

*The Digital Age:
Youth, Disability, and Mental Health*

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Abstract

Drawing on 15 semi-structured interviews with Aotearoa youth, all of whom actively discuss disability and/or mental health online, alongside textual analysis of a variety of posts collected through approximately 100 hours of observation among 15 online community groups and tag searches across the social media platforms Facebook, Reddit and Instagram, I investigate how these New Zealanders engage in and with digital space. A core argument of this thesis is that social media forums and communities provide youth with a place to create a sense of solidarity in a society dominated by ableist assumptions. However, these spaces are also constructed and encoded with these ableist assumptions. As a member of the disabled community examining these issues and what it means to consider mental illness to be a “chronic disease” – or disability – of youth (McGorry et al., 2007:S5) were incredibly interesting. Digital technologies and social media provide spaces for the hidden histories of socially marginalised groups, such as the disabled and mentally ill, to be given their own voices. In this thesis, I investigate how some disabled and mentally ill youth in Aotearoa use the freedoms, information-sharing capacities, and community features of digital and social media (such as memes, photos, and YouTube content) in their communications of their experiences and perspectives. Language, as a social practice, plays a critical political and social role in how disabilities and mental health are understood in Aotearoa and, therefore, how disabled and mentally ill youth communicate on social media. These explorations lead to understandings of the relationship between voice and the activist, something which is non-linear and temporally situated. Activism and the activist are influenced by social norms, often being placed as the Other, leading to temporal retreats from activist activity. Social media provides a space and opportunity for disabled and mentally ill youth to reclaim their autonomy and their voice, which in traditional ableist spaces have been taken from them. Additionally, the Covid-19 pandemic has illustrated our digital technologies of care. The dual use of online groups for social support and information-seeking demonstrate how these social media platforms can perform as what Long (2020:250) calls “vital technologies of care” through which users possess the capacity to sustain relationships and wellbeing. They also demonstrate what I have termed “long social Covid” – the shared sense of social consciousness that reflects the social impacts of Covid-19. I suggest that digital communication, by enabling autonomy, voice, and validation, provides vital spaces for intra-group support that can develop into acts of broader social activism. However, social activism is temporally sensitive, an activity which people *can* and *do* move in and out of according to their capacities, needs, and ability to engage in activism; the retention of their voice is not dependent on their participation in social activism.

Keywords: activism, ableism, Covid-19, digital technologies, disability, mental health, mental illness, social media, social model, voice

*To my mentors, friends, pets, and caffeine: I couldn't have done this without you.
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Introduction

At the outset of this project, in March 2021, New Zealand was “Covid free”. We worked together in 2020 and achieved the goal of eliminating Covid-19 from the community. We enjoyed a Covid-19-free summer with no major scares or significant changes in national alert-level settings, causing us to grow complacent with our freedoms (Ng, 2021), until the implementation of alert level 4 at 11:59 pm on August 17. Generally, people had stopped routinely scanning in at locations, stopped wearing face coverings except where mandated, abandoned the routine hygiene procedures, and largely stopped paying such close attention to news relating to Covid-19 – because we had achieved community “elimination” we lulled ourselves into a false sense of complacency regarding how we lived in a Covid-19 world (Ng, 2021): we so badly wanted to “return to normal”, to be physically, rather than just virtually, present with one another that we stopped being conscientious about a global pandemic we had no hope of keeping at bay forever and did not consider whether a return to “normal” is what we ought to be striving for.

While Covid-19 is by no means the main focus of this thesis, there is no denying the substantial impact and influence the pandemic has had on the participation of youth (16–24-year-olds) with disabilities and mental illnesses in digital spaces. I was particularly aware of this as a large proportion of my observational and interview research was conducted during higher alert-level settings. Online discussions of these topics by youth is nothing new: social media, particularly in its inception, was regarded by many as a form of journaling, somewhere for people to put their random thoughts, to talk about things they could not discuss with “grown-ups” or in person. The internet has offered something unique to those growing up with it: an endless supply of knowledge and data with which people can freely question and explore everything and anything. In my teens, I used social media to explore what was out in the world beyond my small island life. I did not go looking for anything, but I did stumble upon things

that I needed to stumble onto. It was through engaging in fandom on Tumblr that I began to question my sexual identity, to google “how to know if you’re gay”, “what is love”, “what does it feel like when you like someone”. Social media has been the space where I, and many others, have explored and developed the more personal and private aspects of identity for years. Through going on YouTube and stumbling onto transgender content, consuming it, and relating to it for years before putting the pieces together and beginning to google “how to know if you’re trans”, reaching out to openly trans people online to talk to them, and joining anonymous trans groups on Reddit, I came to accept that, like being gay, I am trans. Digital and social media freed me to explore these and many more things that I felt, at the time, ashamed of or that I had to hide before I knew for certain. As one online user wrote, “I had to tell someone, but it’s not really the kind of thing I can tell anyone I know.” For all youth, but especially for minorities, digital and social media is a lifeline. I do not have many disabled friends and try not to talk too much about my chronic pain and fatigue with my able-bodied friends because they do not “get it” and I do not want them to think I am complaining, a sentiment echoed by the disabled and mentally ill interview participants of this study. The disability forums I am a part of on social media, the disabilities accounts I follow that validate my experiences, are a lifeline when I am having a bad pain day.

Researchers are often driven by their own interests stemming from questions and curiosities cultivated from their lived experiences. At time of writing, I am a 23-year-old recently out transgender man. I live with invisible disabilities such as chronic pain, chronic fatigue, and dyslexia, and I have been forced to fight socially and medically for years for recognition of these. I have also suffered from the mental illnesses PTSD, depression, and anxiety, for which I am in therapy and take medication. In my mid-teens I attempted suicide, in large part because of my then-undiagnosed disabilities and the dismissive attitudes of doctors, adults, and my peers. Because of all these compounding factors, I was told that I was

lazy, stupid, and would never perform well academically. I never imagined I would go to university, let alone complete a master's thesis, and this is a proud moment for me. What makes me even prouder is the response I had from the community and that I could do this research *for* them. This is a small snippet of who I am and where I come from in relation to this research. This is the perspective from which I engaged with my respondents and the communities they represent – one of personal understanding and experience.

My positionality as someone who was regarded, and feels like, an “insider” with my various groups of study gave me privileged knowledge and perspective that I believe enabled me to engage in more insightful and open conversations than would have been the case with an “outsider”. Of course, this position is not without its costs. In particular, I had to actively work against projecting my personal perceptions and assumptions onto my respondents and their experiences. There were times in reviewing my interview transcripts where I was unsure of the extent to which I succeeded in achieving this balance. For instance, both my respondents and I focused on how men's mental health is perceived and represented in New Zealand society (at the time of these interviews I still identified and understood myself as a woman) but, unthinkingly neglected to discuss how women's mental health is discussed and represented. I also had to ensure that my privileged access did not lead me to reveal “community only” knowledges that would not have been spoken to an outsider. No doubt, like all researchers, I could add to this list of risks and gains arising from my own position and relationships with the community I engaged during my research. Ultimately, though, while my own subjectivity and interests are present in this research, my close and empathic situation lends value to the study in a field of study often characterised by too much distance. It is from my personal knowledge and understanding that my questions for this research began to develop. I knew that despite all the wonderful literature out there on the topics of youth, disability, digital technologies, and mental health, there has been very little on how these topics intersect. I address this lacuna by

considering how disabled and mentally ill youth use digital technologies. I also examine the interplay between mental health and other forms of disability, asking whether having a disability influences experiences of mental health and mental illness. I consider why disabled youths' experiences of mental health and illness have not been more deeply explored in popular media or academic literature. When I began this study, I had seen next to no research on the experiences of disabled individuals with mental illness, a group within the disabled community I knew to be substantial. There *is* an undeniable link between having a disability and experiencing poorer mental health outcomes and higher instances of mental illness, something attributed to an array of social determinants and strains such as finances, social accessibility, accessibility to services, embodied belongings, and chronic pain (Inhorn & Wentzell, 2012:109; also see Aneshensel et al., 2013; Dashiff et al., 2009; Groce, 2004; McGorry et al., 2007; Mulvany, 2000; Rose, 2018; Webb et al., 2008; Zaffar, 2021; Zito et al., 2001). This research into the intersections between mental health and disability gives us the opportunity to acknowledge a fundamental social problem and take steps to better the lives of all disabled citizens.

