needs** can be a way of reflecting on whether or not you've met the access needs and what access needs need to be met in the future. **Fracturing Disability** can be used in reverse you could map your solution to where it falls on the spectrums giving you a more nuanced understanding of what your solution can and cannot do and the **Biases** can be used to see if any have made it into what you've built.

Sections of the toolkit

Foundations

Foundations are used to prime and help people explore disability. this can be used like a warming up activity or a way of gauging people's understanding and knowledge. it also can be used to develop a common language around disability.

possible activities include discussions about what information is new, listing the questions you have about disability using the card set as a catalyst to develop those questions. and that's a jumping off point for further research.

Access needs

The access needs are granular way of describing the different things you might have to account for when designing a product or service.

possible activities include identifying the access needs that your target group might have. using the access needs to describe your Co designer or specific user. in a checklist format to see if your design is failing to meet any access needs, this can be done by taking each card and looking through at whether or not your solution meets the access need. as an additional layer to personas or experience maps as different access needs might appear at different stages in a process and personas might be complicated by listing out access needs that are stronger than the average.

access needs can also work in a inspirational sense as each card comes with not only a list of common ways that access need is addressed but by also listing communities that experience that access need more strongly. this can let you look at communities that have specialized ways of addressing these access needs and you can learn from them.

Fractuing Disability

fracturing disability looks to really complicate people's understandings of disability. activities that you can do with these cards might be mapping your specific user, Co designer, or persona on the spectrums to see new places where you can intervene and adapt. there's a way to expand your knowledge on a disability by mapping your understanding of that disability and seeing what questions you still need to answer and research. you could also use it in a reversal as in you look at your product or solution and map what parts of the spectrum it addresses to see where there might be gaps or to get a better understanding of who your product would actually work for.

Centering Disability

Centering disability can be used as a critical reflection on what a product says. analyzing your product based on the text of the different cards can give you better insights into whether or not that solution we'll be adaptive or if it actually encodes some norbet of expectations that come from non disabled perspectives.

Biases

The biases list out some common components of abelism. you can use it at the beginning of the design process to see what other solutions in that space are saying and doing, what biases do they encode. you can look at biases and if you see a bias occurring more often in your problem space you can try and address that bias by bringing the card out of the toolkit and into a space where you'll see it more often. you might list out the different ways that bias is enacted in your problem space so that you make sure that you don't fall into those pitfalls. you can also use the biases as a reflective activity to look back on what you have built to see if any biases come out. the biases might also be more useful in places like policies and procedures as these non tangibles can be difficult to analyze without any tools and biases are often inacted through policies and social actions more than physical products or designs. the biases often come from earlier in the process in the forms of assumptions and using common language can help you identify them and address them.

Different.

Not good different.

Not bad different.

Just Different.

A.17 Card set version 3 reasoning

The fallowing section describe the cards, their origins and reasoning for the final toolkit.

A.17.1 Foundations

Naming the discomfort - Foundations 1

Naming the discomfort came out of observations in the survey, expert interviews, and the contextual observations. Often conversations about disability involve participants experiencing some discomfort. Wanting to do this work and wanting to do it well does not make you immune to the uncomfortable dialogues and situations that arise. This card primes people to that and begins to address this by identifying it as a normal part of the process.

What is Disability? - Foundations 2

What is disability is a foundational question needed to understand what this work means and does. There are definitions out there but not all of them are good and the next three sections into fracture disability into sections that people can recognise and begin to understand in a new more nuanced perspective. The decision to not force a definition but instead the three lenses came out of the literature review, the expert interviews and the survey. The three lenses that were chosen came out of the literature review as well as contextual observations as to what has worked or failed to work in past conversations.

The mind-body in disability - Foundations 3

The mind body in disability is a foundational concept that works to link a person's experience of their own body and mind. Often there is a disconnect in dialogues about medicalized bodies between the physical body and the individual inhabiting that body. It is important to recognise that disability affects both and to centre that connection. The language of mind body comes from disability studies.

