ABLEISM AT UNIVERSITY: EXPERIENCING STUDENT LIFE WITH AN INVISIBLE DISABILITY

Tara Tankink – Research Master thesis

Ableism at university: Experiencing student life with an invisible disability
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PREFACE: *LIEVE LEZER,*

Voor je ligt mijn masterscriptie getiteld *'Ableism at university: experiencing student life with an invisible disability'*. Deze 60 pagina's zijn het eindproduct van mijn onderzoeksmaster Research in Public Administration and Organizational Science. De afgelopen zes studiejaren heb ik me niet alleen academisch, maar ook persoonlijk enorm ontwikkeld, en in deze scriptie heb ik die twee ontwikkelingen bij elkaar mogen laten komen.

Ik begon aan het schrijven van mijn scriptie in Februari 2022, na 4.5 jaar nominaal studeren waarvan 2 tijdens de coronacrisis. En hoewel ik vol goede moed begon, trapte mijn lichaam en brein al snel op de rem. Mijn eigen onzichtbare beperking, die al jaren sluimerend op de achtergrond aanwezig was, had aandacht nodig. Ik besloot, onder protest, een tijdje niet te studeren en de juiste hulp te zoeken. In deze periode van rust heb ik mezelf stukje bij beetje terug gevonden. Ik leerde dat onder mijn rationele, hardwerkende en soms harde buitenkant, veel verborgen zat. Ik leerde dat emoties niet eng hoeven te zijn maar juist van veel waarde kunnen zijn, en dat tijd nemen voor een proces de resultaten juist kan verbeteren. In samenwerking met mijn geweldige begeleider Noortje heb ik deze processen en inzichten uiteindelijk een plek weten te geven in mijn scriptie. Ik ben dan ook trots op het resultaat. Een (kunst)werk waarin zowel mijn rationele, onderzoekende en analytische kant, als mijn emotionele, creatieve en empathische kant tot hun recht zijn gekomen. Ik ben blij dat ik deze vorm van onderzoek heb mogen leren kennen, en dat ik op deze manier ook heb kunnen bijdragen aan het leven van mij participanten.

Graag wil ik de tijd nemen om Dr. Noortje van Amsterdam, goed te bedanken. Noortje, ik weet niet of je door hebt hoe veel je voor mij hebt betekend de afgelopen tijd. Ik herinner me de eerste keer dat ik over jouw werk las, hoe enthousiast ik werd van deze kant van de onderzoekswereld en hoe graag ik met je samen wilde werken. Ik stuurde je een mail, puur uit enthousiasme, en ik kreeg er één terug met precies diezelfde toon. Ik weet nog hoe gezien ik me voelde toen ik een cursus bij je volgde en hoe geïnspireerd ik raakte van jouw visie op de (onderzoeks-)wereld. En ook toen we eenmaal samenwerkten bleef je me positief verbazen. Ik herinner me dat ik je vertelde dat het slecht met me ging en hoe jij precies zei en deed wat ik nodig had. Hoe je me ruimte gaf, er op een persoonlijk-professionele manier voor me was en me ondertussen prikkelde om te blijven nadenken over het proces. En hoe, toen ik terug kwam, je me uitdaagde om het onderste uit de kan te halen. Ik heb je begeleiding nodig gehad, niet alleen omdat het slecht met mij ging, maar ook omdat ik niet ben opgeleid om dit type onderzoek te doen: we hebben gelachen om al mijn positivistische trekjes. Al met al heb ik enorm veel aan je gehad waarvoor ik je wil bedanken. De academische wereld -en de USBO- mag in hun handjes knijpen dat jij er bent.

Zonder in emotie of nostalgie te vervallen wil ik ook nog mijn tweede begeleider- Prof. Dr. Paul Boselie- bedanken voor het zien van de waarde in deze studie en zijn bereikbaarheid en feedback, alle participanten voor hun openheid in het delen van hun verhalen, en mijn vriendin Dore voor haar ongelofelijke support in het proces van stoppen en de zaken weer oppakken de afgelopen anderhalf jaar.

Lieve lezer, ik hoop dat je veel leert, en voelt, bij het lezen van de volgende 60 pagina's!

Tara Tankink, Utrecht, 17 April 2023

ABSTRACT

Within universities, the architectural design of learning spaces and intellectual design of learning programs remain a reflection of historical exclusion of disabled individuals. And while research on visible disability-inclusion is increasing, invisible disabilities -which are larger sources of drop-out and affect more students- are being left behind. Moreover, the vast majority of the small number of studies on invisible disabilities at university, exclude the perspective of the students themselves. Therefore this study answers the question *'How do students with invisible disabilities experience studying at Utrecht University?'*. Visual-interviews, diary-interviews and focus groups were applied to step into participants' lived experiences. Results show that there are five important themes within invisibly disabled students' experiences: (1) the invisibility of their struggles and investments to actors at university, (2) the stigma with which they are approached by actors within the university system, (3) the ableism within the university system disabling them through rigid rules, schedules, tests and assignments, (4) the mindset of individuality applied within the university, prohibiting them from reaching out for support and (5) an optimistic idea about a trend towards more inclusion. Findings show a powerful neoliberal idea of being personally responsible for ensuring optimal health and productivity, which decreases care-duties for organizations like universities.

CONTENTS

INTRODUCTION

'Bzz bzz bzz bzz' a rhythmic buzz comes from the back of the lecture room. None of my classmates seem distracted, their faces show focus on the materials. I try to stay in the room, stay in my body, but my mind keeps pulling me back to the times where I heard this familiar buzz before. Trauma therapy. I am back in the room with the dot on the screen going back and forth, back and forth, bzz, bzz, bzz, bzz. It feels like I am in cold dark water and something is pulling at my feet. I don't want to go under, I don't want to remember, I want to focus on my lecture. But this buzz, this buzz is pulling me in, pulling me under, why is nobody distracted?

I am a student and I have a disability which sometimes interrupts my day to day functioning. However, I am not in a wheelchair, nor do I walk with a cane or have a service animal. My disability is invisible, as are most diagnosed disabilities at present (Hendry et al., 2022, p.145). Officially, invisible disabilities are an umbrella term inclusive to all disabilities that interfere with day-to-day functioning but do not have a visible manifestation (Mullins & Preyde, 2013, p.148). These disabilities include but are not limited to ADD, ADHD, dyslexia and mental health conditions such as PTSD and depression (Sierra-Zarella in Baglieri, 2006, p.141). Having a disability is still, and has always been, an obstacle to full participation in society. Even the word disability itself roughly translates to 'loss of power' (Goodwin, 2020, p.63). This loss of power used to be evidently enforced, when even as early as the period of Plato's republic (427-347 BC), disabled individuals were sterilized by force or even killed (Goodwin, 2020, p.63). But also in later societies, the active exclusion of partaking in society and exercising power continued through, for example, participation in higher education.

DISABLING UNIVERSITIES

When the first universities opened their doors, applicants with disabilities were bluntly rejected. And while over time the laws changed and universities became legally obliged to include individuals with disabilities, they were not obliged to accommodate to the needs of these students. Therefore, the architectural design of their learning spaces and the intellectual design of their learning programs remained exclusively accessible for the 'abled' (Goodwin, 2020, p.64). Recently, accommodation provision has been included in disability laws and universities have started providing counseling, extra time and accessible spaces. However, the exclusivity of university spaces and programs is still tangible (Goodwin, 2020).

Universities are now called upon to serve larger roles in society, there is a desire to create environments that are more diverse and responsive to the increased diversity in the student population (Cory, 2005, p.5). At the university where I study, Utrecht University (UU), there is a special committee that focusses on equality, diversity, and inclusion. The inclusion team has five main objectives:

1. Increasing awareness with regard to equality, diversity, and inclusion within and outside the university
2. Actively supporting and promoting equality, diversity, and inclusion
3. Making employees and students feel welcome and valued at the university
4. Stimulating an inclusive, open, and safe learning and working environment
5. Monitoring the progress of these actions

One of the main pillars of their inclusion policy is disability inclusion (see image 1). However, within policy statements or council objectives, invisible disabilities like mine are not mentioned.

Image 1: UU inclusion
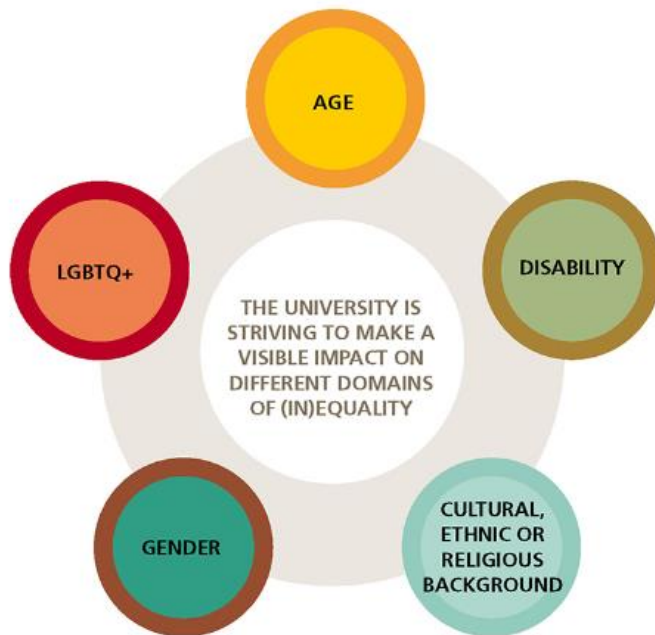
When reviewing the literature on students with invisible disabilities, I quickly understand the UU's difficulty for providing policy. Very few studies are published, and in even fewer the perspective of the students themselves is considered (Cory et al., 2005, p.11; Hendry 2022; Morina, 2022, p.4). Moreover, the vast majority of this small number of published studies is based in the United States, which has a university system that is very different from the Netherlands and is thus difficult to compare. Meanwhile, more and more research is published in which authors state concerning results regarding drop-out rates and deteriorating mental and physical health of university students (Nottage et al., 2022). Recent research even shows an increase of 15% in student suicides in the Netherlands (RIVM, 2021). Specifically in Utrecht, recent analyses show that more than 25% of the student population has invisible psychological disabilities (GGD, 2021). Some researchers state that universities are disabling their students by not providing the right curricula and spaces for those that need it to succeed (Maxam & Henderson, 2013).

THIS STUDY

Since students with invisible disabilities are significantly less likely to graduate after starting university (Goodwin, 2020, p.67), and 85% of students with invisible disabilities feel unsupported to disclose within a university environment (Morina, 2022, p.12), there is still much work to do towards building an inclusive university environment for all. Especially at the UU, where the diversity and inclusivity policy – currently not mentioning invisible disabilities in any policy plan- is set to be evaluated next year, this research could enrich the future of

invisibly disabled students. The first step towards creating inclusive policy solutions, is understanding where the problem lies.

Therefore, I have studied the question: *'How do students with invisible disabilities experience studying at Utrecht University?'*. I have done so through a combination of two arts-based methods: visual-interviews and diary-interviews, supported by additional focus groups. These methods have allowed me to step into participants lived experiences, create a common understanding of their world and have in depth interviews on what matters most to them.

I write this research from a critical-feminist standpoint, which means that I take a deep look into the power structures, societal discourses and narratives surrounding participants' accounts. It also means that I, as a researcher, do not claim to be objective and that there will thus be some normative writing; the goal is to expose power structures and improve the societal position of an historically disadvantaged group, which means that I see a 'right' and a 'wrong' in the way the current system is shaped. I will explain this more in the methods section.

The results of this study scientifically contribute to the scarce body of literature on invisible disability. Methodologically, the application of arts-based methods offers a new and innovative way of gathering data related to invisible disabilities. Societally, this research is in line with bigger discourses on diversity and inclusivity, ableism and individuality, which means it can contribute to a larger conversation about invisible disabilities and their place in this society. And practically, this research provides tangible and concrete data for the Utrecht University Inclusion Committee to work with when evaluating their policy plan next year.

THEORETICAL GROUNDING – THEORIES TO DRAW FROM BEFORE STEPPING INTO THE FIELD

In the previous chapter, I wrote about the meaning of the word disability as the loss of power (Goodwin, 2020, p.63). I think that if we break it down, the one thing underlying every angle of this research is power - individual power, group power, societal power, al creating opportunities and obstacles for those with disabilities-. According to Foucault, power exists everywhere, but the power to control bodies, biopower, is enabled by individuals' desire to live up to the norms of normality (Foucault, 1985 in Norstedt 2019, p.15). This is societal or systemic power because it is institutionalized. When the body is presumed to be something one can control, institutions like universities can use systems of surveillance to make individuals perform to their roles in institutional objectives (Dolan, 2021, p.10). However, Wendell (1989) states that when individuals show that they deviate from the norms of normality, a process of 'othering' is created between groups.

> *If you are 'other' to me, I see you primarily as symbolic of something else – usually, but not always, something I reject and fear and that I project onto you' (Wendell 1989: 116 in Norstedt 2019 p.15)*

In this process of othering, systems of oppression are created and individual power is lost. Think, for instance, about students who show symptoms of ADHD; having difficulty focusing on the task at hand without getting distracted. When assumed that they can control their body and mind, the lack of focus can be seen as a lack of commitment to the task (institutional objective). Within the university system (organizational power), this lack of performance within the assigned role might be penalized with a low grade, and other students (group power) might

conclude that their disabled peer is someone to not include in group-projects anymore (othering). Within this process, organizational, societal, and group power are used as different layers through which to protect the status quo by reproducing standing norms and values and penalizing individuals through exercising power.

Within the broader picture of structural usage of power by organizations and groups, the loss of individual power can be explained by Social Identity theory (Ysasi et al., 2018). On the individual and group level, social identity theory shows how people use social constructs to label individuals that are different from the majority, thus starting a process of othering and shifting the power structure between the majority and the minority. Goffman (1963 in Ysasi et al, 2018, p.24-25) states how this can also create self-stigmatization where internal judgement -regularly resulting from external influences- causes feelings of inadequacy for the minority (I received a low grade so I am not smart). Critical disability researchers seek to flush out attributes of inequality and injustice and replace oppression with empowerment (Allen, 2020, p.103). They do so by changing the narrative from disabilities as a deviation from the norm to disability as a construct and product of social and political power structures.

THE MEDICAL AND THE SOCIAL MODEL OF DISABILITY

Critical disability researchers adopt a social model of disability. In this model, disability is viewed as socially constructed. The explanation of its changing character within society lies within social structures, not within the individual (Allen, 2020, p.15). In other words, if individuals with disabilities are restricted from partaking in society, this is because society has failed to incorporate their needs (Goodwin, 2020, p.64). The social model directly contrasts the medical model of disability. The medical model assumes that disabilities are problems of the individual because the individual deviates from the social standard. The higher education system relies heavily on structures finding their origins in this model. Think for instance of separate high schools for individuals with learning disabilities,- and the individual responsibility to gain accommodations to fit within the standardized learning structures of universities. In the medical model, teachers look for what is missing or 'deficient' within the individual that is preventing them from succeeding in school (Goodwin, 2020; Rosetti & Ashby in Baglieri 2006, p.91). As Morina (2022, p.13) states *'teaching systems are inflexible, overly homogenous and faculty-centered'*. Students with disabilities are tolerated, they are not empowered or seen as unique individuals that contribute to diversity in the classroom (Maxam & James, 2013, p.75).

Previous research suggests that shifting from a medical model mindset to a social model mindset helps students with disabilities considerably. If teaching practices were more inclusive from the start, not reliant on students asking for them to be more inclusive, barriers for students with disabilities could decrease (Maxam & James, 2013; Morina, 2022). Within the social model *'a disability is not a disability until interacting with inaccessibility and ableism'*. Rosetti and Ashby (in Baglieri 2006, p.92-93) describe:

> *Rather than asking what the student needs to change to succeed in the classroom (or stating that certain students do not belong in our classrooms), the social model asks, "what needs to change about the classroom and the teaching to make learning happen for this student, to allow the student to show all that they know?"*

Many researchers compare the medical and the social model like they are black and white (Goodwin, 2020; Baglieri, 2006; Maxam & James, 2013; Morina, 2022). However, there is also a call for a more mixed model in

which aspects of a social model are gradually injected in the current medical model to make a change easier (Griffo, 2014). This indicates that there could be a continuum between the two models, rather than them being two opposites with no in between. Within the results section I will dive into how my participants perceived this at Utrecht University.