My project focuses on the perspectives of youth because they – we – are still in the processes of gaining autonomy and grappling with identity and social roles, which are affected by contemporary systems and policies. Youth are a fascinating demographic because we are trying to figure ourselves out while at the same time taking increasing responsibility for our care and wellbeing in convoluted social systems, such as that of healthcare. This exploration of self creates opportunities for community information-sharing and care. Looking at people's lives online is a critical aspect of this because people tend to be more open and honest, about some things, online, as explored later in Chapter Three. How social media forums and communities provide youth with a place to create a sense of solidarity in a society dominated by ableist assumptions is a core argument of this thesis. The intra-group support in these

communities is critical to the development and expansion of activism. However, this is not a forgone conclusion. I argue that understanding the relationship between voice and the activist requires new consideration as it is not a linear progression but one that is temporal and situational. Activism and the activist are influenced considerably by what we consider socially normal. However, when one is constantly situated as the Other often there will come a point when they retreat from activist activity – demonstrating a more nuanced and complex relationship between the development of voice and the activist. An example of this can be seen in the video “Trauma. Transphobia. And the Internet. (why I left for 2.5 years)”, posted March 5, 2022, by Ash Hardell, a non-binary YouTuber, in which they explain that they left YouTube (where they championed queer rights and representation) because of the barrage of “targeted harassment” from which they developed PTSD and a tick disorder (Hardell, 2022). They go on to demonstrate the non-linear ebbs and flows of the activist:

Watching my friends take a stand against the digital abuse that they and other trans people endured was healing. And it’s empowered me to share my experience. [...] My trauma response is still very much alive and kicking. While I feel super empowered by the recent shift in tone surrounding trans discourse, that empowerment is simultaneously cautious and delicate. [...] I’m worried that by opening up and sharing my story and confessing to some of my personal self-doubts and struggles in the process, folks may try to weaponise those disclosures against me later. [...] I still feel compelled to use my voice. (Hardell, 2022)

My research has revealed that disabled youth feel dismissed and excluded from their own care because of the ableist assumption in society, and often ignored by medical professionals when they try to assert their own expert knowledge about their conditions and the relationships between their physical, mental, and spiritual health. Disabled youth are doubly disadvantaged in these interactions. While “youth” are expected to be gaining autonomy and authority over and taking responsibility for their bodies, if there is an “adult” present society

generally defers to them. Individuals with disabilities are often spoken *about*, rather than spoken *to* (Trnka & Muir, 2021). Hera, a 21-year-old Pākehā/Māori disabled woman and disabilities activist shares a story of taking her disabled brother, who is visually impaired, autistic, and awaiting an autoimmune disorder diagnosis, to the gym. The trainer was

intimidated by his [her brother's] disabilities. And he [the trainer] kept looking to me and speaking to me, [...] as I was sitting next to my brother whose appointment it was. He [the trainer] would just keep looking to me when it was my brother's exercise we're talking about.

This is a common situation: if a visibly disabled individual is with an able-bodied-looking individual then questions and conversation are directed to the latter, not the former, creating an instance of voice poverty – “the inability of people to influence the decisions that affect their lives and the right to participate in that decision making” (Horst & Miller, 2020:225, 229) in traditional spaces of engagement. Voice poverty is a key concept throughout this thesis, recurring in each chapter and discussed in depth in Chapter Three. Recognising voice poverty in relation to embodied experiences of disabled and mentally ill youth is critical to understanding why and how they engage in digital spaces. These spaces give them the opportunity to reclaim their autonomy and their voice, which in traditional ableist spaces have been taken from them.

My research is an examination of the ideas and concepts that demonstrate the ableist assumptions that dominate everyday interactions in Aotearoa¹ and the way these assumptions exclude non-able-bodied people from being active in society, as well as of how disabled youth respond. Despite being a member of the disabled community, there are so many ableist assumptions that I was blind to before doing this research because they did not affect me, and, as one of my interlocutors explains, “everyone has internalised ableism”. I examine activism,

¹ Aotearoa is the Māori name for New Zealand. Aotearoa will be used except when referring to the government and other entities that use the name New Zealand.

language, and digital spaces as three areas of society which illustrate the reality of living in a society and social spaces dominated and constructed by ableist assumptions.

Critical definitions: What is at stake in terminology

Ableism is the assertion that there is one “correct” way to exist as a person, creating a system that values certain people and abilities over others. It disregards and misunderstands the experience of anyone whose bodies are not “correct” (Hartblay, 2020:S32; Kattari, 2020:1171). As one of my interlocutors explained, ableist attitudes are based on “not tak[ing] anyone seriously”, a sentiment another interviewee compounds, stating that ableism is the framing of being “differently abled” (the Other) as a deficit.

Disability is a complex term that is rooted in social, historical, and cultural contexts, with deep ties to morality, personhood, citizenship, biopolitics, and issues of voice (Attrill & Fullwood, 2016; Ellis et al., 2019; Ginsburg & Rapp, 2020; Hartblay, 2020; Inhorn & Wentzell, 2012; Kasnitz, 2020; Loh & Lim, 2019). Mental health is a fluctuating spectrum: rather than merely being the absence of mental disorders (mental illness), it references an ideal state of complete physical, mental, and social wellbeing that helps individuals cope with the normal stresses of life and achieve their fullest potential (Rapoport, 1963:1900; McLean Hospital, 2021; World Health Organisation, 2018). Mental disorders, or mental illnesses, are “condition[s] that affects a person’s thinking, feeling, mood, or behaviour”, whereas mental health reflects “emotional, psychological, and social well-being [a]ffecting how we think, feel, and act” (McLean Hospital, 2021). The dichotomy between mental health and mental illness is further developed in Chapter Two with the aid of Hermaphroditus, a 16-year-old Pākehā non-binary person high school student in Auckland that has experienced mental illness. Social determinants are social, psychological, and biological factors that influence physical and mental health outcomes at any point in time (World Health Organization, 2018). They include

poverty, unemployment, social isolation, and inequalities in status (age, gender, ethnicity, sexual identity), power, and control (Aneshensel et al., 2013; Dashiff et al., 2009; Groce, 2004; McGorry et al., 2007; Mulvany, 2000; Rose, 2018; Webb et al., 2008; Zaffar, 2021; Zito et al., 2001). Rapid social change, stressful work conditions, discrimination, and social exclusion are also associated with poor mental health (World Health Organization, 2018). These factors influence overall mental health and wellbeing as well as the development and severity of mental illnesses. Understanding the above terms and why, when, and how they are used is critical in examining the ever-growing activist content in digital spaces.