Disability as a (social) phenomena -Foundations 4

Disability as a social phenomenon is a key aspect for understanding how disability operates in societal context. Designers who are attempting to build anything related to disability will have to account for, not only, the disabled bodies and brains that they are designing for but the contexts those people exist in. This framing also is connected to the social model which is the model of disability that most people are familiar with and is shaped within institutions.

How disability shapes expectation - Foundations 5

What does it mean to be disabled centers the possibility or lack of possibility that is often socially constructed around disability. It is important to identify that people's assumed possibility is shaped by their perceived ability or disability because it can begin to help make sense of the different ways ableism operates in society. It is also important to identify that there are connotations around disability that are not just social but physically limit what a disabled person is allowed to do. This card is underpinned by the literature review and specifically a in-depth understanding of ableism and how it operates.

Dis-future - Foundations 6

Disability future comes out of an anti ableist framing of the future that also aims to address a eugenics tendency within technology. It also highlights the possibility of technology to address issues and the perseverance and existence of disabled people.

What disability can tell us about technology - Foundations 7

What disability can tell us about technology aims to Center the possibility of disabled insights in technology. This concept comes from disability studies and the contextual observations since when disabled opinions are not seen as insights they are dismissed as well as technology having a deep and rich history with disability that strengthens what we built and collectively what is possible.

Laws - Foundations 8

For many of the target users of the card set a driving factor for picking up the work of designing for disability is that of the legal requirements that exist in many countries and additional accessibility legislation like the EU accessibility legislation. It also highlights the importance of policy and legal structures this is common in disability activism work. Legal compliance is a common factor in why people decide to explore accessibility so it is beneficial to prime that and get teams on the same page.

A.17.2 Centering Disability

The section of centring disability aims to address the chronic under utilisation of the perspectives of disabled people in disability related work. Within disability related work there is the phrase “nothing about us without us” it centres that disabled people are central in this work. That is because disabled people experience the effects of abelism, they understand their own needs and the needs of their community better than an outsider would. It is also a slogan that attempts to dismantle the pity culture around doing disability work and by having this section take concepts and foundational ideas from disability studies and making them accessible to people outside of this work we can prime people to respecting disabled opinions as insight.

Forced Intimacy- Centering Disability 1

Forced intimacy is a disability studies concept that highlights possible experiences of disabled people within co design or simply when interacting with the systems that aim to serve them. It is a critique on the standard operating methodology around disability and it is a concept that may help shape equitable and ethical design. It was also an experience that was discussed in disability studies as well as observed in the contextual observations related to this work.

Disability Pride- Centering Disability 2

Disability pride is a concept and framing that centers and humanizes disabled people, it works against some of the bias are common and is inherently anti ablest. The need to humanise disabled people and uplift their experiences and existence came out of not only the expert interviews and literature review but also the contextual observations, it also is a framing that pushes back against pity as pity does not lead to desirable outcomes.

Access vs Accessibility -Centering Disability 3

Access versus accessibility attempts to create a more nuanced understanding of the two terms beyond the “buzzword” understanding. Access this will work that comes from disabled communities to describe what is limited in certain interactions. Accessibility is more of a broader term that does relate to disability but does not come explicitly from disability in it’s colloquial understanding.

Variety within disability and how it shapes our language - Centring Disability 4

This card came out of the research activities as well as the literature review and attempts to explain one of the common questions that gets asked when people start doing disability related work. The question of what the proper language to use is because there is often discomfort around the fear of using the wrong language. This card attempts to present an understanding that comes with time early on.

Disabled people and people with the disability. The language of curative possibility - Centring Disability 5

Observations about curative possibility came out of an intersection between the literature and the contextual observations, within many systems and tools care is predicated on being able to cure or forever solve the problem at hand. this could possibly come from an attitude of do not put a bandage on a problem, but it’s leads to not necessarily useful assumptions about how to intervene and for many individuals there is no cure and there is no solving there is simply adapting around the disability. this is also further complicated by access to medical spaces as not everybody's access to a listening and competent doctor is equal due to issues like gaslighting, racism, sexism and classism.