SENSITIZING CONCEPTS – CONCEPTS TO TAKE GUIDANCE FROM DURING FIELD RESEARCH

ABLEISM

When looking at society from a social model of disability, a disability only becomes a disability when interacting with ableism (Rosetti & Ashby in Baglieri 2006). Ableism is a term referring to the image of what it is like to be fully human. This image can consist of beliefs, processes and practices constituted within society (Brown & Leigh, 2020, p.13). In my case, I interacted with ableism when the buzz in my lecture room triggered flashbacks and I could not focus. The idea that I had to stay focused, control my body and not get distracted by this seemingly harmless buzzer, was an ableist image of what a fully abled human would do. When I interacted with this ableist image, I felt disabled.

What I felt in this situation was internalized ableism, and I am not the only one experiencing it. Kattari et al. (2018, p.486) described that their participants feel a culture of ableism around them, resulting in internalized notions of ableism. They connect this to 'compulsory able-bodiedness', which constitutes the belief that nondisabled individuals are superior to disabled individuals. Kjaer and Van Amsterdam (2020) have written a book chapter on their experiences being invisibly disabled and working in academia, from which I would like to quote two interactions with ableism to illustrate:

> *Although noting ableist is said, I strongly associate these words with ideals about long working hours and hectic schedules with little time for or understanding of self-care. I say noting. I should say something. But I am not prepared, I do not have my speech ready. I don't know them well enough to assess how to present the fact of my illness to them. Framing the first introduction just right is so important. (p.307)*

> *With the back to back presentations, social events in the evenings and the few hours of sleep I manage to get because my PTSD flares up when I have to sleep in unfamiliar surroundings, I feel like I do not possess the productive body academia is geared towards. (p.306)*

Ableism and compulsory able-bodiedness are notions that are deeply rooted in society and are often internalized by individuals. Therefore, they are easily overlooked within participants' accounts, or falsely categorized into individual (dis)abilities, reproducing a medical model mindset. This is something to be cautious of when studying a topic as sensitive to ableism as (dis)ability. Critically understanding the roots of ableism will help me flush out ableist notions in participants accounts of their abilities in this research. Moreover, taking the history of ableism and disabilities -disabled individuals being killed or sterilized- into account, I wonder whether not all notions of (dis)ability are actually rooted in ableism.

INVISIBLE DISABILITIES

As explained in the previous chapter, research into disability has thus far mostly focused on visible disabilities, while invisible disabilities are currently significantly more common. The definition of an invisible disability seems

straight forward: it is *not* visible. However, in many different articles, many different aspects of the concept are highlighted, which is understandable given the different focusses of the literature. In the coming sections I will outline some features of the literature on invisible disabilities and relating concepts. However, note that these definitions are to be interpreted in their own context, time, and place. There is no one truth or one definition, but being informed on the findings of those who went before me will help both you and me understand the context of this research better.

Mullins and Preyde (2013, p.148) and Morina (2022, p.2) write *'Invisible disabilities can be considered an umbrella term to refer to disabilities that interfere with day-to-day functioning but do not have a physical manifestation'*. However, according to the Invisible Disabilities Association (IDA) they exclude an essential group of invisibly disabled individuals. The IDA suggests that invisible disabilities encompass *'psychological, neurological or physical conditions that constrain afflicted individuals' movements, senses or activities but which are invisible to the spectator'* (De Beer et al., 2022, p.1). Thus, although invisible disabilities do not have a *visible* manifestation, they can have a *physical* manifestation. Dolan (2021, p.2) summarized both definitions when stating:

> *Invisible disabilities refer to any physical, mental or neurological condition that limits a person's movements, senses, or activities, that is invisible to the onlooker*

After providing readers with a relatively general conceptualization like those mentioned above, most authors dive into possible symptoms that fall under the umbrella of invisible disabilities. Syma (2018, p.113-114) for instance writes that symptoms such as debilitating pain, fatigue, dizziness, cognitive disfunctions, learning differences and mental health disorders as well as hearing and vision impairments can be linked to the umbrella term invisible disabilities. They then add that these symptoms can lead to diagnoses such as depression, bipolar disorder, schizophrenia, anxiety disorders, epilepsy, HIV, diabetes, chronic fatigue syndrome, ADD/ADHD or dyslexia. Santuzzi et al (2014, p.204) add sleep disorders, chronic pain conditions and PTSD to the list.

Prince (2017, p.77), I think, gives a wonderful summary by stating: *'invisible disability is not a clear cut clinical category or a distinct social identity, we need to think of visible and invisible disabilities as located along a spectrum of conditions and specific contexts'*.

In stating this, Prince addresses my concerns with the current body of literature on invisible disabilities: most other authors use the word 'diagnosis'. I think this is problematic because a disability is also a disability before a professional puts a label on it: a leg is also broken before a doctor tells you that it is. I think the focus on diagnoses might, in itself, be a result of the dominant ableism discourse in current society: you are able until proven otherwise. In this research I have used Prince's conceptualization for selection, to be as inclusive as possible. This means that I actively deviate from the conceptualization used by the university, which needs a professional diagnosis to take a disability seriously. In doing so, I attempt to shift away from the universities medical model mindset, and get closer to the social model mindset in this research.

INVISIBILITY

One thing that concretely separates individuals with invisible disabilities from those with visible disabilities is their visibility. Research suggests that individuals with invisible disabilities 'travel between two worlds' (Hendry

et al 2022, p.152). They travel being invisible and being visible by highlighting or concealing certain parts of their identity. In an auto-ethnographic story Allen (2020, p.109) shares:

> *I realize now that I have lived my whole life somewhere along the borderlands of being a non-disabled and disabled person. I could present myself as non-disabled person even though I experienced qualities of certain disabilities. I could use the invisibility of my disabilities to my advantage, even if unintended*

Because of the invisibility of their symptoms, invisibly disabled individuals usually face more misunderstandings, stigmatization and misperceptions and navigating daily live can be challenging (De Beer et al, 2022, p.2). Someone with a chronic pain disorder, for instance, is allowed to park in a disabled parking space but is not visibly disabled. This can result in nasty glances or comments from bystanders. Or, as Syma (2018, p.116) states: *"when a disability is invisible, coworkers may believe that the person with the disability is actually faking the disability to get an accommodation, thus leading them to see any accommodation as less fair"*. Previous research shows that many participants highlight the invisibility of their conditions as both a blessing (being able to pass) and a curse (less understanding) (Hendry, 2022, p.146). Mullins and Preyde (2013, p.155) even got suggestions from their participants that some sort of 'marker' for their disability might help validate others understanding;

> *Well it would certainly be easier if I had like a blue spot on my hand so I could say here, see. You know, this is my disability*

These participants, however, did want the mark to be concealable. They did also find comfort in their invisibility. Finding both comfort and discomfort in invisibility, is a trend that I have to critically assess in this study. Finding comfort in invisibility could be linked to the previously described compulsory able-bodiedness; when your disability is invisible, you come across as able-bodied. In a society where ableism is deeply rooted, that is a comfortable path to take. However, growth usually happens outside of the comfort zone.

PASSING

By remaining invisible, individuals can 'pass' as nondisabled. Allen (2020, p.107) describes an act of passing as 'performative able-bodiedness'. Passing is about the creation, imposition, adoption or rejection of identities. Passing refers to the moments where a person with a disability successfully appears to others as nondisabled, by withholding certain information or highlighting certain aspects (Prince, 2017, p.79). Kjaer and Van Amsterdam (2020) write about seeing an invisibly disabled individual in a hospital setting, that they would have not recognized as disabled without the hospital context:

> *I look around at the others. A particularly beautiful woman in chic sandals catches my eye. I think that I would never have known that she had MS if I had seen her in the 'real world'. I think that it must really help her to be able to pass so easily. I wonder if people think about me the same way* (Kjaer & Van Amsterdam, 2020, p.299)

Ginsberg says that passing is about the visible and the invisible, the seen and the unseen, and that those who use passing to cross borders may be seen as trespassers -for instance when identifying as a person with more privilege to escape the oppression of their own identity- (Allen, 2020, p.107). While passing may be seen as a privilege, it also places a huge burden on individuals who seek validation, community, or accommodations (Kattari et al, 2018,

p.478). Passing can cause 'inner dissonance' (Norstedt, 2019, p.15). This calls into question whether passing could actually been seen as a symptom of an invisible disability rather than a coping mechanism.

> *Passing has only ever pushed people further away. (Allen, 2020, P.111).*

Whether you see passing as a symptom of invisible disability, or as a coping mechanism, depends on the comfort or discomfort you experience with invisibility and is thus, again, linked to ableism. If you experience discomfort with invisibility, then passing feels like a symptom of the disability (nobody sees how bad it is). However, when you experience comfort in invisibility, passing can be practiced as a coping mechanism (nobody has to know you are not able-bodied). These two can also co-exist or interchange, they are not black and white. But, in passing, one practices performative able-bodiedness, to fit into the ableism discourse. In this study, it is therefore most important to be critically aware of acts of passing done by participants, within and outside of the research context.

COVERING

Within the act of passing, one is often actively concealing a disability. This involves a very active and effortful management process to downplay the significance of the disability, which can absorb cognitive resources and energy (Santuzzi et al., 2014, p.206). Concealing can involve presenting the symptoms of one condition as those of another, for example stating to have had a bad night sleep while one is actually depressed or suffering from PTSD (Prince, 2017, p.79). Concealing an invisible identity can lead to feelings of isolation and fragmented self, to negative job attitudes, decreased job satisfaction, increased psychological stain and higher turnover (Santuzzi et al, 2014, p.207), it can also lead to a reduced sense of belonging, reduced self-esteem and reduced team-commitment (Santuzzi & Keating, 2020, p.332). However, the decision to keep covering seems justifiable, especially in academia where a 'healthy mind' is your main organ of insight and thought (Dolan, 2021, p.4). In this study, it is important to be aware that covering is yet another way in which invisibly disabled individuals invest more energy into existing within the ableism discourse.

DISCLOSURE

Disclosure refers to making an invisible disability visible (Prince, 2017, p.79). Kjaer and Van Amsterdam describe their thoughts about disclosing their disabilities in their book chapter:

> *The chapter also entails me coming out. [...] What will the content of this writing do to my career opportunities? And how will the academic critique – feedback from reviewers and readers- feel? Do I really want to make myself vulnerable in this way?* (Kjaer & Van Amsterdam, 2020, p.298)

Disclosing or 'coming out' can make an invisibly disabled individual vulnerable to others' opinions, critiques and stigma, which can make it hard to do. Morina (2022, p.12-13) found that of the 1431 students that participated in their studies, 1264 chose not to disclose their disability. This means that even though these 1264 students had self-selected into research on disability, they preferred to go unnoticed. These findings are a constant between studies from 1996 (Milne) and studies from 2020 (Grimes) and 2022 (Vergunst and Swartz). Prince (2017, p.80) calls the reason why so many chose to not disclose the 'predicament of disclosure'.

> *If they do not express their experience, there will be no confirmation of it. However, in communicating their experience, they run a risk of being called into question*

Unfortunately, there are still negative outcomes to disclosing. Economic research has reported negative employment outcomes for workers that disclosed and requested accommodations, as a result of this there was also more stigmatization (Santuzzi et al., 2014, p.213). This stigmatization can in turn affect invisibly disabled individuals deeply. Morina (2022, p.8) describes how the opinions of others influences self-perception and affected self-esteem in participants. Invisibly disabled individuals thus often find themselves in a constant cycle of weighing possible negative and positive outcomes of disclosure, passing, covering and adhering or not adhering to compulsory able-bodiedness.

Luckily, there are also many positive outcomes related to disclosing. Disclosure can reduce stress and feelings of isolation, it can facilitate social support and the building of networks and accommodations. Furthermore, Morina (2022, p.4) describes how students who disclosed in the first year of enrolment had significantly higher graduation rates. This calls into question why there are still so many individuals who choose not to disclose, could this be different in this study because of its different context (country, system, university) and culture? Which external and internal factors come into play when individuals decide (not) to disclose and to whom?

EXPLAINING

Because of the invisibility of their symptoms, invisibly disabled individuals find themselves explaining their disabilities significantly more than visibly disabled individuals. Many participants of previous studies describe this to be very tiring and sometimes emotional.

> *I get fed up with it (explaining), I just stay in the house now so I don't need to (explain). (*Hendry et al, 2022, p.152)

Allen (2020) writes about feeling like people view her as being lazy, selfish and apathetic and about being fed up with constantly having to explain or prove that this is not true. The sigma seems to increase even more when considering psychological disabilities: *'for some reason, people tend to think that if it is a psychological issue, it can be fixed by simple willpower'* (p.102). Explaining is yet another way in which invisibly disabled individuals interact with the dominant ableism discourse, investing time and energy into existing and participating like their peers. In this study, it is important to be aware of the energy it takes for individuals to explain, and to make hem see that their explanations go to good cause in this research.

MICROAGGRESSIONS

Having to explain over and over again can make individuals emotional. This could be linked to a more well-known term: microaggressions. Microaggressions can be summarized as everyday interactions that perpetuate inequalities and stereotypes against people who belong to marginalized communities (Kattari et al., 2018, p.479). When a person is frequently exposed to microaggressions, their mental health can suffer and it sometimes results in reduced academic performance (Kattari et al., 2018). Ableism can be indirectly experienced through many tiny (or not so tiny) situations on a daily bases, which can be dreadful for invisibly disabled people. For example, someone might not use words like 'lame' in front of someone they perceive to be mobility impaired, but they might use hurtful language to those they can't visually deduce it from, – like saying 'this is so depressing' in front of someone who struggles with depression. This can be an important part of participants' experiences with peers or teachers at university. However, they might not directly deduce these tiny interactions with ableism as microaggressions. It is

therefore up to me to be critically aware of this, and help participants in their process of understanding and battling the ableism that they face.

KNOWING YOUR SURROUNDINGS – PREVIOUS RESEARCH ON INVISIBLE DISABILITIES IN UNIVERSITY CONTEXTS

'Standing on the shoulders of giants' is the way we make science evolve. Therefore, it is important to take the results of those who went before me along before I enter the field. Although the literature on invisible disabilities in university contexts is scarce, especially when taking the student-perspective, different researchers have come before me in different contexts. The bulk of the research that I will take you through in this paragraph, has its origins in the US. In addition, there was one article about Canadian students (Mullins & Preyde, 2013) and one based in Singapore (Carlisle, 2022).

OBSTACLES

Mullins and Preyde (2013, p.155) describe how students with invisible disabilities face countless different obstacles in their university life. Specifically, they note that: *'the size of the lecture halls, other noises, speech of professors, and the number of students in the class present them with difficulties'*, resulting in decreased ability to retain key points during lectures. Morina's (2022, p.11) findings underline obstacles such as the number of students in a classroom and noise, and add the structure of the educational system in which a 'one size fits all' lecture method is applied.

> *The system is built for people who are quote-unquote normal and when you're not that normal person, that normal way of learning or that normal way of functioning in the world then you can face additional challenges on top of the regular challenges that are part of university* (Mullins & Preyde, 2013, p.156)

Several participants described how, although their effort was high, their performance was almost never a true reflection of their abilities. One participant of Mullins and Preyde's (2013, p.151) study notes it is like *'riding the wave, where if you're having a few good days you get lots of work done; if you're having a few bad days you don't get any work done and you hope that the bad days don't all clump together at important points'*. Participants also described how taking medication for their disabilities sometimes affected their performance because of lapses in memory, anxiety, decreased concentration or other physical symptoms (De Beer et al., 2022, p.4).