Methodology

I used a qualitative approach in this research, conducting semi-structured one-on-one interviews and online observational research. My research was approved by the University of Auckland Human Ethics Committee (UAHEC) at the end of May 2021, after an initial submission in February. Once I had approval, I identified and contacted various disabilities and mental health groups on Facebook (I approached 27 groups, of which 8 agreed to participate, 3 declined, and 16 did not respond) and Reddit (I approached 17 subreddits, of which 7 agreed, 2 declined, and 8 did not respond). The process of joining these groups and contacting the admins/moderators was quite different between Facebook and Reddit. On Facebook these groups are “private”, which meant that I had to be accepted into the group by an administrator in order to contribute and view the content. Without such access, I could only see the group’s name, cover photo, rules, and description. When requesting to join a private group on Facebook a series of screening questions typically appears, the answers to which are forwarded to the admins. Private groups often used variations of the same questions: why do you want to join the group? have you read the rules? what is the answer to this question (the answer being in the rules)? and for country-specific groups, confirming you live in that country.

In addition to completing screening processes, I directly contacted group admins and moderators to request their explicit permission to be in the group as a researcher. I introduced myself as a University of Auckland master's student in the Anthropology Department, and where applicable a member of the disabled community, before outlining my research project and requesting permission to conduct observational research and advertise for interview participants within the group. I sent them admin/moderator-specific Participant Information Sheets (PIS) that outlined the project and what I was asking for in detail to ensure they understood. On Reddit the process worked slightly differently. There are no screening questions when joining a subreddit. Instead, a welcome message is sent linking the user with the subreddit moderators. I used this link to contact them under the "Research" inquiry option, sending them the same introductory information and PIS document.

Once I gained permission in any group, I started by submitting a post announcing my presence in the group as a researcher, providing a basic outline of my project, and advertising for potential research participants, asking interested individuals to direct message (DM) me. In this post I also explained that anyone who did not wish to be included in the observational research could DM me, email me, or comment on the post; in these cases I noted their screen names down in a password-protected Excel spreadsheet and did not look at or use any of the content they had posted. I then posted around once every few weeks asking for interview respondents in the first few months of the research when I did not have many respondents. I also encouraged members to share my post with anyone they thought would be interested. Finally, I posted on my personal Instagram, Facebook, and Tumblr accounts using keyword tags to spread the post and again encouraged those seeing it to share it around.

I began conducting observational research in June 2021 once I had been approved to interact in these various groups. Using keyword searches I also conducted observational research on Tumblr, Twitter, Instagram, and YouTube as well as accessing archival data. In

the groups I would scroll through the posts for the week, making general notes on the themes and topics discussed and noting whether topics crossed groups and social-media platforms. If a specific post caught my attention, I saved it and messaged the author seeking their permission to use it as well as checking whether they met the research criteria of living in Aotearoa and being aged 16–24. I spent approximately five hours a week for 20 weeks (a total of approximately 100 hours) in these groups collecting observational materials between June and the beginning of October, when I concluded my observational studies. On every social media service and group in which I posted and conducted observational study I used my personal accounts so that people could see my “social media history”, hopefully ensuring that our interactions began with a sense of trust and that admins and moderators would be more trusting of my accounts. This also meant that I received notifications of my phone and computer when people in these groups posted. This would often prompt instances of engagement in clearing the notification and then scrolling through to see what had been added since I was last active.

I interviewed 15 respondents recruited from these Reddit and Facebook groups and Instagram, some being in the Reddit and Facebook groups I posted in and some linked to my posts by others in these groups. When I was contacted by potential participants I would ask them three screening questions: “Do you live in Aotearoa? Are you between the ages of 16 and 24? Do you talk about mental health or disability online?” If they met all these criteria, I sent them the PIS and consent form to look over and sign. All interview respondents were offered the option for in-person interviews (if they were in Auckland and it was safe and legal to do so), phone call, video call, or text interviews. This variety of interview options was to ensure that anyone could participate regardless of any disabilities they may have, their level of comfort in talking to a researcher and stranger from the internet, and their level of access to resources, such as a stable and sustainable internet connection. Interviews were recorded either on a phone recording app (for in-person interviews in Auckland) or using embedded recording software,

such as that available on Zoom (for those conducted online after August 2021, when Auckland went into lockdown). Two interviews were also conducted via WhatsApp messaging, which generates transcripts of the text conversation. Interview sessions lasted between 30 and 80 minutes, with breaks being offered as needed because of the potential for emotional and mental fatigue. All my interview participants were either New Zealand citizens or permanent residents and between the ages of 16 and 24, with 21 being the median age. They offered diverse gender identities, with nine identifying as cis women, two as cis men, one as non-binary, one as trans-feminine/non-binary feminine, one as feminine gender fluid, and one as cis female questioning. While the lack of equal diverse gender representation may be a limiting factor in this research, I suggest the gender ratio is instead reflective of the gender ratios within these online groups, at least on Facebook, where I was able to look at the members and see their gender identity on their profiles. When asked for their ethnicities seven identified as New Zealand European (Pākehā), five as both Māori and Pākehā, one as Indian/New Zealander, one as Filipino/New Zealander, and one as Ukrainian/Pākehā. Respondents were spread out over the country with twelve in the North Island and three in the South Island. Auckland and Wellington were the only regions with multiple respondents, with nine in the greater Auckland region and two from the Wellington region.

For historical materials I used Papers Past, an archive of written and visual records from Aotearoa and the Pacific, offered by Archives New Zealand, and the National Library, which provides a brief description of materials and require materials to be requested with explanation of who you are, why you need the resources, and what you plan to use them for. All this material is considered archival data which dates to the signing of the Treaty of Waitangi on September 6, 1840; demonstrating the eradication of Māori perspectives and histories through the implication that there was no recorded history in Aoteroa before September 6, 1840.

Research in the time of Covid-19

The Covid-19 pandemic influenced this research in myriad ways, one of which was creating limitations in terms how it could be conducted. The first instance of Covid-19's impact was the elimination of many potential participants who were tired out by the trials, tribulations, and emotional burnout experienced during the pandemic. For instance, on August 17,² just hours before the nationwide level-4 lockdown was announced, I received this email:

I saw your advertisement regarding disabled people in New Zealand online and have forwarded it to my flatmate (who is also disabled). We're both disabled – and research technicians – ourselves, and would be more than happy to help out.

After corresponding back and forth for 20 minutes, which concluded with my sending through the PIS and consent forms, I did not receive further communication until after I followed up with them twice, first on September 2 and then again on the 28th, expressing concern about their wellbeing. When I asked if they were okay and if there was anything I could do to help them, they responded:

Not really. I've had a whole bunch of bad occurrences happen all at once, and I'm struggling to keep my head above water. [...] Unfortunately, there's not a lot that can be done. Serious injury + immigration + flight/border issues + exams + surgery + inspection, all compounding in the same period. And then I found out my parents opted out of most childhood vaccinations. I'll be fine. I'm just immensely stressed out right now.

This potential participant's flatmate also never got in contact with me, I suspect because of their own troubles and lack of capacity to participate in a research project. In this situation I was more concerned for their wellbeing than having them participate in my research.

Another example of burnout affecting participation in my research occurred in the online groups. While some groups, such as the meme groups, flourished, disability and

² I received consent to use this email exchange.

mental health-specific groups and discussions saw a significant decline. Unlike in 2020, when people used groups as a means of checking in with one another, it seems that many no longer had the emotional capacity to engage during the unexpected and longer August lockdown, which in Auckland stretched until December 2021. These behaviours are an instance of what I have termed “long social Covid”, a shared social consciousness of cultural experiences, mental health, and navigations of social space influenced by the effects of Covid-19. The kinds and frequency of use of digital technologies change contextually according to users’ needs. As Martí et al. (2017:192) state, social support is multidimensional. The balance of online and offline mediums of support differs for each person. Some people increase their use of digital technologies as their competency increases because they feel more comfortable, while others decide that it is not where they want to direct their limited energies. This may seem counterintuitive to what public health workers and policy – which is increasingly emphasising online care – seem to assume.