Disability Dongles- Centering Disability 6

disability dongles were one of the foundational lenses that began this thesis, the observation of a tool intentions being so out of line with its perceptions and utilizations because of a simplified and one-sided understanding of disability is the cornerstone. This example and line of inquiry is useful in starting to look critically at what has been built. In the past not every technology that attempts to interface with issues of disability is just or equitable and many perpetrate and further ableist tropes. Disability dongles are a distilled concrete example of that and that is why they are included in the toolkit.

Empathy- Centering Disability 7

So often in design education we are asked as designers to have empathy for our target group, we go through work to develop this empathy and it is a cornerstone idea especially in" designing for disability". However this is not always accessible to everybody, being asked to have empathy for someone in crisis or dealing with something really difficult is not always useful. Empathy has a neuro normative presentation which is held above all other presentations, if we want diversity in who designs we have to accept diversity in methods. There is a wide presentations of empathy across all the different types of people. Empathy coming from autistic folks looks different but is not less valid. Empathy coming from people with mental health issues looks different but is not less valid. Sometimes empathy is inaccessible based on a person's circumstance, if a designer is under stress it is inappropriate to ask for empathy. Especially within the fields of designing for accessibility, empathy if not fully developed turns into pity. Disability first spaces have a different presentation of empathy then non disability first spaces. This empathy in disability for spaces looks very different but is oftentimes more authentic. No matter what empathy we end up using when we are designing it probably is not empathy exercises which have been documented to be detrimental and lead to a very one sided simplistic understanding of what is ultimately a human experience.

Access to public space - Centering Disability 8

Understanding that disabled people artificially have their access to public space limited and that this affects how we understand disabled people and their ubiquity is a crucial step in working through some assumptions that are common in not just designers but all people.

Find you access advantage - activity Centering Disability 9

The framing of access as an advantage is a tool used in disability studies to highlight the possibility within disability. This idea presents itself in another form in tools found in the state-of-the-art like the work of Kat Homes and her work in ”mismatched”. This was included as a possible more tactile and hands on framing of some of the theory in the rest of the card set.

Accessibility Statement - activity Centering Disability 10

Accessibility statements are a common tool in disability service design and if used properly can create equity. They force designer to start thinking through the different ways that their design will be used by people and is a practical exercise that may be more appealing to certain groups.

A.17.3 Fracturing Disability

This activity/section aims to create a more nuanced understanding of disability by fracturing the monolithic identity of disability. disability it’s complicated and full of diverse presentations needs conditions and strengths. when we view disability as a monolith it is harder to find handholds for intervening and supporting disabled people. this section aims to create nuance by exposing people to a number of spectrums that can be used to seed different ways of designing.

Spectrums - Fracturing Disability 1

Spectrums are how disability presents. Often in common communications around disability do we only see one end of the spectrum, the severest of presentations this ability is experienced on a wide spectrum and this it's not always understood widely a scene in the contextual observations. Most people think that blindness is on a binary you are blind, or you are not blind but most people who are legally blind have some remaining vision and perceive light as they exist on that spectrum [95].

Who do we design for? -Fracturing Disability 2

Who we design for and who we think we design for is a key question in signing for disability because it is useful to identify that we have preconceived notions of what it means to have a certain disability and what those people will need want and how they will perform.

Timelines and change - Fracturing Disability 3

Timelines and change affect how a person experiences their disability and how outside people, systems and tools can provide help. Disabilities are more often than not not fixed in their presentation and there are many disabilities that fluctuate but because they not understood as natural fluctuations they can be misinterpreted as a lack of impact or under certain circumstances ”fakery”. We all fluctuate in what we need on a daily basis and disabled people are no different but they are often expected to have a fixed presentation not because it is their reality but because it is easier to deal with.

Social vs mind body pain - Fracturing Disability 4

social versus mind body pain is a dichotomy that attempts to help people better understand the social and medical models and their intersection without the black and white understanding of the models. identifying the location of the discomfort of a disability means that we can intervene in the right space. if a condition has political and social pain points then it does not make sense to intervene on the mind body and vice versa. without understanding both sides of the spectrum we cannot map where on the spectrum something exists.

Invisible vs Visible - Fracturing Disability 5

The most colloquial then common understandings of disability tend to resolve around visibility. this is a documented issue in the literature and has been reaffirmed through the contextual observations and survey. The majority of disabilities (and conditions under the umbrella like neurodiversity chronic illness and temporary impairments) are invisible. this card acts as a contextualizing piece of information.