Other noted issues included riding a crowded bus to university and arriving over stimulated with no way to concentrate (Kreiser et al., 2015,p.433), not being able to stay seated during long lectures because of pain but not wanting to interrupt the learning process (Sierra-Zarella in Baglieri, 2006, p.141), financial stress because of periods of absence (Venville et al., 2016, p.572), but most of all: not being able to keep up with the constant pressure to perform because of fluctuating energy and ability without any real accommodations (Mullins & Preyde, 2013, p.152; Venville et al, 2016, p.572).

Many of these experienced barriers are an interplay between the individual ability and the university context. However, some authors also noted barriers that exist mainly on the individual level, mainly on the group level, and mainly on the university level. In De Beer et al. (2022, p.5) one participant noted procrastination as an individual level barrier due to their disability (ADD): *"I'd never be studying and I'd always panic and leave things to the last minute and be very paranoid and lose it and be completely anxiety-driven and that's how we operate,*

you procrastinate until you actually have enough dopamine released to actually do something". On the group level, multiple studies described how group projects within universities often created barriers for students with invisible disabilities. Kreiser et al. (2015, p.433) note that it is the negotiation of group membership and task-division that is most challenging and students with invisible disabilities worry a lot about their group going too fast and having to work extra hard to keep up with expectations:

> *I always feel that people think I'm very weird; maybe doing group work is so challenging. ... I want to be a better team member, and not to disappoint others, be less distracted. (Carlisle, 2022, p.129)*

> *...I don't want to slow anyone down...you remember who works hard, and I don't want to be one of the people that doesn't work hard because then no one's going to work with me (Kreiser et al., 2015, p.433)*

On the university level, several studies also noted how professors create barriers for students with invisible disabilities. Mullins and Preyde (2013, p.155) for instance describe how participants felt like professors think they are trying to get away with something when asking for accommodations. Kreiser et al. (2015, p.436) described this issue very lively in the following paragraph:

> *Threaded throughout the interviews were sentiments of the stigma felt from instructors and other students. Students described feeling resentment or a sense of unfairness regarding their needed academic accommodations. 'The faculty and [other] students almost hold it against me because I am getting special treatment. They can't see disabilities so they don't see something broken...' [student 4]. As conveyed from another student, They [instructors] complain about the extra work they now have to do. Like getting proctors, or simple requests for posting presentations early enough for us folks with disabilities to prepare. ...Why make me feel different or sneaky or less of a student?*

ACCOMMODATIONS

When individuals with invisible disabilities are growing up, the responsibility to find accommodations that they need rarely falls into their hands. Usually their parents negotiate this with the school, with their children operating as a passive recipient of needed accommodations. However, upon graduation from high school to university, the responsibility to actively seek out support abruptly shifts towards the invisibly disabled individual (Kreiser et al., 2015, p.427). This can be a difficult process, especially because the need for accommodations involves a process that can make students extra visible in a negative way, which can reduce the desire to request these accommodations (Mullins & Preyde, 2013, p.153). This visibility also comes with the possibility of resistance from other students or faculty members, who misperceive accommodations as an unfair advantage.

> *You could hear it in little, little comments like, "Oh aren't you lucky"* (Mullins & Preyde, 2013, p.154)

However, seeking out, finding, and providing accommodations has shown to have significant positive effects. De Beer et al. (2022, p.6-8) for instance talked about COVID accommodations with their participants. They got very positive responses regarding the communication and support coming from universities during this period. Participants felt like they were cared for by their university when, for instance, receiving little packages with food or soaps. The blended approach to learning – including more technology and ways to work from home- was beneficial to those struggling with anxiety and ADD and those who experience learning delays.

There were four topics that studies touched upon in terms of helpful accommodations: (1) the visibility of disability services, (2) disability education, (3) architecture of spaces, and (4) inclusive course design. For the visibility of disability services (1) Carlisle (2022, p.132) stated that at the start of the academic year, orientation programs that specifically included disability services meet and greet and peer-support groups were very helpful for students with invisible disabilities. Moreover, the more the clarity of the communication improved, the more helpful disability services were considered (p.133) – this means easily accessible web pages and broad and concise information on disability support-. In terms of disability communication (2), Ysasi et al (2018, p.27) stated that one of the most important actions to take was to educate the general public by replacing misconceptions and false assumptions with accurate information and facts. When writing about the architecture of spaces (3) Carlisle (2022, p.133) describes another important accommodation in providing 'natural restorative spaces' to allow students to escape. These are quiet, safe places for students to manage sensory overload and areas where students can rest between classes when physical exhaustion is a factor. Moreover, Sierra-Zarella (in Baglieri 2006, p.141) describes how students with learning disabilities can be supported by minimizing classroom distractions.

The most important helpful accommodation touched upon in all studies was the course design (4). There are many different facets to course design that proved to provide support. Mullins and Preyde (2013, p.158) for instance touch upon providing an outline of the lecture notes that includes the key points of the lecture with room for additional notes, while Sierra-Zarella (in Baglieri 2006, p.141) states that the freedom to take extra breaks would make all the difference for students with invisible physical disabilities, and flexibility in excused absences and exam scheduling would do so for students with invisible psychological disabilities. Course design and flexible practices can help students feel included, while rigid practices such as attendance requirements may increase levels of anxiety (Carlisle, 2022, p.134). Providing room for every student to show their talent also showed beautiful results:

> *One student consistently turned in sloppy written work. At first, I thought she was not doing the required reading and I assumed she did not care about the course. A few weeks later, during oral presentations on topics the students chose, she gave the most thoughtful and compelling presentation of both sections. Had we not included this assignment, I would have misjudged this student's competence and the class would have missed out on a wonderful learning experience. [...] Ask students how they want to present their work. Go beyond standard practices. The results will be surprising.* (Rosetti & Ashby in Baglieri 2006, p96).

From a more positivist viewpoint, there are studies that link accommodations to well-known HRM practices such as the AMO-model. The AMO-model describes how Ability, Motivation, and Opportunity need to come together to result in high performance (Van Berkel et al., 2022). Applied to the context of invisibly disabled students, this would mean that their ability to study should be supported by motivation to do so (which can be stimulated internally and externally) and strengthened by opportunity given by the university (such as course design, disability visibility and the architecture of spaces). However, within this view of accommodations, there is power play between the organizational level (the university providing or not providing opportunity) and the individual level (the student, the way their 'ability' is viewed, and the way their motivation is perceived). Therefore, I have taken up issues like these with a critical lens when they emerged in the data, critically assessing how power is used and which norms are upheld by these interactions.

METHODOLOGY AND DATA

'I think so I am'

This familiar phrase was first used by the famous philosopher Descartes. In his view, the human brain was the only thing reliable enough to discover objective truths in the world. Thus, senses were not reliable, knowing the truth was only possible through hypothesizing (brains) and testing what is 'out there' (reality). He called this radical skepticism. I do not agree with Descartes, and neither did a lot of other philosopher/scientists in earlier times. The notion of objective brains was resisted and phenomenology was introduced: the notion that truth lies within our senses and lived experiences. My research is built upon this notion. This means that I apply a constructivist ontology: reality cannot be accessed directly (through an objective brain) but rather indirectly through interpretation with our senses within our experiences (Cupchik, 2001).

I complement my constructivist ontology with a critical feminist epistemology, including a localist view (leavy, 2009, p.8). Applying a critical feminist perspective means that I have closely examined power structures surrounding and supporting the data that was gathered, in order to strengthen the societal position of my research group. In a localist view, the production of reality happens between individuals within interpersonal interaction, in which they do not report external events but produce situated accounts. These accounts must be understood in their own social context, which means the researcher (I) needs to be critically aware of social and political context surrounding the narrative that is created (Qu & Dumay, 2011, p.241). As Foucault said: wherever there is language, there is power. Applying a critical feminist perspective also means a dismantling of many positivistic dualisms such as subject-object, rational-emotional and concrete-abstract. Because true accounts can be found underneath the ruling power-structures (leavy, 2009, p.8).

Methodologically, this means that I have worked in an abductive way: I went back and forth between theory and fieldwork and let both feed into each other without using tests or billiard ball causality. I used theory as different lenses through which to interpret what I saw, or from which to draw when encountering something unknown in the field.

ARTS-BASED RESEARCH

In this study, I have employed arts based methods. Arts Based Research (ABR) can be seen as research that uses the arts, in the broadest sense, to explore, understand, represent and even challenge human action and experience (Wang et al., 2017, p.7). The writing of research, as the work of artists, is about (re)presenting a set of meanings to an audience. *"As writers and painters, we try to persuade our readers and viewers to see the world through our eyes"* (Leavy, 2009, p.11). Art and science both work toward advancing human understanding grounded in exploration, revelation and representation. Especially when conducting socially engaged research into lived experiences, like in this study, ABR can result in rich and meaningful data and outcomes.

> *A creative task may encourage thinking in non-standard ways, avoiding the clichés and ready-made answers which could be easily replied. In this way, an arts-based method or graphic elicitation tool may encourage a holistic narration of self, and also help overcoming silences, including those aspects of one's life that might for some reason be sensitive and difficult to be related in words* (Bagnoli, 2009, p.566).

ABR also gives voice to a larger critical movement in society in fragmenting many of the positivistic dualisms in research, like subject-object, rational-emotional and concrete-abstract. It does so by allowing researchers to be artists, allowing them to be both subject and object and creating space in the research process for emotions (leavy, 2009, p.19). Researchers using ABR are necessarily engaged, working on projects of importance to both self and others.

Moreover, the arts are known for being emotionally and politically evocative, captivating, and moving. Thus, as a representation form, arts can effectively communicate the emotional aspects of life. Emotions are often at the center of ABR, utilizing both the participants' and the researchers' emotions, and fragmenting the rational-emotional dualism. Emotions can even be seen as 'validity checkpoints' in ABR (Leavy, 2009, p.19). In fragmenting these positivistic dualisms, the role of power in the knowledge building process can be exposed and researchers can avoid creating knowledge that continues to be complicit in the oppression of minority groups (Leavy, 2009, p.9).

ABR can be used as a means of creating critical awareness, which is important in social justice related research that seeks to reveal power relations (p.13), like this study. Moreover, communicating data in an artistic way helps challenge stereotypes, build empathy, promote awareness and stimulate dialogue (p.14). Thus, applying ABR in my methodology gives body to the critical feminist epistemology of this study.

ABR also provided me with a pathway to understanding my participants differently. For example, visuals like photo's make up the vast majority of internet communication by students, using photographs and visuals in this research provided multiple opportunities to understanding and communicating with them (Wang et al., 2017). Moreover, the topic of this research is surrounded by stigma, which means it has to be approached with caution, and ABR provided a way to come close, while staying sensitive.

There are several things that differentiate ABR from regular interpretive, qualitative approaches. An important one is the target audience. ABR regularly targets a more diverse group of stakeholders including but not limited to community members and policy makers, because of the inclusion of a full range of sensory and literary levels. In this study, I will do so by using specific forms of dissemination in addition to academically written text: a form of exhibition including visuals, poetry and spoken word. This way of dissemination often enables more empathic participation and stimulates new forms of dialogue for social change (Wang et al., 2017, p.13). During data gathering and analysis, I have used visual art (visual-interviews) and literary art (diary-interviews and the creation of poetry) to gain close insights to the participants' meaning making processes surrounding their lived experiences of invisible disability.

VISUAL-INTERVIEWS

To visualize the invisibility of disabilities experienced by UU students, I used visual-interviews. Visual interviews are a variation of photo- interviews, which means that I have inserted the use of visualizations like photographs or drawings into interviews (Harper, 2002, p.13). Visualizations evoke deeper elements of human consciousness than words. This has a physical bases: '*the parts of the brain that process visual information are evolutionarily older than the parts that process verbal information*' (Harper, 2002, p.13). Verbal exchanges use less brain capacity than

exchanges in which images are being processed, which is a reason why photo-interviews have shown to process significantly more information than regular interviews (Harper, 2002).

> *Photographs appear to capture the impossible: a person gone; an event past. That extraordinary sense of seeming to retrieve something that has disappeared belongs alone to the photograph, and it leads to deep and interesting talk* (Harper 2002 p.23)

As described in most qualitative method books and articles, there is a need to bridge a gap between the world of the participant and the world of the researcher. Visual-interviewing overcomes some of the difficulties within in depth interviewing because within the visualization there is an anchored common understanding, which only increases through the interview process. '*In viewing photographs during interviews, meaning is co-created between the researcher, respondent and the image itself, further destabilizing the boundaries between 'insider' and 'outsider' positions'* (Shortt & Warren, 2011, p.24). Visual-interviewing adds validity and reliability to any research by creating common ground between the interviewer and the interviewee (Dempsey & Tucker, 1994, p.56; Harper, 2002, p.22).

Harper (2002, p.14), for instance, describes a study in which both photo interviews and regular interviews were used to study psychological stress. The conclusion of this research shows that photo-interviews provided precise and encyclopedic data, while control interviews were less structured. Moreover, in the control interviews the data seemed to be governed by 'the mood of the informants', while in the photo-interviews, the statements were in direct response to the graphic probe, and were thus seemingly more objective data.

There are different forms of visual-interviews. The first and most widely used one is the usage of visualizations made/selected by researchers within an interview setting. However, to get participants even more involved, interview forms such as reflexive photographs – using pictures made by participants- and photo novella -using photographs by participants specifically to empower them to create narratives about their lives- were introduced. The main goal of the last method – photo novella, lately called photovoice- is to allow those with little resources to document and discuss life conditions as they see them to communicate to policy makers where change should occur (Hemsworth et al., 2005, p.53-54). This is the method that I think is most fitting for studying the experiences of students with invisible disabilities, the method that will empower them most. It will also provide a more visible and almost touchable element to this research. However, I have not limited participants to the usage of photo's because of the sensitivity of the topic: I knew that I would not feel able to take a picture of my surroundings every time I felt disabled. I would, however, be able to draw something, write a poem, or find an image online to visualize my experience. Therefore, I would call it 'visual-voice'.

DIARY-INTERVIEWS

To gain even more insight into the lived experiences of students with invisible disabilities, I have combined the main method of visual-interviews with a supplementary method of diary-interviews. This means that I have asked participants to keep a diary during the period of data-gathering in which they wrote about their disability, the visualizations that they made, or other things they deemed important. Many scholars have come before me in using this method, Thomson and Holland (2005, p.203) for instance, draw from Foucaults 'technologies of the self' and German feminist scholar Frigga Haug's theory of how people become selves when constructing their method. In

their memory books, participants write memories down, which are later reappraised collectively to uncover and document their meaning within social constructs.

> *A method par excellence for exploring the ways in which emotions, motives, actions, choices, moral judgements, play their part in their memories. It gives insight into the way people appropriate the social world and in so doing transform themselves and it.* (Thomson & Holland, 2005, p.203)

Harvey (2011, p.665) states that diaries as methods can be both structured – with guidelines, almost like a survey- or unstructured – more autobiographical, recording events and emotions- . Diaries can be used to analyze the process behind experiences and provide context on participants' behavior and feelings, they can be a tool for scientists exploring sensitive topics (Harvey, 2011, p.666). I have allowed my participants as much freedom as possible and applied unstructured diaries. When I asked participants to gather visuals and keep diaries, I used the following prompt:

Beste X

Wat fijn dat je hebt besloten mee te doen aan mijn onderzoek naar de ervaringen van studenten met onzichtbare beperkingen. In de bijgevoegde tekst beschrijf ik hoe jouw deelname eruit kan zien.