Literature review

Historical background

Anthropological studies of digital technologies, youth, disability, and mental health all began in the second half of the 20th century raging from the early 1960s to the 1990s (Aouragh, 2018; Brake, 1985; Budka, 2011; Keniston, 1970; Moore, 1990; Schwartz & Merten, 1967). The anthropological approach to mental health and youth are the oldest of the four sub-fields, both gaining traction in the 1960s. Anthropological notions of the nexus between culture, mental health, and mental illness gained notoriety in the early 1960s with the views of community care, cultural stigmas, and holistic approaches to mental health found in Margaret Mead’s “Mental Health and the Wider World” (1962) and Robert Rapoport’s “Social Anthropology and Mental Health” (1963). The youth studies rose in popularity in the late 1960s and early

1970s with the establishment of journals dedicated to this area, *Youth & Society* in 1969 and *Journal of Youth and Adolescence* in 1972. In the 1990s youth studies developed into an independent field of study, as demonstrated by the creation of the *Journal of Youth Studies* in 1998. Anthropological interest in disability began with the burst of interest in disability studies in the mid-1980s, when Louise Duval published the newsletter *Disability and Culture* in 1986–1988 (Kasnitz & Shuttleworth, 2001). While the portfolio of publications in the anthropology of disability gained momentum in the late 1990s and early 2000s, Kasnitz and Shuttleworth (2001) criticised the discipline for its sub-par embracing of the key messages of disability studies:

Anthropologists have the capacity to move disability theory forward, feeding it with ethnographic fuel. While the anthropology of disability uses insightful ethnographic methods to understand specific impairments in specific contexts, often from a western or indigenous medical diagnostic perspective, this approach often fails to deploy a dynamic relational concept of disability. (Kasnitz & Shuttleworth, 2000:S18)

I infer that this “dynamic relational” conception of disability relates to the holistic cultural approach that Mead and Rapoport were advocating for as well as being an early nod to the newer concept of social determinants. The holistic approach views the person as a whole, examining how the spiritual, the physical, the mental, and the social influence one another and how they are interconnected.

Recent developments

The beginning of the 21st century saw many shifts in how academics and the general public think and talk about the topics of mental health, youth, disability, and digital technologies. Many academic discussions of mental health in 2021 continue to revolve around the same points they did in the early 2000s (Aneshensel et al., 2013; Dashiff et al., 2009; Groce, 2004;

Kattari, 2020; McGorry, 2007; McGorry et al., 2013; Mulvany, 2000; Rose, 2018; Zaffar, 2021). The key points I am taking from the literature are that mental illness is to be classified as a disability to reflect the role of social determinants in constructing the environment in which mental health declines and mental illness develops, and the significance of stigmatisation and social branding – the negative labelling of those with mental illness – in contributing to further declines in mental wellbeing (Aneshensel et al., 2013; Dashiff et al., 2009; Groce, 2004; Kattari, 2020; McGorry et al., 2007, 2013; Mulvany, 2000; Rose, 2018; Webb et al., 2008; Zaffar, 2021; Zito et al., 2001). I employ these concepts through examining the cultural perception of mental illness in Aotearoa, with particular focus on how men with mental illness are viewed and branded in society.

Disability is a historically and culturally shaped political object. Chapter One demonstrates the shift in social sciences away from a biomedical model – the medicalisation of illness and framing of impaired individuals as the “problem” (Aneshensel et al., 2013) – to a social/political-relational model of disability which focuses on the how society is politically constructed to limit the engagement of those with impairments (Aneshensel et al., 2013; Groce, 2004; Kattari, 2020; McGorry et al., 2007; Mulvany, 2000). The shift in models align with changes in social opinion in terms of how individuals with disabilities are seen. Like disability and feminist scholars, mental illness scholars advocate for the voices and needs of individuals with mental illness to take precedence over those of experts and professionals (Aneshensel et al., 2013; Kattari, 2020; McGorry et al., 2013; Mulvany, 2000). Additionally, scholars in these fields emphasise that the lived reality of mental illness is different for every individual because it is informed by their embodied realities which are biographically, temporally, and culturally specific (Aneshensel et al., 2013; Groce, 2004; Kattari, 2020; Mulvany, 2000; Rose, 2018). These realities are entrenched within the cultural norms of a society. Mental illness is not dependent on social determinants to develop; however, it is severely worsened by them because

individuals impacted by social determinants lack disposable resources (income, time, travel capacities, and so on) needed to “treat” them. The system of social determinants is explained by the notion “cycle of deprivation”, or the “poverty trap” (Oxford Reference, 2022). It is the system of self-reinforcing mechanisms which perpetuates poverty and other forms of socio-economic disadvantage across generations, which increases the likelihood of mental illness and poorer mental health continuing intergenerationally because they do not have the capital to move beyond the sociocultural and economic factors affecting mental wellbeing (Rose, 2018; Oxford Reference, 2022). Intergenerational social deprivation creates a persistence of social ideas, standards, stigmas, and problems born of poor housing, low education, unemployment, and so on (Rose, 2018; Oxford Reference, 2022). The cycle of deprivation supports Mulvany’s argument that mental illness should be considered a disability – defined as the disadvantage or restriction of activity caused by a social organisation that excludes people with *mental* or physical *impairments* from mainstream social activities (Mulvany, 2000:584). Because disability is a socially constructed *idea*, grounded in dominant social stigmas and perceived limitations of impairments (Mulvany, 2000) – the difference in a person’s bodily or mental structure or function (CDC, 2020) – the day-to-day life (lived reality) of a person with impairments is often much different than able-bodied peoples imagining of their reality. Therefore, mental illness can be classified as a bodily impairment and therefore a disability.

In applying disability theories and frameworks to analyses of mental illness, a complex and multifaceted framework of social restriction, disadvantage, oppression, and stigma begins to emerge, transcending the clinical medicalised views of disability and impairments. This shift represents an acknowledgement of the stigmas towards mental illness created through processes of social oppression, discrimination, and exclusion. The prominent fallacy of mental health policy is the assumption that medical symptoms and problems are caused solely by an illness, underplaying the impact of sociocultural influences (Mulvany, 2000:587; Zaffar,

2021). Such disregard of the sociocultural influences on the embodied experiences of mental illness or impairment perpetuates cycles of deprivation. Stigmatisation of the mentally ill strips individuals of their personhood and citizenship and reduces them from a whole person to a tainted and discounted one (Aneshensel et al., 2013). It causes social isolation, discrimination, and prejudice, creating environments where people feel they need to hide their mental illness; preventing them from seeking help for fear of being “branded” mentally ill. For instance gender expectations effect how people are seen and deal with mental illness, as will be explored in Chapter Two (Aneshensel et al., 2013; Dashiff et al., 2009; Groce, 2004; Kattari, 2020; McGorry et al., 2013; Mulvany, 2000; Webb et al., 2008). These social stigmas can manifest as microaggressions, perpetuating inequalities and stereotypes of minority groups and mental illness and adversely affecting mental health outcomes (Kattari, 2020), as can be seen in the Kiwi phrase “man up” that is frequently addressed to men struggling with mental health issues. These microaggressions are mostly targeted towards aspects of identity – age, sex, ethnicity, religion, sexuality, disability, having a mental illness, etc. – which has negative effects on the mental health outcomes for these populations (Kattari, 2020; Webb et al., 2008).