Stigma -Fracturing Disability 6

Stigma, surround disability and around the technology that is associated with disability is a factor that impacts what people end up making and shapes how easy or difficult it is to get at the information that is needed it is a factor that will impact how designers do this work so clearly stating it may help them identify potential and existing issues.

Medical understanding - Fracturing Disability 7

Medical understanding is often privileged in the space of designing for disability but not all medical understanding are equal for every condition. There are medical definitions both in the past and still that are racist and sexist and out of line with reality. Even when these understandings are not held by the medical community they are still in our language and in our social understanding of disability. I opening up the possibility that something could be misunderstood medically or that we just do not know that much about it yet we can place the value of medical explanation in different places and understand the different perspectives and ways of understanding are needed.

Assistive technology (AT and Cultural Adaptations) - Fracturing Disability 8

Assistive technologies are the most common presentation of disability that people can name. This is in part due to the visibility of them as stated in the card above but also because they are clear markers. There is a tendency to lean towards assistive technologies over cultural adaptations when there are issues that cannot be efficiently resolved through technology and are better suited to be equipped through cultural adaptations. This card aims to give people more options when they are designing and helps give an understanding of when that option is appropriate. When designers develop AT over cultural adaptations they often end up designing disability dongles.

Time of onset - Fracturing Disability 9

The common colloquial understanding of disability has few and clear origin points. We often believe that disability is exhibited from birth or after a traumatic accident or illness. But there are many disabilities that can arise after mild accident or injury, some disabilities that have been present since birth but only exhibit later in life. Some disabilities that are simply side effects of living a full and rich life. Some disabilities that exist in birth and are symptomatic early in life but fade out later. Some disabilities that are symptomatic at birth do not fade out later in life. All these presentations are valid and require their own logic to think through in order to design for them but if you only know the classical presentations then you will miss a richness to the presentations.

Vulnerability vs Susceptibility - Fracturing Disability 10

Vulnerability and susceptibility are two key ideas that are often confused aspects to disability. When we do not distinguish between the two we may lose a sense of agency over the problem. To illustrate with an example, disabled women are the most likely to be a sexually assaulted, this problem is often constructed in an only vulnerability sense when in reality it is often that they are more susceptible to it because they are more exposed to the possibility. Perpetrators of this crime often have access to these people in vulnerable settings, they understand that their word will be valued over the word of their victim, they simply have the opportunity to commit the crime and get away with it more for this group than another. Proposed solutions to this problem do not often attempt to interface on the side of the disabled person (but there are recommendations to increasing this populations access to language around assault and education around assault so that they can communicate when it has happened) but there is also another school of thought saying that we must avoid exposing this population to the people who would commit crimes against them by shaping our culture around the value of a disabled woman's life, atonomy and consent. By decreasing access to this group of people by those who would assault them and increasing reporting and filtering mechanisms to make sure these people do not end up in positions where they can assault. To lower the number of occurrences the advocates in this space want to reduce the susceptibility by reducing the exposure to the harm.

Intersectionality- Fracturing Disability 11

Intersections and intersectionality are key to understanding the diversity of experience within disability. without an understanding that factors beyond disability shape how a person experiences technology and the systems they live in is key to identifying spaces and places for intervention and possibilities of intervention. disability is 1 characteristic that people have it disabled person is not just a disabled person they are a woman or a doctor or a mother or a person experiencing poverty or high access to wealth. all of these factors shape how what we as designers build gets perceived and used so it is a useful tool for understanding these complexities.

A.17.4 Access Needs - 14 cards

The access needs section came out of an expansion on an concept often presented on public libraries websites. The websites of the New York city public library and the internet archive both have a section on print access needs to describe the tools they have to address the needs of blind and low vision people but also people with language needs. This idea was interesting since it maps across disability and it show in a concrete manner how people adapt tools to them. It also lets people see disability on a vary practical level. From there I observed and classified other access needs starting with my own mind-body, then of disabilities I have experiences with and then expanding out to other common conditions. Observations were also made in daily life as once a person begins to look for different access needs they become visible[2].