Ik wil graag dat je probeert bewust te zijn van de momenten waarop je je beperkt voelt in de context van de universiteit. Wanneer je zo'n moment meemaakt zou ik het fijn vinden als je een visualisatie maakt; een foto, een tekening, een gedicht, een collage, een plaatje van het internet, de invulling hiervan is vrij en niet gebonden aan de genoemde voorbeeldcategorieën. Daarnaast wil ik je vragen om een klein dagboek bij te houden. In dit dagboek beschrijf je situaties waarin jouw beperking naar voren komt in de context van de universiteit. Bij het beschrijven van een situatie kan je bijvoorbeeld denken aan een beschrijving van de ruimte, de mensen die erin een rol spelen, hoe jij je voelde en waarom jij je zo voelde. Ik kan me voorstellen dat een notitie op je telefoon het beste werkt, omdat je die vaak bij je hebt, maar voel je niet verplicht het dagboek digitaal bij te houden.

Je mag je verzamelde materiaal voorafgaand aan het interview naar me opsturen als je dat prettig vindt, maar het is ook okay als je het op de dag zelf meebrengt. Wel wil ik je vragen om ervoor te zorgen dat je de visualisaties of uitprint of vooraf met mij deelt, zodat ik die ook bij de hand kan hebben tijdens het interview.

Mocht deze tekst vragen oproepen, of je gedurende het proces vragen hebben, neem dan vooral contact met mij op.

Tara

Participants' diaries have allowed me to come even closer to their lived experiences and have helped them to recall their emotions, feelings and thoughts in specific moment. This created richer and more in depth data from which to draw more valid conclusions.

INTERVIEWING

As both of my main methods include interviewing, I also want to take you through the kind of interview I have performed. For my interviewing technique, I drew from narrative interviewing. Narrative interviews have proven

to help researchers better understand participants lived experiences and behaviors by not setting out with a fixed agenda but letting the interviewee control the direction, content, and pace of the interview (Anderson & Kirkpatrick, 2016, p.631). In the narrative approach, the participants are at the heart of the process and their narratives provide the data. Within a narrative interview, the researcher usually poses one broader question like 'how do you experience X' and the participant takes over the interview direction from there. This provides rich insights into what is really important for the participants. Usually, a narrative interview ends with a combined narrative and semi structured stage with some questions the researcher prepares from literature and markers along the interview (p.632).

The main skills a narrative interviewer needs to have is being able to establish rapport and trust early on. Qu and Dumay (2011) describe how in qualitative interviews, a positive relationship with the interviewee and maintaining the flow of the interviewee's story are essential (p.148). For the narrative/semi structured phase of the interviews, I drew from Qu and Dumay's question list (p.149) in which they propose to use probing questions, specifying questions, structuring questions and interpreting questions like: Can you give me a more detailed description of what happened? How did your body react? Was anyone else present in that situation? Is it correct that you feel X? Moreover, for establishing rapport and trust early on I included a 'before the study' phase in this research, in which I sat down with participants to have a coffee in a café of their choice to get to know each other a little better. This proved very successful in creating trust.

FOCUS GROUPS

Although interviews were my main method of data gathering, I followed the interviews up with focus groups to provide room for open-ended questions that emerged from the data and brainstorming about advice, which all participants stressed as important. This resulted in another new pathway of looking at participants lived experiences and ways of fragmenting the dominant discourses. Especially the co-creation of narratives within the focus groups provided new and interesting data (Bryman, 2016).

DATA GATHERING AND ANALYSIS

I collected the data for this study between January 10th 2023 and March 8th 2023, before which I had done a pilot study in December 2022. In total, I performed 10 interviews of about 1.5 hours and held 3 focusgroups with 3-4 participants each that took around two hours. Before the interviews, I sat down with almost all participants to establish trust and account early on. Participants told me that this helped them be honest with me and gave them more trust in the research. Moreover, the one participant with whom I did not get the chance to sit down before the interview told me that they did not feel safe enough disclosing some personal information during the interview, because they did not know me that well and even connected this to missing our 'coffee date'. Therefore, investing this time (around one hour per participant) into establishing rapport, turned out to not only be worthy for the ethics of this study (hit-and run ethnography), but also for the depth and richness of the data.

Within the interviews, I approached the visuals that participants made as data while using the diaries as support material to enrich their narratives. Some of the visuals are therefore also included in the results chapter. Participants told me that they found the assignment that I gave them almost therapeutic. Robin said: *"The moment I saw my thoughts rolling out of the printer I felt rest, it felt so good."* While Jesse said: *"It really helped me to take a moment to reflect on these feelings, it felt great"*, and Sam said: *"I really noticed things that I would not have*

noticed had I not actively been reflecting.". All in all, they were positive about the assignment and the research in general.

During data analysis, I transcribed interviews and focusgroups in word, and coded them in NVivo, first thematically and then axially. Themes that emerged ranged from 'individuality' to 'relations with teachers' to 'need for action', which formed into paragraphs of the results chapter during axial coding. The interview transcripts ranged between 8 and 15 pages each. The total number of pages of data used for analysis was 163. Additionally, I performed an affective analysis. In other words, I coded fragments of texts from interview transcripts based on their affective resonance. Affect is *'the thing that gives you away: the tell-tale heart; my clammy hands; the note of anger in your voice; the sparkle of glee in their eyes…'*(Ahall, 2018, p. 39). As Ahall (p,37) notes, affect refers to *'A gut feeling [that] has its own intelligence.'* As described when outlining Arts Based Research (ABR), ABR gives substance to a critical shift away from positivistic dualisms such as rational-emotional. In positivistic research, researchers must be rational, while in critical research emotions are at the center of the data. Performing an affective analysis made the affect in this study tangible, utilizing emotions as data and getting to the core of participants accounts of invisible disability within systemic power structures (Leavy, 2009).

Analyzing on affect is another way in which I tried to expose power structures and gave substance to this research' critical feminist underpinnings. Emotion has long been associated with the feminine, juxtaposed to the 'reason' associated with the masculine (Ahall, 2018, p.37). This is still used as a strategy of keeping the feminine out of politics and political spheres and therefore also, research. In placing affect, emotion and body at the center of this study, I aim to resist this discourse within the academy. Moreover, performing an affective analysis helped me make participants' experiences tangible; bring across their true message. In this way, it provided rich and meaningful data for this studies' conclusions (Hemmings, 2012).

THE SAMPLE

Within this research, I spoke to people who identified as male, female, non-binary and genderqueer. To make sure no statements are retraceable to participants, I have used gender neutral pronouns and pseudonyms for everyone. I spoke to people who feel disabled by ADHD, ADD, Dyslexia, PTSS, Depression, Anxiety, Autism, Bipolar disorder, Chronic pain and many different home situations. There were two people who identified having (had) a physical disability (chronic pain & cancer), 7 people who identified having a learning disability (Dyslexia, ADD, ADHD) and 8 people who identified having a psychological disability (PTSS, depression, anxiety, bipolar). A lot of participants acknowledged more than one invisible disability in themselves, which is why I will not try to link any results to specific disabilities. Many disabilities intertwined and participants with physical disabilities showed psychological symptoms, while participants with psychological disabilities showed physical symptoms. My participants' ages ranged between 19 and 28 and they were in different phases of their studies: bachelor, pre-master and master. Together, they created a very diverse and interesting group.

THE LANGUAGE

Since all participants preferred participating in Dutch, all data was gathered using the Dutch language. Therefore, the affective analysis was also done and presented in Dutch. I did so to keep the integrity of participants' words intact, making their affect more tangible. However, as you can see the rest of this research is written in English. This is a conscious choice, made because using the English language can increase the outreach of this studies'

findings. All conclusions, analysis and results, as well as theory and methodology are understandable for anyone who reads the English language, and the Dutch poetry is available in an English translation for those who need it. However, those who use the translation must be cautious of affect that might be lost in it.

POSITIONALITY

While approaching this study as the researcher, I am also part of my population since I am an UU student with an invisible disability. This presented both difficult and beautiful situations during data collection. During data analysis, I coded all fragments of text where my personal experiences were touched upon or where I used them to gain more depth in the conversation and affectively analyzed them. This resulted in the following poem:

Ben ik een subjectieve onderzoeker of ben ik onderzoeks-subject?
Kan ik door mijn ervaringen betere vragen stellen of ben ik te direct?
Voel ik met je mee of raakt jouw ervaring er één van mij?
Ik ben geen psycholoog, ik ben niet je vriend maar ik ben er wel bij

Je vertelt me over vroeger en ik zie de tranen in je ogen
Ik bouw een muur op terwijl ik je vertel dat die er zijn mogen
Ja jouw tranen zijn van waarde en helemaal op hun plek
Maar tussen jouw en mijn emoties ligt een leegte waarin ik ergens een grens trek

Je haalt even adem en ik doe met je mee
In dit rustmoment zijn alle gevoelens okay
Ik leer veel van jou en jij ook wat van mij
Je bent interessant maar je mag niet te dichtbij

In jouw verhaal over je vader herken ik de mijne
In het gevoel dat een verhaal over prestaties welkom is terwijl de emoties er niet mogen zijn en
Wanneer je vertelt over heftige emoties en altijd zijn op je hoede
Weet ik dat je pijn raakt die komt van mijn moeder

In mijzelf herken ik de angst die komt vanuit mijn DNA
Jij vertelt over je bipolaire beperking en ik denk alleen maar aan mijn mama
Ik voel mijn adem steeds hoger in mijn keel
Jouw ervaringen raken iets in mij en het wordt me wat te veel

Hoe benader ik dit met een professioneel perspectief
Het gaat over jou, maar ik neem mijn eigen ervaringen niet voor lief
Ik besluit te proberen het met je te delen
En het gesprek dat volgt blijkt me stukje bij beetje weer te helen

In veel gesprekken hebben we het over een donker gevoel

Over dagen in bed, niet voor jezelf zorgen, en een leven zonder doel

Ik ben blij dat we er in de verleden tijd over kunnen praten

Want het is zowel voor jou als voor mij iets wat we het liefst vergaten

Je complimenteert me met de keuze voor dit ontwerp

Het lijkt je heel moeilijk en je vindt me zo sterk

Ik moet even slikken en vertel je dan open

Dat dit voor mij voelt als een overgangsritueel vanuit de tijd die is afgelopen

In this poem I spoke about how my experiences played into this research: how they presented difficulties to my role as researcher but also presented opportunities for more in depth conversations, creating a safe space and building trust with my participants. Jesse, for instance, told me: *"You know what it feels like to study with an invisible disability, you have always been understanding and open and I trust you to be sensitive when I share things with you. It feels safe."* My experiences allowed me to apply reciprocity, a strategy that feminist researchers have long used to challenge hegemonic practices (Huisman, 2008, p.374). They allowed me to come close to a more equal relationship with my participants, which is at the core of this study.

However, because my experiences allowed me to ask the right questions to go more in depth during interviews, they also lead interviews to truly emotional places. Participants opened up to me about traumatic experiences and showed me their emotions. While these instances were beautiful and, of course, presented rich data, they were also tricky for me as a researcher. The boundaries were blurred in these situations and my role as a researcher shifted to that of a friend, or even at times that of a therapist. I became worried about betrayal; about letting my participants down or crossing a line within the research. At times it left me overwhelmed with their pain and unsure what to say or do, questioning if I had the adequate skills to act in any way. Luckily, I had conversations with all participants upfront about co-creation within the interviews and about my role as a researcher. This allowed us to both step in and step out of emotional situations without doing harm.

ETHICS

Ethical principles, just as data quality criteria, are not comparable between positivistic and interpretive studies. Where a positivistic researcher is a fly on the wall, an interpretivist researcher gets involved with participants and plays a significantly different role in the research.

Orb et al. (2001) advice to use ethical principles: autonomy, beneficence and justice. Autonomy is a form of informed consent in which the researcher recognizes that the participant is an autonomous person that has the right to be informed and the right to freely decide to participate or withdraw without penalty. Beneficence is doing good and preventing harm, this is done by making sure to not reveal participants identities through pseudonyms and, when in a small community, being careful about circulating the research without specific permission. Justice refers to equal share and fairness; avoiding exploitation and abuse, and recognizing vulnerability of participants. These ethical principles can be expanded by those of Tracy and Hinrichs (2017). Tracy and Hinrichs state that researchers need to apply four types of ethics. First, researchers need to apply procedural ethics, which encompass avoiding fabrication and omission through confidentiality, anonymity and the protection of participants' identity and privacy

(p.8), this connects to Orb et al.'s criterium of Justice. Second, researchers need to apply situational ethics, which refer to upholding constant reflection upon in-the-moment ethics within their choices of recording and disclosing stories. Third, researchers need to apply relational ethics, which encompass reflection upon the researchers impact on the people and the site, and treating participants with dignity and acknowledging their values, voices, and beliefs rather than seeing them as subjects of observation (p.9), this connects to Orb et al.'s criterium of autonomy. And fourth, researchers need to apply exiting ethics which refer to thoughtfulness in leaving the site and sharing results with the community (p.9), this connects to Orb et al.'s criterium of beneficence.

I have applied these criteria before, throughout and after data collection in multiple ways. First, I used pseudonyms and gender neutral language to make sure none of my participants were recognizable from their statements. Second, I kept a reflection journal in which I wrote down thoughts about my actions towards participants and the community throughout the entire research. Third, I approached this study as a research 'with' rather than 'about' students with invisible disabilities, thus acknowledging every human participant and their feelings, values, voices and beliefs during the research process. Fourth, I deleted all recordings directly after transcribing the interviews and focus groups and will delete all transcripts after evaluation of this study to ensure data-safety. Fifth, I have engaged in member reflections with all of my participants, meaning that the results I present in this study are a true and honest reflection of their accounts.

DATA QUALITY

The quality of data gathered through positivistic studies is usually judged through whether a simple set of quality criteria was adhered to. However, since the ontology, epistemology and methodology of this research are significantly different, applying the standard quality criteria would not fit the study. Therefore, I have consulted multiple interpretive and critical studies on quality criteria, which I will use to make sure my study provides reliable and valid results. I mainly draw from Tracy and Hinrich to establish data quality.

Tracy and Hinrichs (2017) describe seven big tent criteria for qualitative research which are followed and shown in this study. First, a study needs to have a worthy topic. A worthy topic is one that is relevant, timely, significant, and compelling. In many cases, a study commissioned or called upon by an institution, like this one is by the UU inclusion council, is a perfect example of a relevant, timely and compelling topic (p.2). Second, a study should have rich rigor, which is demonstrated by attention to detail, methodological thoroughness, and precision of the evaluation (p.4). In this study you will find account of this in the 'data gathering and analysis' paragraph, in which rich detail is used for the amount of data collected, the duration of time spent in the field and the types of data contributing to the research. Moreover, clear accountability for the organization of data and the analysis process is shown (p.5). Third, a study needs to show sincerity, which is achieved through self-reflexivity, vulnerability, honesty and transparency of the researcher (p.5). In this study you will find honesty, vulnerability and reflection to the ways my position, background and experiences as a researcher influenced this research in the positionality and discussion paragraphs. Moreover, I have consequently used the first person, 'I', to remind readers of the my presence, and personal interpretations of the data. Fourth, a study needs to attain credibility to create confidence that people can act upon data and findings to make decisions in their own lives or in future research settings (p.6). In this study you will find the results section to be full of thick descriptions, using several quotations for the reader to draw their own conclusions from. Moreover I draw my conclusions from theory, interviews and focusgroups, which means that this study has multiple data points from which to understand the topic, also called triangulation.

Furthermore, I have engaged in member reflections, to increase the credibility of the conclusions. Fifth, a study needs to make a significant contribution (p.8). The conclusion and discussion chapter of this study shows clear theoretical, methodological and practical contributions. Sixth, a study needs to be ethical. The previous ethics paragraph shows that four types of ethics were applied: procedural ethics – confidentiality, anonymity, and privacy-, situational ethics – constant reflection upon the effect of researchers' choices participants-, relational ethics – treating participants with dignity, and acknowledging their values, voices and beliefs-, and exiting ethics – care for leaving the site and sharing results- (p.9). And lastly, there needs to be meaningful coherence in the study. This refers to the consistency, soundness and rationality of the study: the literature should present a fitting context for the research questions, the questions should be suitably addressed by the methods, the data should fit within the literature and questions and the goal of the study should be achieved within the analysis (p.9). This is, hopefully, visible throughout the entire study.