There have been several developments in disability studies in recent years. As anthropologist and disability scholar Devva Kasnitz argues, “Disability is a concept that grows as we think about it, forcing us to adjust our conversations in vocabulary and rhetoric depending on which disability world we inhabit or address”, forcing disability to become a political exercise (Kasnitz, 2020:S16). Ginsburg and Rapp (2020:S9) and Horst and Miller (2020:104) refer as “disability worlds” to explain the lived realities of the disabled, which are shaped by the intimate and broader contexts in which they evolve; the aim is to foster understandings of what it means to be human. The social model of disability emphasises the *need* to focus on the underlying social processes that *create* barriers, which in turn construct disability by rendering physical and social environments inaccessible to those with

impairments (Aneshensel et al., 2013; Attrill & Fullwood, 2016; Ellis et al., 2019; Hartblay, 2020; Kirsten et al., 2009; Raffety, 2018). The social model is also known as the “eco-systemic anthropological perspective” (Kirsten et al., 2009:1); which considers the impacts of various social factors, such as economic, urban planning, policy and so on, on people’s wellbeing and embodied belonging in society (Aneshensel et al., 2013; Ellis et al., 2019; Kirsten et al., 2009; Raffety, 2018). Anthropologist Erin Raffety (2018) argues that the social model of disability seeks to interrogate social attitudes towards differences, highlighting the constructed nature of the category of disability. The social model aims to demonstrate that disability is a socially constructed category that institutionally excludes and prevents (or disables) individuals with impairments from existing and participating in mainstream society (Aneshensel et al., 2013; Ellis et al., 2019). Disability scholars Alison Kafer and Tanya Titchkosky developed the “political-relational model”. This builds on the social model in that it reminds us that disability is *always* a political category (Ellis et al., 2019:250). It moves beyond the inaccessibility of society and the urban environment for those with impairments to engage with the ableist policies and beliefs that perpetuate these inaccessible spaces. This model also acknowledges that disability and ability are relational fluid states, based on the policies which construct engagement with and in space (Ellis et al., 2019:250; Ginsburg & Rapp, 2020:S11–S12; Hartblay, 2020:S33; Inhorn & Wentzell, 2012:112). Regardless of what the model is called, there is a consensus that framing an individual’s impairment as the “problem” is unacceptable. It is not an individual’s body that is the problem but rather social space and environments being inhospitable, arduous, and unaccommodating to the point of disabling and preventing these individuals from accessing them.

A critical development in disability studies has been the emergence of the concepts of voice and voice poverty. Voice is understood as the right to expression and the agency to represent oneself; voice poverty is the “inability of people to influence the decisions that affect

their lives and the right to participate in that decision making” (Horst & Miller, 2020:225, 229). Voice poverty does not affect everyone equally; those with intersecting marginalised identities or less “attractive” or uncommon disabilities are at greater risk of facing instances of voice poverty because they have multiple socially constructed barriers suppressing their voice (Aneshensel et al., 2013; Ellis et al., 2019; Ginsburg & Rapp, 2020; Inhorn & Wentzell, 2012; Kasnitz, 2020). This can be explained through Appadurai’s concept of the “gravest lacks” of the poor, referencing to these individuals who do not possess the social and cultural capital or resources that would give them a voice (Appadurai, 1990, 2004). The cycle of voice poverty is extremely detrimental to disability care because it ignores what Hartblay (2020:S26) has termed “disability expertise”, that is, the specialised knowledge that individuals with disabilities have accrued through their lived experiences (Hartblay, 2020:S27). Such expertise is critical because it encapsulates specific social and medical knowledges that are specific to how disabilities affect individuals and how they should be cared for. However, voice poverty reflects that these individuals are not granted agency in their own care. Rather, individuals are perceived through a generalised medicalised lens which devalues their expert knowledge in favour of ableist notions and expectations (Hartblay, 2020).

Youth studies did not begin to gain interdisciplinary notice until the late 1990s. Along with the development of youth studies as a field of study on its own came debates over what and who “youth” is. This is complex. As Andy Ruddock, a communications and media studies specialist states, “the term youth is no longer seen as straightforwardly linked with the condition of being young” (2013:11). Anthropologists explain that the ambiguity of who youth are and what it means to be a youth occurs because they are culturally and contextually dependent (Brake, 1985; Bucholtz, 2002; Durham, 2004; Hill, 2011; Keniston, 1970; D. Moore, 1990; Nilan & Feixa, 2006; Rohrer, 2014; Schwartz & Merten, 1967). Thus, “to call someone a youth is to position him or her in terms of a variety of social attributes, including

not only age but also independence – dependence, authority, rights, abilities, knowledge, responsibilities and so on” (Durham, 2004:593). Anthropologists use the term “shifter” to encapsulate what youth culture is. A shifter is something that points to cultural (contextual) meaning but changes with each use, creating a context-renewing and context-creating environment, for instance the use of “I” (Bucholtz, 2002:528; Durham, 2004:589, 592, 593; Rohrer, 2014). Youth, as a term, is, therefore, flexible, agentive and contestable in the eyes of these anthropologists, because in its role as a shifter, it “invokes youth as a political, or pragmatic act” (Durham, 2004:592).

A common theme in youth studies literature is that of youth positioned as social delinquents. This narrative of social deviance is perpetuated by the media, which produces and reproduces public sentiments and concerns, demonstrating instances of the politics of representation (Ruddock, 2013:2–3). Youth are framed as aloof delinquents who have become “liabilities” to the socioeconomic order because they are often at the centre of sociocultural change (Erikson, 1965:166), for instance the moralisation against youth during the UK punk rock era in the 1970s. However, as youth studies has developed, the theme of youth delinquency has been replaced by the view that youth are social actors and activists who shape culture and society (Barber, 2013; Brake, 1985; Bucholtz, 2002; Décieux et al., 2019; Durham, 2004; Erikson, 1965; France, 2000; Griffin, 2001; Keniston, 1970; Nilan & Feixa, 2006; Rohrer, 2014; Ruddock, 2013; Truzzi & Manning, 1972). These behaviours are referred to as “youth consciousness” and are punctuated by “revolutionary movements” (Truzzi & Manning, 1972:26) and various forms of resistance that act to form a subculture of “youth”. The positioning of youth in terms of a subculture – “meaning systems, modes of expression or lifestyles developed by groups” (Brake, 1985:7) – allows for an evolution away from youths as delinquents. The shift in understanding youth as social actors shaping society and culture comes with the recognition that youth is not a developmental stage bridging the gap between

adolescence and adulthood but rather a subculture that can/might/may revolt against the hegemonic norms of society. This shift in the understanding of youth and youth culture also means that there is a turn away from rites of passage as an exclusive focus of youth's motivations (Erikson, 1965; Nilan & Feixa, 2006; Rohrer, 2014).

Recent youth studies have focused on postmodern approaches, such as post-subcultural theory, that focus on the role of social media, the internet, and consumerism (Cieslik & Simpson, 2013; Fu & Cook, 2021). In such approaches, globalisation is seen as playing a critical role in “youth phases” and shifting conceptions of identity, such as extended timeframes for the social transitions of marriage, homeownership, children, and steady jobs (Cieslik & Simpson, 2013; Erpyleva, 2021; Fu & Cook, 2021; Henn & Foard, 2014; Kitanova, 2020). This extension of social transitions, often involuntary, leads to greater instances of youth political activism and unrest (Cieslik & Simpson, 2013; Erpyleva, 2021; Henn & Foard, 2014; Kitanova, 2020), again demonstrating that what mainstream media frames as youth delinquency and social deviancy is activism (Bucholtz, 2002; Hill, 2011; Nilan & Feixa, 2006; Reis & Berckmoes, 2018; Ruddock, 2013).

The current and past literature has done much to advance the studies of these areas and continue to develop them under the care of the social model. However, there needs to be greater intersection of these ideas and examination of their relationship to one another: this is where the literature can grow. Society is changing and how we act socially is changing, and the literature's analysis needs to continue to advance to reflect these changes.