A.17.5 Biases

Biases were a reoccurring silent theme throughout this thesis. Specifically, the bias of ableism, most people and sources that I interacted with knew that ableism is bad, but to pull apart and parse out the different components was more difficult. In an earlier approach to this problem I thought that models would be a way of helping people identify the built in assumptions surrounding disability that exist in the world we live in. however the models were found to be very academic and disconnected way of looking. however these models are still important because they encode their respective biases. therefore the biases that intersect and overlap between the models were pulled out of their models and described in granular detail. that is what the following set of cards is a line by line description of what possible biases exist because of the models we hold. the assumption being that if we know the biases we can look out for them and mitigate their negative effects.

Normative bias- Biases 1

The normative bias was reaffirmed in the literature surveys and contextual observations. it describes a bias that exists in most spaces. it is also a bias or family of biases that we see in the failure to address the medical needs of women and of people of colour. We also see it re encoded in the machine decision tools that are becoming more ubiquitous.

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[2] This did take a few weeks of observations outside of the setting of the university but took place in several cites, 2 countries and many settings

Rarity bias - Biases 2

The rarity bias is one underpinned by the literature survey and contextual observations. It shapes a lot from a business and utility perspective and is arguably one of the more damaging ones because unlike the other biases it is harder to point people towards examples because the bias is that those examples are not in your space. It is possible to start illustrating it with statistics and to point out that there are more disabled people than we expect but statistics do not connect with people in the same way lived experience does.

Gratefulness bias - Biases 3

Gratefulness bias is often seen in the work of designing for disability as many people want to design for disability from an ultimately feel-good perspective. it is so built into our cultural dialogues around disability and exacerbates and is exacerbated by the other biases. it prevents critical reflection when people need to be critical about what they have built.

Infantilization bias - Biases 4

Infantilization bias clouds who we design for, it has been documented by a number of disabled people in the literature and also has been observed in the contextual observations. This bias is dangerous because it restricts the expertise of a disabled person about their own experience. It also limits what individual disabled people are allowed to become proficient in. This bias may exist more outside of technical design spaces then inside of them but it is shapes the knowledge and access to disability that then shapes these technical design spaces.

Exploitation Inspiration - Biases 5

exploitation inspiration is common bias that exists in especially designed and technical spaces. Would there be so many“first sign language translation gloves” if it were not for the exploitation inspiration bias?[3]. People keep “solving deafness for the first time”, over and over again because it is socially advantageous to do so. it is not a cost-effective solution, it is not even a solution but the deaf community asks for. It is a solution that gets you awards and praise regardless of the efficacy of the technology. This technology is not widely adopted, it would be a stretch to say it is even adopted, some may say that this is because the technology is in its infancy however there are other examples of high tech AT that were adopted even though they were in their infancy.[4] There has always been a high tolerance for **safe** trial and error within disabled communities, the difference is that the disabled people were asking for it and understood its value even when it was not ready. You cannot push innovation forward fully on influence alone.

Visibility Bias - Biases 6

Visibility bias predominantly came out of the models and the observations that disability studies has a much richer and wider understanding of disability than the colloquial understanding. This is in part because disability studies has taken the time to understand invisibility and how many disabilities are invisible. This bias is most likely so prevalent because of compounding factors of the other biases: rarity bias is exacerbated because you can not see invisible disabilities, exploitation bias exploits visible disabilities, infantilization bias interacts with visibility as people who are more visible or who shift from invisibility to visibility within an interaction experience infantilization more. By articulating this bias hopefully people will begin to understand a more nuanced definition of disability that includes invisible conditions.

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[3] 1)“The Talking Glove”, 1988, Stanford University. 2)“AcceleGlove”, 2002, The George Washington Univ. 3)“SignAloud”, 2016, University of Washington. 4)“BrightSign”, 2017. 5)“Sign-io”, 2017. 6)“Wearable YSSA”, 2020, UCLA

[4] speech to text software made it into schools well before it was good, in the beginning it was incredibly difficult to use not only in the accuracy respect but also in the user experience respect, however it was used, because for its target audience even a bad job was better than nothing. I have been using speech to text since the mid 2000s and I am very thankful for its improvements because it was not great in the beginning and the way it was used in the beginning was even more difficult difficult to use for the target audience then the general population.