RESULTS

The answer to the main research question *'how do invisibly disabled students experience studying at Utrecht University?'*, lies within five themes that emerged in participants accounts. In this chapter I will take you through the results and analysis by describing the invisible theme, the stigma theme, the ableism theme, the individualism theme and the optimism theme.

THE INVISIBLE THEME

When asked how they experience studying at UU, participants talked about many things that remain invisible to others but impact them greatly. These experiences shape and influence the way they participate in their lectures and the way they perform during tests or assignments, but stay largely invisible to their teachers-, advisors-, and peers.

AT HOME

Almost all participants spoke about their home situations, their romantic relationships, their relationships with their parents and their housing situations as important influences on their study experiences. They told me that they didn't expect others to want to know about these experiences and noted that they didn't know what any person within the university could do about them, but that it was a big part of their stories and it needed to be told. Some participants even told me that while there was no diagnosis for a bad home situation, they felt more disabled by it than by their official diagnosis.

Several participants noted that they were in romantic relationships with people who needed care from them. While these relationships were important to them, being a caregiver at home prevented them from being able to study. Ash visualized this by writing a poem about staying up all night with their partner to enjoy a moment in which there were no worries and everything was all right:

> *Yesterday might have been miserable*
> *Tomorrow could turn out bad too*

But tonight time doesn't exist
Tonight I'm here with you

So if yesterday's pain becomes too much
And today was your last tomorrow
This night could stay with me
To help me fight the sorrow

Ash told me that staying up with their partner, worrying about them and sometimes physically taking care of them had a negative effect on their sleeping pattern, which in turn had a negative effect on their capacities to study. Ash was not the only participant to describe this. Participants also noted that growing up with unstable parents, parents who have mental disabilities, who were aggressive, did not accept them for who they were, or had passed away, created a major obstacle in their student lives. Having unstable social relationships left participants with trauma, as a caretaker or simply without any basis to fall back on. Ash and I discussed the effect it can have on your student life when your parents do not provide a steady base for you. Ash said:

> *It must be nice to be able to go to your parents' house during test weeks, have them take care of you, eat everything in the fridge and just completely focus on your studies. Or to have a family to send questionnaires to when you have to gather participants for class. Not having this can be a major stress factor.*

Participants' social relationships stay largely invisible to others within their university lives, while the impact of these relationships on their study experiences is described to be immense. On top of this, participants also discussed how they lived in student housing, in tiny rooms with lots of roommates, lots of noise and sometimes with bad landlords. These living situations added to their stress levels, decreased their quality of sleep and thereby influenced their study experiences in a major way. Jesse and I spoke about the importance of a stable housing situation, of a roof over your head and about how it literally feels like the ground is taken from underneath your feet when you have to move and are unsure if it is going to be safe there. Jesse told me about their aggressive landlord and the effect this had on their sleep and ability to concentrate on their studies: *"My landlord got aggressive and hit my boyfriend after we started a process with the Dutch rental commission to test our rent. The nightmares of this event kept returning"*.

During the affective analysis I created a poem based on my interview with Ash, in which this theme of not having a stable base and stable social relationships emerged. Ash told me about living in a tiny room with their partner, about being a caregiver and not being able to recharge at their parents' house, about reaching out and not being taken seriously and about feeling alone in this fight.

Ik wil niet je bubbel bursten
Je blije bubbel met je perfecte bubbelleven
Maar geen huis heeft maar 1 kamer
Ik sta 1-0 achter, begrijp dat even

Jij ziet mij niet onzichtbaar zijn
Jij, zij, hen, die met ouders en zonder pijn
Ik wil niet zeggen ik ben zielig boehoe
Maar ik ben wel mantelzorger, en hoe

Ik heb fucking hard mijn best gedaan
Maar ik weet het gewoon niet meer, ik wil gewoon gaan
Ik moet keihard janken maar jij bent erbij
Dus neem ik geen ruimte in, voor jou ben ik blij

Niemand ziet het, het boeit niemand echt ene aars
Onbetrouwbaar en lui denken ze, nee dat is niks raars
Gisteravond heb je zeker lekker gezopen
Niet wetend wat of wie mij gisteravond echt is bekropen

De alarmbellen luiden zo hard door me heen
Ik wil verandering, van het hele systeem
Waarom geen empathie, waarom is jouw begrip fake
Waarom kleineerde je mijn probleem totdat het niks meer leek

Waarom voelt het nu alsof er niks meer zou moeten zijn
Jij bent zo groot en ik dus maar klein
Ja jij moet het kunnen, dus ik in verlenging dan ook
Maar het hele systeem staat in de fik man, overal is rook

Within the conceptualization of invisible disabilities that I have used for this study, being (mentally or physically) limited in day-to-day interactions because of the situation participants face at home, can also be understood as an invisible disability. Participants' reaction to my telling them this was often surprised and relieved, they felt like they were being taken seriously without any diagnosis, which is not often done within the university context. This signals an interaction with ableism, as described in the theory about invisibility (Allen, 2020). The situations participants face at home are largely invisible to people at university, which involves an act of passing, covering and performative able-bodiedness from participants (acting like everything is fine) (Kattari et al., 2018). In doing so, participants 'blend in' with the dominant ableism discourse around them signaling that societal-, and probably organizational power are at play to protect the status quo of the ideal able-bodied student.

THE INVESTMENT

A second pattern of invisibility that emerged from the interviews, was participants' experiences of putting more time and effort into their studies than others -and not being recognized for it-. Several participants told me that studying with a disability feels like a negatively double-edged sword. Because on the one hand navigating life with a disability takes so much energy already that there is less to spare for studying, while on the other hand studying with a disability means putting in more time and energy than others. This leaves little to no energy for themselves.

Generally, this was described to result in exhaustion, stress, and decreased self-care for participants, which often enhanced the symptoms of their disabilities.

Participants described studying to take more energy because it quite often literally took more time. They described needing more time to understand texts, to navigate course manuals, to write papers and to understand lecture materials. However, while the university recognizes their need for extra time during tests, the rest of the university system is built around the idea that every student needs approximately the same time to prepare their materials: 40 hours a week. This means that participants who need more than this approximated amount of time, invest countless hours of their free time into participating 'like normal', which is often invisible to the people at university. Sam and I discussed the matter of time as an invisible investment at length in our interview. Sam, for instance, told me about a test where there were no accommodations available for their disability. They told me that they wanted to make the test at that moment because the information was fresh in their mind, and making the test with accommodations at a later point would just mean studying again (also investing more time). So they did it, they made the test. They invested all of their mental capacity into surpassing the borders of their disability to make the test and when they arrived home they went straight to bed and slept for almost 24 hours to regain strength. All of this time regaining strength, is also time they invested in the test that others did not. Charlie described a similar situation when they told me about repressing traumatic flashbacks during a test. Charlie said:

> *The first thing I think when I get out of the flashback is 'where am I, what was I doing?' I feel disoriented and want to start grounding myself like I always do after a flashback but I see the screen of my test in front of me. I notice it saying that there are 25 minutes left. I think to myself 'what, the last time I checked there were 120 minutes left'. (...) It is a fight or flight response and this time it was fight but it [repressing the flashback and not grounding before re-entering the world] took so much of my energy that I did not have any left after that.*

Participants also described that studying takes more energy because they feel like they're fighting for their rights within the university system. Fighting for rights was described as having to insist that they cannot do something – e.g. make a test- without the arranged accommodations or convincing peers, teachers and advisors that their disability is real. This is a fight that specifically relates to being invisibly disabled: the chances of others questioning a visible disability are a lot smaller (Hendry et al, 2022, p.152). Imagine if a wheelchair user came up to you and asked if there was an elevator available for them, would you question their ability to use the stairs? This is something that was described by almost all participants, instances in which they told others they needed accommodations to do something and others either questioned their disability or their need for accommodations. Sam explained to me that it is so common for teachers to forget that they need accommodations that they always email their teachers before tests to remind them, and that the one time they didn't send the email, the accommodations immediately went wrong. This way, Sam invests numerous hours of their time into making sure the system creates the opportunity for them to participate equally. Charlie and I also talked a lot about this invisible fight, which happens almost on a daily basis. They shared a specific example of an experience with their study advisor with me. In this example the study advisor has just told them that participating online is not an option, which would mean that Charlie cannot participate in any education for a long time:

I told her I think this is discrimination, I am sick, it is not like I am making this up, I want resources. (...)
I forced it (the resources), I told her I will sew because I deserve education, I am paying for it, I deserve
it

And when participants do get accommodations, after investing time and energy into convincing others that they truly need it, getting used to the resources also takes time and energy. Sam, for instance, had me listen to their reading software. I have to tell you, it did not sound the way I thought it would. The voice reading the text was very monotone and took breaks in the middle of sentences where there were no logical breaking points like comma's. This made it very hard to understand the text. Sam said: "*Resources take time to get used to. (...) Many people think reading software is amazing, until they hear what it sounds like, you don't get used to that easily.*" .

This theme is heavily linked to the theories on explaining and microaggressions (Kattari et al.,2018). A large part of the extra time and energy participants put into their studies goes to explaining to others what they need, and reminding them that it is important (Hendry et al., 2022). Moreover, the fact that they feel like they have to fight for their rights, signals many interactions with ableism, of which several are described to be microaggressions (teachers forgetting to arrange accommodations). The struggles that participants face with explaining and fighting for their rights, find their basis in the medical model applied the university system, given shape, for instance, in the standardized workload of 40 hours a week. All in all, this theme shows how connected participants' practical experiences with studying with an invisible disability are to the theories on ableism, the medical model of education, and microaggressions.

In conclusion, the invisible investments that participants make are large, they invest more time and more energy into understanding the materials and fight for their rights on the side while already having less energy to spare. This makes participating like their peers more difficult, and creates a feeling of not being seen. These invisible investments could be compared to an 'invisible curriculum'. Case et al. (2014) describe how groups of students – like first generation students- have to invest more time and energy into figuring out how to be a student, how to find literature, which words to use, and how to write in an academic way. This invisible investment is very similar to what invisibly disabled students face at university. Investing extra time, also takes away from students' abilities to develop their social capital, which is another way in which they are being placed 'behind' their non-disabled peers (Chenoweth & Stehlik, 2004).

Within the poem that I made during the affective analysis of Sam's interview, this theme emerged a lot. Sam told me about feeling 'overheated' in the current system, about having too much to do and too little time to do it. About everyone telling them that if they want to succeed, they would have to make a large time and energy investment but no one telling them where to get this time and energy from.

Mijn brein lijkt een computerbrein
Het is meer een stop- dan een sneltrein
Met te veel te doen wordt het snel oververhit
En ik ben het die dan met achterstallige taken zit

Het koelsysteem staat hard te loeien

En heel hard op alle openstaande tabbladen klikken zal het alleen verder vermoeien

Er is tijd nodig om af te koelen

Maar ik weet niet goed hoe ik dat moet combineren met nog niet behaalde doelen

Als je wil studeren met dit probleem

Zal je extra tijd moeten investeren, en dat niet alleen

Nee motivatie kan er ook niet aan ontbreken

Zeker niet als je moet leren dealen met alle systematische gebreken

Maar waar haal ik die tijd en energie dan vandaan

Het is een rollercoaster waar ik niet vrijwillig in ben gegaan

Je kunt niet zomaar meer tijd creëren, dat is niet hoe de wereld werkt

Al zien ze dat allemaal als MIJN probleem heb ik nu wel gemerkt

Uitstel is een illusie en tijd inhalen bestaat niet,

Is het niet de voorbereidingstijd voor een ander vak, dan is mijn vrije tijd of mentale gezondheid in het geniet

Maar ik zet door, als het lukt ben ik trots

Dat diploma daar kijk ik naar uit, als in een wilde zee een grote rots

Ik weet niet welke kant ik op ga en of ik juist zwem,

Die laatste 300 woorden zetten me klem

Ik krijg mijn hoofd er niet bij, hoe de fuck krijg ik dit klaar

En als ik bij mijn tentamen kom is de laptop niet eens daar

Ik probeer rustig te blijven maar dit is een oude wond

Net als bij de wiskundetoets waarbij er geen woorden zouden zijn en ik versteld stond

En alle andere keren dat ik besloot te vertrouwen

Maar de wereld een systeem bleek waar ik absoluut niet op kon bouwen

Soms voel ik me vergeten en voel ik me alleen

Dan zweven woorden en letters in donderwolken om me heen

Maar ik zet door, ik ben altijd van de partij

En als ik dan investeer, doe jij dat dan ook in mij?

THE STIGMA THEME

A second theme that participants shared with me within their accounts of studying with an invisible disability was one about a world in which others treated them in a negative way, often based on stigma about either their disability or the way they behaved because of it.

Riley, for instance, told me that people with learning disabilities have, at the age of twelve, already received 20.000 more negative messages from those around them than people without learning disabilities. This is because people with learning disabilities often study and/or function in a way that deviates from the social norms and is therefore seen as 'failure', which connects to the dominant ableism discourse in society: if you do not function like 'normal', you are different and that is 'wrong' (Goodwin, 2020). This failure is treated with negative messaging and results in participants being used to disappointing others. Several participants described not being believed in or being told that they were lazy, that they were not smart or not capable. Moreover, they told me that they got hypersensitive to rejection because it happens so often, and that they internalize these messages of failure. This pattern falls in line with the previously described social identity theory, in which people use social constructs – like being dumb, lazy or incapable- to start a process of othering between themselves and the 'other' (Ysasi et al., 2018, p.24). In this process, the individual power of the invisibly disabled person is decreased within an interplay of group power and societal power, protecting the status quo of the able-bodied human.

During the affective analysis I created a poem based on several participants' accounts of negative messaging and stigma. This poem visualizes the message they all told me, using their own words.

Ik ben lui, dat is wat je zegt
Ik kan er niet echt iets tegenin brengen, het klinkt wel terecht
Ik kom inderdaad heel moeilijk uit mijn bed
En als ik er dan uit ben, is het niet alsof ik veel werk verzet

Als ik een opdracht lees, dan lees ik hem vaak verkeerd
En het slechte cijfer dat daarop volgt is omdat ik dom ben, heeft de wereld me geleerd
Ik raffel mijn werk af, of probeer er onderuit te komen
En dat heeft te maken met mijn persoonlijkheid, niet met mijn symptomen

Ik snap wel wat je zegt, ik vertel het mezelf ook heel vaak
Ook al zijn al die negatieve berichten misschien wel een oorzaak
Van het feit dat ik me al een tijdje niet zo goed meer voel
Ik vind mezelf nu niet leuk meer, of is dat niet wat je bedoelt?

The negative, stigmatizing, messaging already happens far before participants start university, but they also described it to continue within their relationships with peers, teachers and advisors at university. Participants described teachers and advisors who did not take them or their disability seriously. They told me about being sent away by study advisors, losing their hope of being supported within the system. They told me a lot about insensitive teachers, teachers who told them they did not have time to listen to them, who brushed away their issues without offering to help, who did not understand, try to understand or seemed uninterested. This connects to previous research by Kreiser et al.(2015, p.436) in which participants described teachers to express stigma in a similar way. For my participants these actions resulted in a feeling of not being taken seriously, which Ash formulated in the following way:

I really do not think teachers will take me seriously. The default attitude of a teacher is that a student is out for the highest grade with the least effort. (...) When I tell a teacher I can't do something, they will automatically assume it is a trick to get a good grade. If they are sensitive, it is fake.