Chapter outline

Drawing upon the existing literature, I build my argument that digital communication and intra-group support are vital to develop autonomy, voice, validation, and even activist activity for disabled and mentally ill youth in Aotearoa, a society dominated by ableist assumptions.

Chapter One examines the historical background of disability and mental health activism in Aotearoa. These hidden histories of disability, mental health, and voice poverty are exposed and discussed in relation to this study. I frame history not as an event occurring in the past, but rather as something that no longer has active social consequences. As such, I argue that because of their hidden histories and the continued disability and mental health activism in New Zealand, they are not history. Furthermore, I examine the hidden Māori perspectives on these issues based on traditional oral histories as told through the narratives of Māui. These histories are hidden by the ableist and colonial domination of public discourse and information, preventing the expression of minority expert knowledges. These affect the records kept, the information taught, and the way scholars approach these topics. I draw on historical documents from the New Zealand National Archives and Papers Past, policy documents, acts, and traditional Māori histories, as well as the works of historians, anthropologists, and sociologists, to develop and examine these ideas in a historical and modern context.

Chapter Two discusses the politics of language, delving into the importance of the language we choose to use and the sociocultural implications, particularly in English, of choosing one word over another when there are several that can be used to express the same thing. For instance, in place of the term disabled the terms handicapped, crippled, lame, or differently abled can be used; each has specific temporal, historical and social implications. This chapter contains foundational frameworks from which to view subsequent chapters and examine the importance of language used when discussing the past, present, and future. Here I demonstrate the power of language as a key component in cultural performance and social practice, revealing embodied dispositions in Aotearoa's habitus. I argue that a social model of disability suggests that mental illness should be considered a disability because it is a permanent impairment. I draw heavily on my interview and observational materials in this

chapter alongside government definitions and documents to illustrate how these topics are framed and presented in Aotearoa society.

Chapter Three explores expressions of disabled and mentally ill youths' voices on social media. The complex duality of social media and its impacts on mental wellbeing is a critical theme explored in this chapter. In this chapter I introduce the term "filtered lives" to evoke the harmful elements and pressures of social media on youths' mental health. Furthermore, I examine the politics of web design and the exclusionary consequences of inaccessible social media design elements because of dominant ableist assumptions when coding websites. I primarily focus on what social media and digital participation offer to disabled and mentally ill youth in terms of identity exploration, community, and information sharing.

I further develop these discussions of digital technologies and social media from the perspective of the impacts these technologies have had in the context of the 2020–2021 Covid-19 pandemic in Aotearoa. I argue that the pandemic has demonstrated how society is systemically constructed through policy and urban design to be unaccommodating for individuals with disabilities. I argue that pseudo-nationalism (Sturm et al., 2021: 2020–22) was a critical element of the New Zealand government's Covid-19 response. Furthermore, it fostered an environment of infantilisation towards and displacement of disabled individuals because of the impermanent collectivism pseudo-nationalism creates.

Throughout this thesis, my focus is on listening to the voices of the forgotten and shining a light on the people so often spoken *about* but seldom spoken *to*. While there is a growing chorus of those wanting to "return to normal", I argue that this pandemic has offered us the perfect opportunity to reflect on our systems, biases, and perceptions in terms of so-called "vulnerable" groups. It has brought the issues that disabled groups face to the forefront

and has caused able-bodied individuals to partially “live in their shoes” by experiencing the everyday trials and tribulations of individuals with disabilities.

Chapter One: Hidden Histories

Disability and Mental Health Activism in Aotearoa

Most people are familiar with the utterance, “History is written by the victors.” The origin of this phrase remains unknown, yet many have evoked it: for instance, Winston Churchill, in his address to the House of Commons on June 8, 1940, said, “History will be kind to me, for I intend to write it.” As this view implies, hegemonic histories miss critical pieces because they are produced by and represent a singular group, their perspectives, and their voices (Trouillot, 2015). “Hidden histories” are the omissions and erasure of people and their experiences from history, because of “histories” that are incomplete and one-sided. Hidden histories are the histories of people who are not afforded the opportunities or positions to write accepted histories – people who are the hidden, forgotten, overlooked, and deemed undesirable (Pacheco de Oliveira, 2020; Driver, 2013; Rose, 2021; Tikao et al., 2009). In essence, these people and their histories are silenced through the lies and oppression wrought by the dominant authority, often leading to their accounts being destroyed, guarded, or hidden away (Pacheco de Oliveira, 2020:215; Driver, 2013:420; Hocking, 2020:217; Prasad, 2021; Rose, 1992:14; Tikao et al., 2009).

Central to understanding hidden histories is understanding what history is. While this seems simple – that it is the study of the past and past events – what does this mean? What is the past? Historian Edward Carr’s *What Is History?* (1961) was one of the major works to discuss this issue. Carr concluded that history is “a continuous process of interaction between the historian and his [*sic*] facts, an unending dialogue between the present and the past” (Carr, 1961:16), making it a social and political process of interpretation. Rose (1992:16) builds on this, claiming that control over the past – history – comes from the power to define the present. This defining of the past and present is a means of controlling abused minorities who, when

they question the hidden histories of abuse, are accused of “living in the past” (Rose, 1992:16). Rose argues that, these groups are not living in the past because these events continue to permeate the present as they continue to be confronted by them in the form of arguments and debates (Rose, 1992:16–17). I interpret Rose’s argument to mean that if events or the social repercussions are *active* in the present it cannot be said “that is history”. Histories of oppression cannot be regarded as *history*, simply because they are in the past, as they continue today in the form of neo colonialism, structural racism and ableism in education, the justice and systems. These are layers of historical and contemporary trauma which continue to perpetuate harm against the Other. For instance, the Treaty of Waitangi or Te Tiriti o Waitangi (Aotearoa’s founding document between the British Empire and Māori) was signed in 1840 and the dawn raids (the forced entry into the homes of suspected illegal overstayers from the Pacific Islands in the early hours of the morning) occurred from the mid-1970s to early 1980s, and yet there is still hurt, debate, and social atonement occurring in 2021; despite these events being considered history, they are still active and “current events”. These instances of history are hybrids of past and present, because public discussions, policy reform, and activism related to these events are still occurring.

The uncovering of new information can be transformative. History shifts and changes with the revelation of transformative details; they are “corrective” (Hocking, 2020:212). They are truths that can change understandings of the past, in turn affecting how something is remembered and shared, and the relationship between the past and the present (Hocking, 2020:217; Rose, 1992:15). Stories are critical transmissions of history; they are open to *retelling*, *rethinking*, and *rewording*, allowing them to shift and change as information is uncovered (Rose, 1992:15). These details, and our willingness to accept that history is a practice of interpretation that can be reformed, allow us to understand that events previously thought to be over are still ongoing, with new chapters emerging as time goes on. I explore two

such events in the histories of mental health and disability activism in Aotearoa that have been hidden from the public view (Driver, 2013:421, 423). I demonstrate how these are hidden histories and why it is important that we pay attention to them, and how documents, or a lack thereof, can reveal hidden histories and the general ‘whitewashing’ of history both in terms of sterilising history and erasing traditional Māori perspectives of health (Pacheco de Oliveira, 2020; Hocking, 2020:217–19; Prasad, 2021; Tikao et al., 2009).