Siloed Bias - Biases 7

Siloed bias interacts with rarity bias as they are often brought up in the same Instances and under the same conditions. Siloed bias constructs a mythical reality where in disabled people are fully cared for in a space outside of the public. This bias most likely comes from historical mistreatment of disabled people like that of institutionalisation. People holds this up as an example of the good they are doing looping back into the exploitation inspiration bias and the gratefulness bias. This idea in addition to not being true in every case (there are many disabled people who exist within the community because their presentation does not warrant institutionalisation and disability rights activists have been fighting for community based care since the 70s) it could also be rephrased to segregation. Segregation is a much less appealing idea to defend, because widely we understand segregation as a negative because it has the detriments that we see in a wide variety of documented instances. but this bias is used so often to warrant why and the institution or organisation or technology does not need to account for disabled people.

Data and AI -Biases 8

Ableism being encoded in machine processed decisions is a expanding and deepening concern. Within the literature and work being both done by academics and disability rights activists there is an increased concern that decisions made by machines will encode the biases above within their outcomes. We have already seen this within hiring, medicine, and we will most likely see this in the outcomes that are becoming increasingly common with the releases of new “artificial intelligence” tools. Large data is not currently equipped to deal with disability. There is not a single definition of disability. There is not a list of conditions that constitute a disability. There is not a list of behaviours that exhibit disability[5]. It is also worth noting that if disability does become observable from data that data may become medical and require extra protections under a variety of laws, not to mention the ethical concerns around being able to potentially diagnose someone with a disability from data you have collected possibly

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[5] There is barely a common language around disability see 4.7

without their consent for the purposes of diagnosis [6]. Disability is more malleable, exists on a spectrum, and fluctuates in ways that make it inaccessible via data. These tools collect averages, look for average presentations and exclude presentations that deviate too far from these averages. Normal disabled people may look like errors, flaws, or outliers in data. The visibility bias has the potential to be greatly exacerbated by machine process decisions. Machine processing and these tools may have a role in identifying ableism and its biases. It may have a role in developing the tools and facilitating people to develop the tools but solely a technological "solutions" are not really in the cards right now. whether these tools will settle into their place and where that place will be is yet to be seen (who knows maybe this section will be incredibly dated within a few years) but as I can see the current landscape AI facilitated solutions to disability problems is a red flag. By hopefully bringing an angle of critique to these tools from the perspective of disability it will bring to light the possible harms and maybe make people think twice about using these tools in relationship to disability and how we value the outcomes of these tools.

Curative bias - Biases 9

Curative bias is exhibited quite often within disability focused technologies. it privileges cure above adaptation. it is not always a realistic goal to cure or "solve" an underlying issue, often how technology and people intervene is by facilitating adaptation. adaptation of the environment, the technology, the system to the person. often this pursuit of cure bends the person instead of bending the system. By presenting this bias people might more easily be able to see the goal the adaptation over a cure.

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[6] This in and of itself is a widely impactful question. Is it legal or ethical to collect data that could lead to a diagnosis or identification of disability? if we count addiction as a disability is it fair that we now expose large swaths of the public to inherently addictive technologies? Is it ethical to diagnose someone who does not want a diagnosis? We often use proxies for sensitive categories because we cannot ascertain those directly, what are possible proxies for neurodiversity and is it ethical to collect these proxies when they do not actually measure the thing they aim to measure and instead create a messy potentially misinformed presentation of a person? But these are all questions for an ethicist, a lawyer or a philosopher or someone who is not trying to finish their thesis.

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communities, geographies and people, via coloisum, limit our ability to learn and care in appropriate ways for the wide range of conditions and ways of being. given the interpseronal nature of diablity it is important to remember that different cultures and languages have different approaches and that they may provide insights as to how to think about disability and how it works within our systems and what we build. [Online]. Available: https://cjds.uwaterloo.ca/index.php/cjds/article/view/645/899https://cjds.uwaterloo.ca/index.php/cjds/article/view/645

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