In this statement, Ash points out the stigma that is associated with their disability: they are lazy and out for an easy solution, instead of: they are disabled and are looking for accommodations. Participants also described situations in which teachers or advisors just bluntly transgressed personal and professional borders. Charlie and I had the most in depth conversation about this in which they shared two statements with me about interactions with a tutor (the first statement) and interactions with a study advisor (the second statement), in which both handled in an insensitive and stigmatizing manner towards Charlies disabilities.

When I started studying I had anorexia, I came straight out of a clinic and I told my tutor this. Half a year later I had gained 10 kilo's with a lot of effort and he literally said to me: I see you have gained a lot of weight, are you okay?

She just told me, maybe you don't have it in you to finish University, because you need to be present and you're not so maybe you need to quit. (...) These trauma's make you relive things and maybe that means you're not competent. She really said that.

Both of these statements illustrate a stigmatizing insensitivity to invisible disabilities by major actors within the university system. Participants' lack of faith in the system and the actors in it was supported by many more stories like these in which multiple accounts of microaggressions were described (Kattari et al., 2018, p.479).

Moreover, participants described a difference in treatment between a physical illness and a psychological illness, hinting towards the specific stigma associated with psychological disabilities. Some participants presented pressing examples of treatment differences, while the others hinted towards it by stating that they would call in sick, because teachers could understand the flue better than depression. Sloan and I talked about their need to be abroad with their parents when their bipolar disorder flared up. Sloan told me that they wanted to participate in classes from abroad but they were often prohibited, while other students weren't: *"I tried to attend lectures online but they said this was not possible, because of the 'group work'. But as soon as someone was physically sick they would just call them in".* Charlie and I also went in depth on this matter, because Charlie experienced having both a psychological and a physical disability. Charlie told me about their shock experiencing the flexibility of the system when they needed chemo, after years of experiencing how rigid the system was when they needed therapy:

What saved me was that I had a diagnosis from a psychiatrist but also a physical illness. If I didn't have the physical illness I don't think I would have gotten accommodations (...) When I tell them I have chemo they change whole schedules for me, but when I say I have to go to therapy they tell me to move the appointment. Like, without chemo I will die yes but it is not like I will survive without therapy (...) They always told me to show up, but as soon as I got cancer everything was possible. I could attend classes online, make tests from home, get papers instead of tests.

During the affective analysis I wrote a poem based on my interview with Charlie in which this pattern emerged of being stigmatized and not taken seriously. Charlie told me a lot about their experiences with teachers, tutors and advisors and the way they handled physical and psychological disabilities. They told me about fighting the rigid system but wanting to quit.

Misschien ben je wel niet competent
Misschien moet je gewoon stoppen, misschien is dat wel wie je bent
Misschien heb je het niet in je, was je gedoemd van het begin
Misschien ben je niet écht ziek, hallo het is niet alsof ik dit verzin?

Nee niks, zero, no response
Jij krijgt er tien maar ik krijg maar 1 kans
Als je had gekeken had je gezien dat ik het kon
Maar ik vertelde je alles en jij deed alsof je me niet verstond

Het zit in je hoofd, zet het toch op zij
Je moet maar gewoon komen hoor, ben er maar wel bij
Want als ik je niet zie dan doe ik alsof je niet bestaat
En als je anders bent dan de anderen sta ik niet voor je paraat

Ik verdien onderwijs, ik vecht, maar ik ben uitgeput
Ik wil niet aan iedereen mijn levensverhaal vertellen, wat heeft dat voor nut
Ja ik heb gruwelijke dingen meegemaakt en daarom heb ik nu PTSS
Maar het is niet alsof het feit dat iedereen dat weet bijdraagt aan mijn proces

En toen kreeg ik kanker en keek je me aan
Dit bleek een verhaal wat je wel kon verstaan
Het systeem bleek flexibel, flexibeler dan ooit
Want zonder chemo ga ik dood, maar zonder therapie red ik het ook nooit

Je maakte boos, dus nu kan het wel?
Ben je alles vergeten wat ik je tot nu toe heb verteld?
Ik wil je de les lezen maar ik ben doodop
Je A's en je B's die tellen niet op

Je propte me in een keurslijf maar ik paste er niet in
En nu ik iets fysieks heb geloof je pas dat ik het niet verzin
Ik hoop dat je meer vertrouwen krijgt, dat je veranderen zal
Because there really is no one size fits all

Lastly, an interesting pattern within this theme was one where almost all participants offered me small presentations of self as prove to their abilities, almost as to show me that it really was not them that was failing, it was the system that was failing them. Within their words I felt their fear of me also having this stigmatizing gaze towards them or their disabilities, of me not taking their stories seriously or doubting their judgements. To me this showed their deeply internalized notion that nobody would take them seriously by default, that they had to prove they were 'good' students like others before they deserved the credit of being taken seriously when asking for accommodations or help. Jo, for instance told me about their very active participation during classes and their motivation for their studies. Charlie told me about having the necessary knowledge and obtaining high grades. Jesse told me about their good grades and their possibility of doing two bachelors at the same time. Riley told me about their motivation for their paper topic. Sam told me about their determination to get things done. And lastly, Ash told me about giving their all: *"I tried so hard, I really fucking tried so hard, how do I do this better, what can I focus on, I just don't know anymore, I don't see it anymore. I studied so hard and I failed anyway".* What all of these accounts had in common is that I did not ask about their ability once. I think these descriptions can be understood through the theory of self-presentations (Baumeister & Hutton, 1987). Self-presentations are the impressions that individuals create about themselves for others, often to manipulate others' perceptions of them to the positive side. These self-presentations are deeply rooted in ableism, expressed through social and group-power structures and often used as means to increase individual power. Therefore, participants accounts of prove to their abilities, can be seen as small ways to increase the weight their stories carried in this research and thus small acts of performative able-bodiedness.

In conclusion, participants describe fighting the social stigma around their disabilities, often because their disabilities are invisible causing misperceptions on intent or skill (Syma, 2018). They describe facing microaggressions through hearing numerous negative messages inside and outside of university (Kattari et al., 2018). They describe stigma through not being taken seriously, being mocked, being treated without sensitivity, being separated from those with visible and physical illnesses and being treated differently. Moreover, participants show to have internalized the ableist idea that everyone they meet will look at them with the same stigmatizing gaze, even me, a peer student with a disability. Thus, these practical examples of issues faced by participants paint a worrisome picture of the effect of an ableist, medical model mindset within university education on the experiences of students with an invisible disability.

THE ABLEISM THEME

Within participants' accounts of their experiences studying with an invisible disability, there was a clear third theme that emerged: a story about ableism within the structure, the rules and the system at university.

THE SYSTEM

When participants spoke about their experiences with the University, they spoke about being stuck in a system that is built around the medical model, in which their disability is viewed as their own problem and makes them 'abnormal' (Goodwin, 2020).In the interview with Jo we discussed this matter. Jo told me:

> *The more I learn about the way I function, the more aware I am of how our society and university is programmed towards productivity. How we are structured to accommodate the way a neurotypical brain functions, and with that I don't only mean a brain without ADHD or autism, but also without any mental*

disorders. We are fully structured towards one type of person.

The 'one right way' to do something, was talked about a lot during interviews. Some called it a structure, some called it ableism, some called it a 'one size fits all' mindset, but almost all participants touched upon it. Several participants noted that 'this is just how a large-scale university works, we can't change it'. This relates closely to the previously described organizational power which is used to exercise dominance over individuals (Nostedt, 2019, p.15). It also comes back to a conclusion of Mullins and Preyde (2013, p.156) who said that the system is built for 'normal' people and if you don't function or learn that way, you face additional challenges on top of the regular challenges that are part of university. Participants told me that they did not feel understood or heard by 'the system', that they felt like their disability was being put away as an illness, something to fix with medication, while to them it is just the way their brains function. In a conversation about 'fitting' in the system Ricky said:

> *These medications are made because people thought hey there is a deviation from the norm, lets correct it by putting a pill in it. It [the medication] does help, it does, but I feel like we mainly take these pills so that the system doesn't have to be adapted to people who function a little bit differently.*

In several interviews, like in the interview with Jo and Ricky, the situations participants described were so similar to the theory of the medical and social model that I told them about it. I explained the way our educational system is currently shaped after the ableist, medical model, while disability scholars promote a shift towards a mixed, or social model. This resulted in some of the most interesting conversations. In my interview with Jesse, they added to my explanation of the current medical model:

> *Yes and sometimes we just build an add-on to the model to fit someone in – like extra time during a test- but I think we should rethink the whole model to actually make me feel a part of it – like not having tests at all-.*

Charlie and I talked a lot about the straitjacket (NL: keurslijf) that the university seems to want to put them into, while it really does not fit. Charlie said: "*They often put you in this straitjacket but it is just not you. I don't learn things the way that is presented as the only right way*". Many participants quite literally called for a more mixed, or even social model of education during the interviews when I asked them what they needed. Several participants also visualized this. Ricky told me that their brain just doesn't function like others' does, that it goes on turbo mode sometimes which is not something that should happen in a university context (Image 10). Other participants told me that their functioning and their view on the world depended on their experiences and their backgrounds, that the whole picture of their beings needed to be taken into account for it to work. Charlie visualized this by a person literally bursting out of this straitjacket and showing all of their colors, experiences and differences from others (image 11), while Jesse visualized a number of little Jesse's holding up the Jesse that was trying to keep their studies together (image 12)
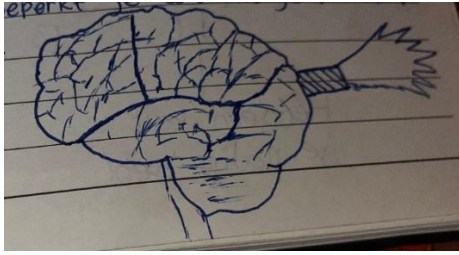
Image 10: turbo brain

Image 11: not fitting into the straitjacket

Image 12: taking into account all factors surrounding a person

Within this notion of functioning a little bit differently, several participants stressed that for them, reaching a state of concentration needed for a lecture or an assignment was significantly more difficult than it was for others and that this seemed to not be recognized within the university system. Not only because of taken for granted stimuli within classrooms – ticking microphones, flickering lights, distracting objects with many colors, an open door with chatting students outside- but also because the way in which their brains functioned differently from others was simply put down as wrong. Jo and I had a long conversation about the functioning of their brain. Jo said:

> *I am just having a bad brain-day, I feel like my brain is a DVD screen that never reaches the corner, or that I am stuck at that part where you wake up and your dream, that you desperately want to remember, just flutters away.*

Jo described their brain to feel like an idea-generating center in which new and exciting ideas were produced every second. However, to get those ideas into action, into the part of the brain where it was actually processed, the idea needed to be funneled through this tiny tunnel. Therefore, almost all of the ideas were lost or needed to be thought of at least a couple of times before they got processed (see image 4). Like Jo, Ricky, Ash, and Riley also visualized their issues with reaching a state of focus needed from them within the university system. They visualized a state of non-focus as an alphabet with the letters in the wrong order (image 5), as the need of setting many timers (image 6) and with drawings of being distracted and not being able to start (image 7 and 8).

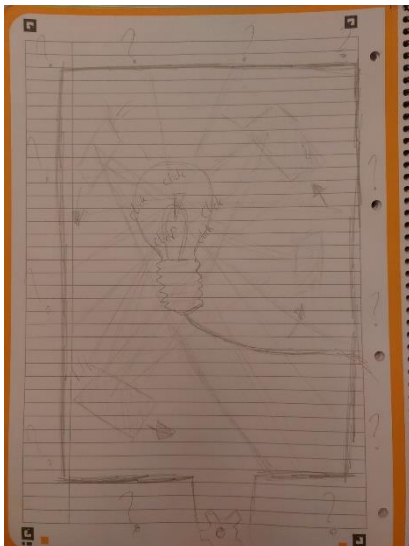Image 4: idea generating machine brain   Image 5: alphabet   Image 6: timers
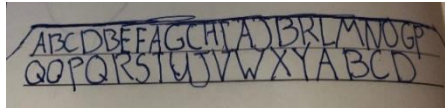

Image 7: being distracted   Image 8: not being able to start

During the affective analysis of my interview with Ricky, I created a poem in which this pattern of focusing emerged. Ricky told me about sitting in class not being able to recall anything that was said, about trying to read papers but taking half an hour on one page and about not taking enough medication to get through the day like others.

Focus is voor mij meer een oefening in vitaliteit
Het ene oor gaat het in en het andere oor zo weer uit
Ik zit in een collegezaal maar mijn ogen zullen me niks vertellen
Die zitten namelijk in een bioscoopbank van mijn hersenen die dagdromen tentoonstellen

Het is misschien ook een vlucht uit de realiteit
Want de openstaande collegedeur zorgt niet echt voor concentratie kwaliteit
Hij fungeert als luidspreker voor de rumoerige studenten op de gang
Maar ik durf niet te zeggen dat het me stoort, ik ben toch te bang

Ik kom in een negatieve spiraal
Met prikkels om me heen, op het scherm en in de gang buiten de zaal
Dan vlucht ik maar in de white noise, die is niet zo overweldigend dichtbij
Maar ik zit hier weer voor niks, ook al ben ik er fysiek bij

THE SCHEDULES, TESTS, AND ASSIGNMENTS

Specific examples in which participants experienced ableism within their studies were in schedules, tests, and assignments. Riley told me:

> *My schedule has really disabled me lately. On Monday I had only one class, but then on Thursday I had class from 11am until 7pm. But, at 5pm my medication stops working, so I kind of can't go to this class.*

I haven't been able to go to this class the whole block. It is being made impossible for me to attend, so I feel disabled by the system.

Riley was not the only participant that spoke about their schedule like this. I had in depth conversations of a similar nature with Charlie and Jesse. Jesse stressed that the way the larger schedules are made – the year calendars, the division of ECTS per period- was ableist in its core. They told me that without a disability obtaining 15 ECTS per period was already stressful, but with a disability this was mostly impossible. Charlie told me about the need for routine in their life and how their schedules made this impossible:

For me, it really doesn't work that there is no routine in when we have classes. If it is just every Monday at 11 then I can create a routine, but if it is at a different time or even a different day every week that makes it very hard for me to keep track.

Several participants also stressed that assignments were often presented to them in an ableist way because they were simply too vague for them to understand the true focus. Especially when you already have trouble getting the main message out of texts, a vague assignment can exclude you from participating like your peers. Jo and Ash gave examples of their experiences with vague assignments:

This essay assignment was very vague, you had full free choice in topic and it was not clear how concrete your intervention needed to be, how formal your writing style needed to be, what the minimum number of words was etc. Even neurotypical students complained about this. It was very hard to assess whether your idea was right and fit within the framework that the teacher had in mind. That made it impossible to start making a plan on how to work on this assignment.

The assignment was very vague and looking back I think I made it way too difficult for myself. We needed to create a paper from eight different pieces of literature, which were not coherent at all. Other students really did it point-wise but I tried to integrate everything because I thought that was wat I needed to do.