People in Aotearoa, like many other colonised nations, relied on oral histories before European settlers came and have since had many of these oral histories lost, altered, or dismissed as myths and fables by the colonial power (in this instance the British) (Tikao et al., 2009:7). Such resemantisation (the total eclipse of original meanings) is an example of “passive” structural censorship of histories and historical facts, creating a cycle of systematic exclusion in constructing the Other (Pacheco de Oliveira, 2020:215; Prasad, 2021; Tikao et al., 2009). An additional form of “passive” censorship that constitutes the construction of the Other is through scholarly neglect (Trouillot, 2015). These are all elements that create a culture of hidden histories that cannot be accounted for, erasing some citizens (Others) from view while prioritising the so-called dominant groups and their experiences. This is not a new phenomenon. To the point of this chapter, which is the erasure of disability and mental health activism, it often takes someone having a personal stake or interest in a topic for the lack of scholarship on it to be revealed, and to demonstrate the hurdles to accessing the resources necessary for investigating these hidden histories and addressing these gaps in the literature.

For these reasons, I have had many interview respondents thanking me for doing this research. When something is lacking or has been overlooked, there is a sense of gratitude that comes with it being noticed, along with the anger over its neglect. They often noted that there is nothing like it or that they do not feel represented by what there is and state the importance of the research I am doing, particularly given how it is driven by a shared viewpoint. As I have

said above, often researchers are driven by their own interests; I am no exception. I am a disabled individual who also lives with mental illness, but I have very rarely seen disability and mental illness discussed together, particularly in academic settings. Similarly in professional situations: when I am at the doctor's, for example, unless I bring it up, they are never discussed as elements that can affect one another. Furthermore, the voices of Aotearoa disabled youth and youth that experience mental illness, and the histories of these groups, are often overlooked or manipulated and changed when decisions are made that affect these groups.

Disability activism in Aotearoa over the last 130 years

I define activism as “the activity of working to achieve political or social change” (Oxford Learner's Dictionaries, n.d.). What these activities are and what it means to be an activist or to engage in activism has changed over time alongside shifting social expectations for the care and treatment of those with disabilities and mental illnesses. This is evident in the content obtained from the national newspaper archives, which reveal changes over time in how the term “disability” was used. In my archival research I found a hybrid use of the term disability. In the 19th and early 20th centuries, “disabled” largely used to refer to those that were *disadvantaged* in some capacity, rather than relating to “a physical or mental condition that means you cannot use a part of your body completely or easily, or that you cannot learn easily” (Oxford Learner's Dictionaries, n.d.) as we understand it today. For instance, the *New Zealand Mail* (May 14, 1902, p.45) states, “[L]et disability of sex be withdrawn, as have those other disabilities of colour, race, caste, and class”. These understandings of disability as both physical and mental disadvantage or social disadvantage presents a challenge for interpreting and understanding what we consider disability and advocacy when examining it from these historical perspectives. However, I am able to infer that in the 19th century, during the period

of early colonisation, it was unthinkable to talk about disability in a non-negative light. This is demonstrated in the numerous immigration policies implemented after the British Empire claimed sovereignty that sought to keep disabled individuals out of the country, as will be discussed later in this chapter.

Māori views of disability

Before missionaries and British colonisers arrived in Aotearoa, Māori histories pre-dating 1840 were shared orally and through art. Written records dating from 1840, when the Treaty of Waitangi was signed, and for many years after were written by non-Māori individuals – often British missionaries – whose understanding of te reo Māori (the Māori language) was usually limited and often expressed the writer’s cultural biases. For instance, their interpretations of what Māori said reflected their own knowledge and biases, which in turn influences what is said, seen, and interpreted by Māori (Tikao et al., 2009). A perfect example of this is the conflicting understandings between the English and Māori versions of the Treaty of Waitangi. A major misunderstanding is that the English text stated that Māori gave the Queen all rights and powers of sovereignty over the land, whereas in the Māori text, Māori gave the Queen te kawanatanga katoa (complete government over the land with Māori retaining the rights and powers of ownership). These mistranslations were compounded by Māori not having a written language pre-colonisation. Social perspectives, particularly of disabled individuals, in these oral histories are remarkably distinct from those of more modern written histories. In these older oral histories, individuals with impairments were considered ‘gifted’ with god-like power and status. Their differences and talents were praised rather than marked as deficiencies, as was the custom in British society (Tikao et al., 2009:7). For instance, Murirangawhenua, also known as Matakerepō (cloudy vision), was the blind grandparent of Māui, a well-known hero and trickster in Polynesian history. In the well-known story of how the North Island of

Aotearoa was created, Murirangawhenua gifted her jawbone to Māui, with which he created a fishhook, which he used to fish up the North Island. Māui used karakia (prayer) and smeared blood from his nose on the jawbone to catch the whenua (land). This tale demonstrates the high esteem in which Murirangawhenua was held for their knowledge and wisdom, qualities that resided in the jawbone and allowed Māui to know what he needed to do to be successful (Tikao et al., 2009:5). There are other early oral histories which depict impaired figures as powerful, such as another relative of Māui, Mahuika, the goddess and guardian of fire, who is described and depicted as having no eyes (Tikao et al., 2009:5–6). These are only two examples in early Māori history which depict impaired individuals – particularly female elders who were elevated in society - as powerful and capable figures, “acknowledged by te iwi Māori [Māori tribes/nations] as gifted people with talents to share with their hapū [kinship group]” (Tikao et al., 2009:12).

However, as time went on, these stories began to change. Instead of celebrating those with impairments, they began to be viewed as being “cursed” and as an infringement of tapu (that which is set apart or forbidden) rather than valuable members of society (Tikao et al., 2009:8). As these histories cannot be dated, there can never be exact certainty that the colonisation of Māori and Aotearoa was the cause of this shift. However, given the perspectives of English society at the time, and even now, it is not far-fetched to claim that English (i.e., Western) perspectives and influence were at least a factor in this shift (Pacheco de Oliveira, 2020; Prasad, 2021; Tikao et al., 2009). Furthermore, this shift in how people were thought of and treated demonstrates the violence of “passive” structural censorship and information distribution in the form of ableism and colonialism.

Historical disability activism

So how does the history of Aotearoa activism fit into this socio-political narrative? Here I include the history of disabled policy and acts to show how disabled individuals in Aotearoa were viewed during the first 100 or so years of our “documented” history. For instance, the Imbecile Passengers Act of 1882 sought to deny entry into the country to those that would challenge the ideals of the “new society” and be a “burden” on that society, identified as “cripples, idiots, infirm, blind, deaf and dumb” (Stace & Sullivan, 2020:2). These social restrictions on immigration represented the views of society at large, and in 1899 the new Immigration Restriction Act was brought into legislation. This Act banned the “idiotic”, the “insane”, and the “contagious” from immigrating (Stace & Sullivan, 2020:2) – expanding the notion of social “undesirables” from just the disabled to include the mentally ill as well. I will be exploring the historical view of mental health and illness in Aotearoa and activism in this area further on in this chapter; for now, it is important to note that these policies were likely influenced by the popularisation of social Darwinism in the 1870s, a social interpretation of Darwin’s theory of biological natural selection, published in 1859 (Stace & Sullivan, 2020:5). These ideas saw a resurgence in the early 20th century with the introduction of eugenicist policies in Aotearoa. The eugenics movement aimed to sterilise all individuals deemed “unfit” to breed (Harvie, 2018). This movement targeted the disabled, mentally ill, and Chinese. Sterilisation of the “unfit” was first introduced into the historical archive in 1903 but came prominently into public view in 1928 and 1929 when the government was debating it as a “moral issue” and considering implementing it into law (*Ashburton Guardian* November 18, 1929, P. 5; Harvie, 2018). The Mental Defectives Amendment Act of 1928 sought to implement these views of the “socially defective” as “unfit” by adding in several clauses that would strip them of their agency and human status. The most notable of these clauses were 11, which created a eugenics board; clause 15, which established a register of mentally defective

children; clause 21, which prohibited the marriage of people on the register; and clause 25, which authorised unconsented sterilisation (Harvie, 2018). While clauses 21 and 25 were withdrawn before the Act was passed, there were several instances of people being forcibly sterilised in the 1920s and 1930s, and likely many more, though this cannot be proven due to the special permission required to access the relevant files in the New Zealand Archives on “privacy grounds” (Harvie, 2018) – a situation that further compounds the sense of these histories as hidden (Hocking, 2020).