Ash visualized their experiences with papers in a (Dutch) poem:

Mijn aandacht stroomt weg
Naar alles wat urgent lijkt te zijn
Een mailtje, een planning, een lijstje
Ook woon ik alle extra colleges bij

De woorden van mijn paper
Zijn in de war, bang en verlegen
*Ze maken wolken in mijn hoofd*
En verstoppen, zoals een put in de regen

Van binnen overstroom ik al
Ik wil een ander weerbericht
Graag eentje zonder tranenregen

Participants who had negative experiences with tests told me that the structured environment of tests did not provide enough flexibility to deal with symptoms of their disabilities. Robin shared a part of their world with me when they took me into a recent test experience. They told me about feeling an intense loneliness in this instance with no way to change the situation:

> *I am in the room making the test. What am I doing here? I feel so alone. The only thing I hear is people typing and clicking on their keyboard. I can't focus, the only thing I can focus on is the fact that nobody wants to have anything to do with me in this moment. I'm on my own and I don't know what to do, it is such a lonely feeling.*

Image 9: visualization of feeling alone during tests
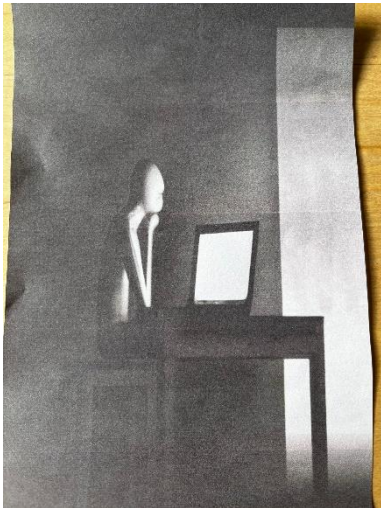
Tests are described as ableist experiences by participants, because they present this one right way to show your knowledge, this one moment in which everything has to come together. Moreover, Sam told me that the accommodations that they needed – like a laptop with good reading software- were often not arranged for them during tests. This resulted in much higher stress levels which made making the test even more difficult. Sam told me: *"Today, 8:30, I am at my test but there is no laptop. They tell me they will fix it. They are friendly but it is so hard to stay focused, even with medication. I ended up waiting for two hours until the laptop was there."* Even for someone without any disability, it would be very hard to focus on a test after waiting on the test to arrive anxiously for two hours.

With both tests and assignments, participants told me they struggled with the fact that they had to be eligible for the retake. They told me it felt unfair that they had to get a minimum grade or at least hand something in, because sometimes they just couldn't. Sloan said: *"I told them, this is what I have so far, I know it is bad, but I want to be eligible for the retake and I can't do any more now. It took a lot from me".* With this, they described yet another ableist notion within the university system.

Thus, while participants described the entire system of the university to feel like an ableist structure in which they were forced into a straitjacket and expected to participate and function like everyone else, they specifically felt

disabled when interacting with the rules surrounding schedules, tests and assignments, signaling the specific systems in which organizational power is at play and individual power of the invisibly disabled individual is decreased.

INTERNALIZED ABLEISM

A last trend that I observed during analysis was how much participants voiced an understanding of why the system, and the people in it, functions the way it does. Several participants voiced understanding for inflexibility within the system, they told me they understand that not everyone can be accommodated, not everyone can be taken seriously and that there simply is no way to include everyone in a university system. Robin said: *"I mean everyone has some kind of issue, it is hard to accommodate everyone."* While Sloan said: *"I would like to participate online but of course you don't want 28 students online and 2 in class, I get that.".* And Riley said: *"I would like more check-ins but almost all students want that and of course they can't check everyone".*

These statements are true examples of internalized ableism as described by Campbell (2009). Campbell states: '*Once oppression has been internalized, little force is needed to keep us submissive. We harbor inside ourselves the pain and the memories, the fears and the confusions, the negative self-images and the low expectations, turning them into weapons with which to re-injure ourselves, every day of our lives'* (p.19). When we look at participants' statements through this lens of internalized ableism, it is evidently clear that they are, as Campbell would say, 're-injuring' themselves by not asking for accommodations because of their 'understanding' for the ableist system.

During the affective analysis I created a poem based on several participants' accounts of internalized ableism. In this poem I used less of their literal words and more of their meanings: the model student is a metaphor for everything participants have described not to be in their interviews.

Ik wil zo graag zijn zoals jij
Jij hebt motivatie, structuur, een planning, jij hoort erbij
Jij bent wat ze willen, het plaatje op de site
Jij bent de modelstudent, de basis van al het beleid

Jouw brein werkt zoals het zou moeten
Zonder rare paadjes, afleidingen, zonder eeuwig ploeteren
Jouw tong vormt de woorden die hem worden opgedragen
Zonder stotteren, afleiding, of vertragen

Jij wordt door iedereen begrepen
Bij jou zullen ze nooit afwezigheid strepen
Jij hebt geen aanpassingen nodig, je valt nooit
Jij hebt de taken van volgende week nu al voltooid

En ik, ik zit er maar een beetje bij
Ze vertrouwen mij niet, er is groot verschil tussen jou en mij
Als jij ze iets vraagt staan ze klaar om te gaan

En ik blijf achter in een wervelwind van vraagtekens 'ze komen er zo aan'

In conclusion. Almost all participants also voiced their own internalized ableism to me in small fragments of understanding of the system. This shows how deeply rooted the ableism in university culture is, and how easily it is reproduced. The idea that you are too much, you are too different and that your disability is your own individual issue to solve is at the core of the medical model, which is deeply rooted in ableism. Thus, the practical accounts of participants in this theme, call for a larger shift towards the social model of education in which organizational power does not decrease individual power but both exist simultaneously.

THE INDIVIDUALISM THEME

Intertwined with the societal discourse surrounding ableism, is the societal discourse surrounding individualism. This also emerged from the data in this study. Within the ableist medical model that is currently applied in higher education, a disability is viewed as an individual problem to be solved instead of a product of societal power relations. This is also a pattern that participants described to me, sometimes between the lines.

Within the poem that I wrote during the affective analysis of my interview with Jesse, this pattern of having to do things alone without someone to lean on emerged. Jesse told me about navigating student live as an individual, without leaning on teachers or the system for support because of a lack of faith.

Ik draag altijd een kleine ik met me mee
Een kleine nietige ik op mijn schouder
Een ik die niet studeren wil
Een ik met een verloren ouder

Een kleine bange ik verstopt
Voor de reacties van anderen
Een gestreste kleine ik verstikt
In een wil om te veranderen

Ik denk terug en verkramp in malende gedachten
Ik duw het weg en ploeter door, ik wil hier niet op wachten
Ik word meegesleept in de waan van de dag
Ik wil iets inleveren maar het is niet perfect, wacht

Mijn maag rommelt, heb ik wel gegeten
Ik probeer voor mezelf te zorgen maar wat ben ik nu weer vergeten
Kleine ik schrikt en schuwt voor het grote probleem
Er is altijd wel wat, en met irrationele angsten ben ik nooit alleen

Ik stort soms in, ik kan het niet vermijden

En omdat jij niet in mij gelooft kan ik dan ook niet meer strijden

Maar morgen gaat de zon weer op en dan is het niet meer nacht

En ik hoop dat kleine ik dan bij jou een veilige schouder wacht

Several participants told me about the change in system between high school and university, which they describe to be a drastic change from a more communal to a more individualistic approach . In high school, they felt like the system was more or less developed to keep them in track, with regular check ins with teachers, mentors and parents. While in university, they felt like the system was more or less developed to keep them out, with rigid deadlines, very small support systems and an 'you're only as good as your grades'-mindset. Participants told me about how shocked they felt when they found out how little communication there was at university. Not only was there almost no regular communication with them, there seemed to also be little to no communication between teachers and/or advisors about them anymore. The system feels fragmented. This closely relates to a conclusion of Kreiser's (2015, p.427) about the shift between high school and university being too hard on invisibly disabled students. Sloan and I had a long conversation about this. Sloan said:

> *When I tell my advisor that I am struggling, they know, but my teacher doesn't, he just sees someone missing for two weeks. In high school teachers discuss their students' wellbeing, but at university all teachers are suddenly like 'I just give my course and be done', there is no whole. What is the responsibility you carry for your students?*

Several other participants talked about how easy it was to go off the radar at university, because nobody was in frequent contact with them. They felt like they could just disappear. The lack of communication with and within the university system left participants feeling alone. They told me about feeling too small to take on this big system on their own and that when they reached out about this, they were told that they would be on their own in the real world too, so they better got used to it. I think this message and this feeling of loneliness in a world that is not shaped for you leads to a tendency of participants to blame themselves for issues that seemed more structural than individual. Participants described issues like having less energy than others, not being able to focus, having triggers, and not wanting to claim space, and related these symptoms of their disabilities to their personality-traits. While many of these issues can be seen as an individual problem, the true obstacle lies within the structural functioning of the university system, in which here is no room to be absent, or take a break to go outside and deal with these issues. Messages like these have come forward in all interviews and heavily relate to structures of power between the organizational, the societal, the group and the individual level in which the status quo is protected through governing societal norms (like being present and only taking breaks when allowed) and individual power is lost.

Building on the affective analysis of Jo's interview, I wrote a poem in which this pattern of individualizing their disability emerged. Jo told me they questioned whether symptoms of their disability might be a part of their personality after hearing that they were lazy one too many times.

Heb ik een beperking of ben ik beperkt

Werk ik niet of ben ik het die niet werkt

Kan ik het niet of maak ik en keus
Zoek ik een excuus of is het serieus

Je weet niet wat normaal is als je niet anders weet
(Z)onder druk is een studie niet compleet
Maar ik ben lui, dat geeft de wereld me mee
En wanneer ik dat internaliseer is het zelfhaat, okay

Soms voelt de wereld als door drijfzand waden
Dan brengt elke prikkel mij meer en meer schade
Dan brengen mijn acties me in een neerwaartse spiraal
En voelt mijn hoofd als een dvd scherm die nooit het hoekje bereiken zal

De wereld wil van alles van mij
Als ik neurotypischer word is iedereen blij
Maar wat zou dat voor mij betekenen
Dat ik al mijn leuke kanten voor jullie weg moet rekenen?

A big part of making it easier to study with an invisible disability is disclosing your disability and communicating about your needs (Morina, 2022, p.4). However, because of this individualistic mindset that participants are taught to have, they describe that disclosing gets harder and harder. First, because they blame themselves for their issues so they don't feel like they are allowed any accommodations. Jo said:

> *I feel ashamed to ask for accommodations, because it feels like a choice and there is a possibility that I am asking for something that is not expected from someone with my disability, that I can do even less than they expect of me.*

Second, when they do know and acknowledge that they need accommodations, participants get afraid of being turned down, not being taken seriously, or facing the stigma relating to their disability. Ash for instance said: *"People will think hey there comes the ADHD person, they will associate all my behavior to my diagnosis and I don't want that, I am a person".* Participants described to have gotten so used to not being taken seriously or being sent away because their problems are not something the university can help them with. This deeply rooted ableist individualism shimmers through in all of participants accounts of living with an invisible disability.

This individualistic theme can be linked to what Elraz and McCabe call '*the dominant wellbeing discourse'* (DWD). DWD seeks to produce subjects who take responsibility for their wellbeing and, in this way, render themselves productive (2023, p.490). In other words, there is a dominant idea that wellbeing can be achieved through self-discipline, that we should all be proactive people who do not blame circumstances, conditions, or conditioning for their behavior (p.494). And thus, that everyone can be 'healthy', as long as they take responsibility for their wellbeing (ableism). This idea relates to Foucaults governmentality, because if individuals govern

themselves by adhering to societal power structures (like DWD), there is no need for organizational or governmental interventions, because individual power is already decreased (p.491).

Moreover, Elraz and McCabe describe how people with mental health conditions deal with DWD by applying 'chameleon resistance', by making their condition invisible and making themselves visible as 'normal' subjects (p.492). Making oneself visible as 'normal' is something we have previously called performative able-bodiedness, passing, or covering (Kattari et al., 2018). Relating this individualism theme in participants accounts to DWD, governmentality and chameleon resistance, shows us that teaching individualism can be seen as just another way to exercise organizational power in a university setting. Because, if students learn to 'govern' themselves, by not disclosing, thus staying invisible and passing like able-bodied, they already decrease their own individual power by fitting themselves into the ableist medical model that the university provides for them.

In conclusion, participants described to feel alone within the system of university. They described how all networks of communication surrounding them disappeared within the shift to university and how they are supposed to handle their issues by themselves. They described a dominant individualism discourse around them, which made them afraid to reach out for accommodations. Their fear of disclosure can be related to Elraz and McCabe's DWD, chameleon resistance and Foucaults governmentality (2023, p.492). All in all, teaching individualism can be seen as a way to exercise organizational power in the university setting.

THE OPTIMISM THEME

On top of all the negative experiences, almost all participants also really wanted me to know that they did have good experiences with their disabilities, their studies, their teachers, their advisors and the system. Several recounted that they felt there was change happening and that while it was slow, it was important.

Participants told me about workshops and wellness week activities that worked well for peers that were struggling less than they were. They said that while maybe the workshops were not for them, they could see that it benefitted others and that made them happy. Some indicated that they were glad there was now a platform that centralized mental health, which functions as a conversation starter. Participants also gave examples of teachers and advisors who really made the difference for them. They told me about teachers who made them feel confident, teachers who checked in often, took the effort to tell them they were proud of them and of the work they do despite their disability, and keep the contact personal. Sloan said: *"It really also helps me when they tell me they are happy to see me again and that they are proud I am finishing things, just the human contact".* They also told me about teachers who sent out emails before their courses started, stating that students who need any assistance, with anything, could reach them at any time. Teachers who were flexible and open to individual solutions. Charlie gave two specific examples about different teachers:

> *He just creates so much room for who you are as a person (...) he starts every lecture with music to calm the mind (...) he always asks how do you feel, let's do a check in, how is the workload. He was not afraid to adapt the workload if it was too much or too little. He was flexible with deadlines if needed, but he was not vague.*

This teacher used a lot of colors and images in his slides. One day one of the students told him he was actually colorblind and the colors the teacher used did not work for him. The next class, this teacher had adapted all colors to colors the student could see the differences between. I was so amazed by his flexibility that I felt more room to tell him about my own issue; I felt very triggered by images that he used. I thought I couldn't say anything, that it was just my own problem, but this situation made me feel hopeful. So I told him. Not only was he very sensitive, he changed all images for upcoming lectures ánd lectures that had passed. He sent everyone the new PowerPoints. I was amazed.

Not only teachers were game-changers for participants, study advisors were also described to be heroes from time to time. Charlie told me about a specific time when they went into their study advisors' office:

I just entered her office, I told her I had just had a panic attack, with tears in my eyes. I told her I had been outside in the car for an hour reliving my worst trauma's. She looked at my calmly and told me to sit down. She got me some water and started grounding with me. She learned a lot from the sensitivity training that I suggested to her.

Within the affective analysis I also created a poem based on several participants' optimistic accounts. This illustrates how not everything is seen as dark and dirty, but there is a silver lining and a positive view about the future.

Wat jij misschien ziet als gebrek
Zie ik meestal als kwaliteit
Af en toe opent het een gesprek
En soms zorgt het voor wat nieuwe wijsheid

Mensen zien het vaak als een grote grijze wolk
Als een dreigende storm boven mijn hoofd
Maar als ik heel eerlijk ben
Voelt het meer als de zevende kleur van mijn regenboog

Kijk, er gaan veel dingen slecht dat kan ik niet ontkennen
Maar hoe mooi zou het zijn als we er allemaal gewoon aan zouden wennen
Dat we anders zijn is toch juist wat je maakt wie je bent
Uiteindelijk zijn we allemaal mensen, beperkt, niet beperkt, student of docent

Thus, while there are many negative patterns in participants' accounts of studying with an invisible disability, there are also positive patterns being stressed. Participants describe teachers, advisors and policy makers who make their lives better by keeping their doors and their minds open.

However, while I do trust that these stories are true and important, the fact that almost all participants felt the need to stress that there were positive things happening could be critically linked to a performance or a presentation of self (Leavy, 2009; Tarvainen, 2019). Goffman notes that social life can be conceptualized as a series of ongoing performances, linking to Shakespeare's famous line 'all the world is a stage' (Leavy, 2009, p.7). Within these

performances, there are front-stage and back-stage behaviors, impression management and face-saving behaviors according to Goffman. When looking at participants' positive storylines through this lens, the fact that they were presenting me with proof that they are not pessimists, and that they are able to see multiple sides to the story, could be seen as front-stage impression management. It could show how they try to give their stories and positionality more merit by showing me they are not only negative 'whiners', thus convincing me of their credibility, and again, positioning themselves within the dominant ableism discourse through an act of performative able-bodiedness (or performative able-mindness).

Putting on this lens while looking at the optimism theme brings us full circle. It brings us back to the invisible theme (they put much invisible extra effort into making me believe their stories are true and credible), the stigma theme (they assume that I won't take them seriously if they don't present themselves as rational, intelligent humans), the ableism theme (they describe that the system does not work well for them, but it does at times and for others so they assume they are the outliers) and the individualism theme (the default mode is that they are responsible for their own wellbeing and productivity, so even the smallest form of help coming from within the system is stressed as something very positive, and needs to be told).

CONCLUSION AND DISCUSSION

CONCLUSION

This study has indicated that there are five important themes within invisibly disabled students' experiences of studying at Utrecht university. First, participants experienced invisibility of their struggles, both inside and outside of the university context. They experience being held back by their social relationships, housing situations and care duties while simultaneously having to invest more time and energy into their study than their peers, due to a slower process of understanding the materials and an exhausting fight for accommodations on the side. Second, participants experienced stigma about their disabilities holding them back. Because their functioning differs from the 'standard', they experienced being told they were lazy, dumb or incompetent and not being taken seriously by teachers, advisors and peers. Moreover, they described a painful difference in treatment between psychological disabilities and physical disabilities. Participants also showed to have internalized the idea that they have to prove they are not lazy, dumb, or incompetent before they will be taken seriously. They showed this by offering small presentations of self to influence my image of them during interviews. Third, participants describe experiencing the university as a deeply ableist system. They experienced a 'one size fits all' mindset in which their disability was being put down as something to fix rather than embrace. They gave examples about ableist schedules, assignments and tests withholding them from participating like their peers. Moreover, they showed to have internalized ableism in their accounts of understanding towards the functioning of the university system, which held them back from asking for accommodations. Fourth, participants described experiencing deeply rooted individualism within the university, holding them back from reaching out for support. They described a lack of communication about disabilities with- and around them, a fragmented system and a feeling of loneliness. They described linking symptoms of their disability to parts of their personality, which shows internalized individuality and ableism: you are the one that is responsible for your disability. Moreover, they described being afraid of reaching out because others might not take them seriously or say it is their own problem or fault. And fifth,

participants described positive experiences with teachers, advisors and workshops, which could be seen as a performance or presentation of self, linking back to all previous themes: investing extra energy to convince me of the credibility of their stories (invisible theme), assuming that I won't take them seriously if they don't present themselves as rational (stigma theme), noting that they are probably the outlier because the system does work for others (ableism theme) and seeing the smallest positive effort from someone else as something very noteworthy (the individualism theme).

DISCUSSION

THEORETICAL INSIGHTS

Taking them in from the critically feminist epistemological position, these findings show a powerful neoliberal idea of being personally responsible for ensuring optimal productivity and health, which strips organizations like universities of their duty to give care. This neoliberal idea sends out a message that opportunities for marginalized groups such as disabled individuals, are equal as long as they put in sufficient commitment and self-management (Jammaers & Williams, 2021).

Putting in sufficient commitment and self-management would (presumably) result in being productive, healthy and able-bodied (Jammaers & Williams, 2021). Thus, a disability, in this neoliberal idea, can be seen as the result of *not* putting sufficient commitment and self-management into being 'able'. This brings us back to the translation of disability to 'loss of power' (Goodwin, 2020), and the origins of the ableist, medical model of education in Universities (Morina, 2022). The medical model revolves around the core idea that the disability is the problem of the individual, because the individual deviates from the social norm (because of a lack of self-management). Thus, individual power is lost when a disability occurs, because the individual is now labeled as 'the other' through social constructs (social identity theory) (Norstedt, 2019). These social constructs, are then applied within the medical model, to problematize and individualize the disability.

In turn, the disabled individuals facing this ableist and individualistic model, often try to navigate it by applying chameleon resistance, acts of performative able-bodiedness, presentations of self and covering, making them appear 'abled', thus well-managed (Kattari et al., 2018; Santuzzi et al., 2014). However, in doing so, they 'govern' themselves, as Foucault would say, which, again, decreases their own power and increases the organizations' power over them (Dolan, 2021).

To fragment the current power structure between the university and the invisibly disabled student, a move in the direction of the social model of education could be made. From a social model of education, the disability would be seen as a construct and product of social and political power structures (the individual is not disabled, the university is disabling the individual by not providing the right curriculum) (Allen, 2020). This would increase chances of disclosure (because the disability is not framed as an individual problem anymore) (Prince, 2017), and decrease moments of passing, covering, explaining, and micro-aggressions (Kattari et al., 2018; Hendry et al., 2022; Prince, 2017; Santuzzi et al., 2014). All in all, the internalized ableist, and individualized, medical model view on disabilities, currently reinforces the marginalized position of individuals with invisible disabilities at university.

With being able to state the strong sides of this research, also comes the responsibility of reflecting upon its possible pitfalls. There are three things that I deem important to reflect upon and advise scholars to look into further: (1) self-selection, (2) confirmation bias, and (3) the use of the word invisible disability. First, I chose to let individuals self-select into this study. However, this comes with the risk of excluding groups that I didn't reach and/or are too disabled to participate. I took several steps to minimize this, by using both digital and physical ways of participant-gathering and using the snowball effect to ask participants if they knew invisibly disabled individuals that might have not self-selected into the study because of their disability (for instance: social anxiety). I created room for participants to participate on their terms, by coming to their houses or meeting in neutral locations and by adapting the assignments to their needs. However, there always is a possibility of exclusion with self-selection and I would advise researchers that want to perform a similar study to actively reflect upon this issue more than I did; I think taking a larger timeframe and, for instance, working together with study advisors or tutors could help you limit this bias even more. Second, after analyzing the data I wondered whether the large number of negative statements was something I could have influenced. I reflected upon this and realized that, while my research question is neutral (how do you experience studying at Utrecht University), my prompt was negative (reflect upon instances when you feel disabled). While I think using this prompt rendered the most meaningful data, I do realize it's effect on the color of the data. Follow-up research should take this into account by, for instance, performing a similar study but with a positive prompt and comparing the results, or by using a more neutral prompt. Lastly, during data-gathering my participants made me realize that the use of the concept invisible disabilities was ableist in its core. The linguistic impact of the word is twofold: (1) when is something invisible and (2) is it truly a dis-ability? The use of the word invisible is too easy, my participants stated. *'My disability is not invisible to my psychologist, a social worker or someone who experiences the same symptoms. It is only invisible to an un-trained and sometimes un-interested eye'* Sloan said. Moreover, what is a disability? By using this word dis/ability you assume that I am *not* able to do what is 'normal', but within this already lies an ableist notion of normal. I realized that they were right. My own disability is also not invisible to everyone and I do not feel like I am *not* able, I just function somewhat differently than others. I get my things done, I just sometimes take a different route so I am not dis-abled. Follow-up research should investigate a better terminology for invisible disabilities taking its linguistic impact into account through, for instance, starting at the root of the word disability, which is translated to 'loss of power' (Goodwin, 2020, p.63). I think it is time to change that. If we want to work towards a future where the division of power is more equal, we should start by not naming these individuals 'the ones who lost power'.

HOW TO: IMPROVE STUDY EXPERIENCES FOR INVISIBLY DISABLED STUDENTS

TEACHERS:

1

MAKE YOURSELF MORE ACCESSIBLE:
- Tell students your doors are open via a section in the course manual, an email, or during the first lecture
- Be sensitive when students reach out; take them seriously
- Take feedback seriously

2

MAKE PREPARATION MORE ACCESSIBLE:
- Standardize the course manual; important info first page
- Send out the course manual as soon as possible
- Put readings online in PDF format
- Send out powerpoint slides before class
- Offer reading questions
- Use sub-deadlines for big assignments

3

MAKE PARTICIPATION MORE ACCESSIBLE
- Offer an online participation option
- Record lectures
- Be flexible with attendance requirements
- Send students in-class cases beforehand
- use slidenumbers and overview slides
- Use a clear time planning during lectures

POLICY MAKERS:

4

INVEST IN FACILITIES, INVEST IN:
- Camera's with microphone in every room
- Noise cancelling headphones during tests
- Power outlets in every lecture room
- Room in Osiris for personal accommodations
- More quiet study rooms
- Soundproof exam rooms

5

INVEST IN SUPERVISION, INVEST IN:
- More study advisors
- Giving teachers a few extra hours to invest in students
- Providing a clear overview of all accommodations
- Personal supervision during all study years
- Increasing visibility of study advisors
- Training teachers to be more sensitive

6

REFLECT UPON THE CURRENT SYSTEM, REFLECT UPON:
- Education as a service, not a product
- The communication surrounding struggling students
- The need for diagnoses for accommodations
- The structure of the academic year

ADVISE FOR PRACTICE

During the course of data collection, it became clear to me that participants did not just want to talk about their experiences, they wanted to do something about them. This pull towards advice, action, was so strong that I decided to act upon it and make room for collaborative discussion about advice during the focus groups. Participants came up with wonderful points of advice and we discussed them together.

I have divided our advice up into two: advice for teachers and advice for university policymakers.

TO THE TEACHERS

Our advice for teachers is threefold: (1) increase your own accessibility, (2) increase accessibility of preparation and (3) increase accessibility of lectures.

There are several things you can do to make yourself more accessible. First, we would advise you to make very clear that your doors are open. You can do so by including a section about this in your course manual, in any first email your send to students and/or during your first lecture. By doing this, you take away a big part of the barrier of disclosing for invisibly disabled students. Secondly, when students reach out, remember to be sensitive, take them seriously, try to do so even if they don't have any official diagnoses (yet). Trust that they know what is best for them. We have never seen anyone abuse accommodations that weren't needed. Try, also, to be sensitive when your students are late or fail an assignment. You can talk to them about this. You could for instance approach a student after class and say *"Hey, I've noticed X (that you were late/failed the assignment/don't seem your usual self), I just wanted to stress that you can talk to me about anything if you need. My door is open."* This is enough, don't pry but make sure students know you are safe. Finally, make sure to use feedback that students give you and show or tell them how you did so, this makes them feel understood and taken seriously, which increases the feeling of safety in your classroom.

To increase the accessibility of preparation, we have drafted six clearcut advisory points: (1) Use a standardized course manual in which important dates and information are easily findable on the first page. This makes it easier for students to prepare for your course. (2) Try to give students access to the course manual as soon as possible. If it is not fully finished, send students a first draft in which at least the readings and approximate deadlines are included, so students who need reading software or planning assistance can arrange this before your course starts. (3) Put all readings in clear PDF format (not scanned in) on blackboard, this decreases anxiety about finding the right literature and increases accessibility for those who need reading software. (4) Send students your PowerPoint slides before class. This makes it easier to keep track and make notes which decreases stress and anxiety. (5) Use sub-deadlines for big assignments. This way you divide the stress and keep track of students who are falling behind. And lastly (6) be sensitive when students fail to prepare, sometimes it already takes them a lot to get themselves to the lecture.

To increase accessibility during lectures, we have drafted 6 clearcut advisory points. (1) Make sure online participation is an option. Of course you want the default to be offline, but be flexible when students ask for it, sometimes it makes participation doable. We understand that providing hybrid lecture environments also takes a lot from you and we truly appreciate the work you put into it. (2) Record lectures. Sometimes students are physically in your lecture, but they cannot attain the information because of their disability, it can help them to watch it back. We understand that it might feel as making yourself redundant, but if we are able, we would always choose to come to your classes and pay attention (3) Be flexible when it comes to attendance requirements, sometimes disabilities prevent students from being able to participate, but they are involved, they do study at home. (4) when you want to use a case during a lecture, send it to your students beforehand. Having to read something during class is impossible for some students and increases stress and anxiety levels for others. (5) Make sure you give your PowerPoints a slide number and an overview slide every now and then. This makes it easier to make notes and keep track. And finally (6), make sure to use a clear time planning during your lecture and give enough breaks. Tell students beforehand when (approximately) they can count on a break and how long it will take, this will help them focus.

To the policymakers

Our advice to Utrecht Universities' policymakers is also threefold: (1) invest in facilities, (2) invest in supervision and (3) reflect upon the design of the system.

There are several facilities that would improve invisibly disabled students' experiences with their studies. (1) invest in camera's with microphones in every lecture room, this way online participation is made possible. (2) either invest in- or allow noise cancelling earplugs/headphones during tests so focus gets more easy. (3) Invest in enough power outlets in lecture rooms. Some students do not have the money for a laptop that can function without being connected to power, or forget to charge it before class. This way you make participation possible (4) Create room in Osiris to include personal accommodations that were agreed upon with students, so teachers know this without the student having to disclose every time. (5) Invest in more quiet study rooms, the library is often full and studying at home is not possible for everyone. (6) invest in soundproof (small) exam rooms. Make sure exam rooms are not next to construction or busy streets. This makes exams easier for students. And lastly (7) make sure that there is overview of situations in which accommodations are wrongfully not arranged -when a Kurzweil laptop has not

been arranged during a test for instance- , you could do so by making it mandatory to report an instance like this to the exam commission.

More supervision would also improve invisibly disabled students' experiences. We would advise you to invest in: (1) More study advisors. Students currently face long waiting times and feel like there is no one to turn to if their relationship with the current advisor is bad. (2) Invest in teachers, give them a couple of hours per month to invest in guidance of students who are struggling, to take time to unwind from providing us with a hybrid classroom that we so desperately need, and to support them in recording lectures and providing them to us. Giving them more hours, would give them the room to move a deadline, sit down with a student or simply have an open door policy. (3) Invest in providing and promoting a very clear overview of all accommodations the university provides. This should not be something you can only find by clicking through many times on the UU website, but an easily accessible platform (like a separate website or app) where every accommodation (per disability) is noted. This makes it easier for students to put in requests, and for mentors to refer students. (4) Invest in personal supervision during the whole course of the study. This could be done by a tutor (teacher) or a mentor (older student). The most important note is that meetings with this supervisor should be a default, they can be canceled but they never have to be initiated by the student. This supervision starts year one, month one, so disabilities are recognized early on and students are made aware of accommodations. If the troubles a student faces are very serious, the supervisor can refer them to the study advisor. (5) Make study advisors more visible. This could for instance be done during introduction, or on the social media of the study/study association. (6) Invest in training teachers to be more sensitive. Include, for instance, a small training about invisible disabilities in the BKO.

Aside from investing in more facilities and supervision, we also think it is important to start reflecting upon the way the system is currently shaped. For this reflection, we want to put in three points for discussion. (1) Reflect upon the current communication/interaction network surrounding struggling students: in the switch between high school and university, the communication network around a student is lost and all responsibility to get accommodations is shifted towards the students. This can be hard for invisibly disabled students. Should there be a more substantive communication network surrounding them? This can also prevent pretend students -students who pay tuition but do not take classes for years- and drop outs. (2) Reflect upon the need for diagnoses to claim accommodations. Why not open up all accommodations to all students? This way students can experiment with what would help them. Sometimes there is a problem, but no diagnosis. This does not mean there is no issue or need for help. And lastly (3), reflect upon the current structure of the academic year. Several students express a need for more frequent short breaks. Is it really necessary to have an eight week summer holiday, or could you also cut that down to four weeks and give students 1-2 week breaks between blocks? In restructuring like this, you create more room for students to prepare for new courses or wrap up old courses. You create breathing room to destress and recharge for the next block.

MERIT

While research on invisible disabilities is growing, the experiences of invisibly disabled individuals is missing from much of this research. Especially targeting students in a European context, this study is one of the first. Theoretically, the power of ableist discourses upon self-positioning of individuals is shown, which is crucial for understanding how these discourses are reproduced, resisted and internalized. Socially, the results of this study place invisibly disabled students as subjects who can change the ableism discourse within the university, rather

than mere objects of the universities policies. This representation is vital to social change. Practically, the advice produced by the participants of this study discussed in the section 'practical advice' helps teachers decrease the ableism in their courses and helps policymakers find the right focus for future policy on invisible disabilities. Moreover, the data quality is high because of the large time-investment made into building confidence and trust between the participants and the researcher. Therefore, this study provides a steady base from which to build onwards.

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