These acts demonstrate that disabled individuals were viewed by the law as burdens to society, worthless people to be kept out, excluded, and locked away – as will be discussed later in this chapter. However, while these were the prevailing views at the time, they were not the *only* views. There were many people who spoke out against these perceptions of disabled individuals and who advocated on their behalf. In an example from the *Ashburton Guardian* (November 18, 1929, p. 5), the author cites criticism towards the forced sterilisation of disabled individuals, stating, “If you are going to sterilise mental deficient, why not criminals, drunkards and political apostates”, and pointing out that the likelihood of inheritability is low and that children save women from “insanity” – that is, hysteria. Simply putting this in writing was a form of advocacy. This article advocates for disability rights through the implication that the sterilisation of “mental deficient” was injudicious. Pointing out these issues is the first step towards social change. Social recognition of these issues is the catalyst for “change” – or at least an illusion of social change, as is evident in the historical repetition of social prejudice that will be explored later in this chapter.

There are two interesting instances of disability being “accepted” – or, at least, receiving advocacy for fair treatment. The first, like in the Māori historical tales mentioned above, relates to blindness/visual impairment. In colonial Aotearoa blindness seems to be one disability that did not necessarily imply ‘undesirability’ and a need to lock a person away. In

1887 a blind teacher, Mr Tighe, came to the country from Australia to teach blind children and give them a chance at a “normal” life, which I infer to mean unincumbered participation in society and the workforce. In 1890 the Jubilee Institute, later known as the Blind Foundation, was created, funded by the Association of the Friends of the Blind established a year prior in 1889 (*New Zealand Herald*, February 15, 1887, p. 5; *Lyttelton Times*, July 10, 1890, p. 6), with the purpose of proving blind individuals as having an “elementary knowledge” that would allow them to “earn their living” (*Lyttelton Times*, July 10, 1890, p. 6). Its creation was the outcome of activism: without vying and advocating for funding these kinds of programs do not exist, even in 2021. Another example of vision impairment being privileged over other disabilities occurred when a worker lost his sight in 1915 because of an incident at work. The worker went to court seeking compensation for lost wages and the new burdens of living with decreased sight; he won, setting a new precedent for workers’ rights and the accountability and care of disabled citizens (*Maoriland Worker*, April 14, 1915, p. 8).

The second instance of positive association of disability was when it is attached to war efforts and returning soldiers; as (Schorer, 2012:156) states, “the [First World] war had created a new class of disabled people”. In the early to mid-20th century, a large majority of the articles that I could locate in Papers Past, Archives New Zealand, and the National Library centred on activism for the care of disabled soldiers. While this could be attributed, in part, to the moral discourses of sacrifice and obligation, I argue it is also because of the undesirability of individuals with disabilities. The newspaper evidence indicates that surges of disability activism occurred after the First World War and saw a resurgence towards the end of the Second World War. In 1918 there were protests throughout the country led by war widows and families aiming to obtain greater financial support for injured or permanently disabled soldiers and their families, many protestors claiming that the default soldiers’ pensions were insufficient to cover the costs of medical treatments, loss of wages, and ability to work. There

were both those that supported the protests, claiming it was the government's responsibility to care for their citizens, and those that condemned them, claiming that the care of these individuals, beyond what was promised upon enlistment, is not the problem of the government (*Poverty Bay Herald*, August 5, 1918, p. 5). While these protests and campaigns made waves to change how disabled veterans were viewed and treated in society by 1924, this was also around the height of the eugenics movement in Aotearoa society (Fleming, 1981). The influence of the eugenics movement meant that disabled civilians and soldiers were viewed under different lights: while disabled veterans received compensation and support from the government, disabled civilians – particularly those with genetic disabilities – received no such support, and if they did they had to “prove” their disability and its origins (*Auckland Star*, February 23, 1924, p. 5; *Ashburton Guardian*, November 18, 1929, p. 4). Disabled citizens began to argue that they also deserve to receive support and should not have to “prove” their disabilities to receive assistance, because these standards end up preventing assistance (*Auckland Star*, February 23, 1924, p. 5), something that is still very relevant today. While some progress had been made in terms of disability care for soldiers, it was still lacking, prompting petitions requesting implementation of a system which would provide wage compensation for soldiers disabled because of the war (*Hawera Star*, July 28, 1927, p. 5). The type of system these activists were calling for is comparable to the ACC system Aotearoa has in place today in the 21st century, which provides 80 percent of the wages earned prior to injury/permanent disability. Protests and petitions continued throughout the 1930s and 1940s by workers and veterans alike fighting for their rights to care and an equal place in society and to not be thrown aside or hidden away (*Timaru Herald*, February 18, 1930, p. 7; *Auckland Star*, September 3, 1931, p. 3; August 27, 1945, p. 6; *Star* (Christchurch), May 24, 1932, p. 10; *Northern Advocate*, November 30, 1932, p. 5; October 31, 1944, p. 4; March 3, 1945, p. 6; *Stratford Evening Post*, November 30, 1933, p. 6; *Evening Post*, December 20, 1943, p. 6;

Manawatu Standard, November 2, 1944, p. 4). As the Second World War raged, the eugenics movement lost credibility due to the Nazis' zealous and extreme application of eugenics. The language referring to disabled individuals moved away from references to "defectives" who were "unfit to breed" (Tolerton, 2011), but this did not lead to a change in their treatment as second-class citizens in Aotearoa. Disabled veterans challenged the ideals of eugenics and the movement's notions of the disabled. Through the activism that grew out of disabled soldiers' mistreatment in inequality came the blueprint for how disability activism occurs today in Aotearoa. Associations are created, protests and marches are organised, petitions are filed to the government, and most importantly, we make noise. And sometimes these moves are effective. From the 1960s onwards, the rise of global disability rights movements caused a shift, leading to several acts being implemented in Aotearoa that sought to provide equal treatment for disabled individuals. These included the Disabled Persons Employment Promotion Act of 1960, which sought to advocate for employment opportunities for disabled individuals; the Disabled Persons Community Welfare Act of 1975, seeking community support for impairments not caused by accidents; and the Education Act of 1989, legalising the right for disabled children to attend the same local school as non-disabled children. It is evident that from the 1930s there was a desire for and willingness to socialise and integrate disabled people into the broader community (Burt, 2013:28). These shifts in social perceptions began as people became more willing to engage in self-advocacy, refusing to be patronised (Schorer, 2012:155).

Disability activism today

In 2021 there is an ongoing role and need for protests, marches, petitions, and campaigns for disability rights. The beginning of the 21st century, propelled by the legislative changes mentioned above, saw a re-examination of how disability was engaged with and viewed in

Aotearoa. Many dedicated disability sectors have been established. In 2000–2001 the New Zealand government developed its New Zealand Disability Strategy based on the social model of disability. This model states that an individual with an impairment is disabled by the barriers created by their physical and social environments (Aneshensel et al., 2013; Attrill & Fullwood, 2016:3; Ellis et al., 2019:113; Hartblay, 2020:S26; Kirsten et al., 2009:4; Raffety, 2018). The World Health Organization also adheres to the social model of disability, defining disability as arising from an interaction between health conditions and contextual factors – the difficulties encountered in reference to impairments, activity limitations, or participation restrictions (areas of functioning) (World Health Organization, 2011). In 2002 the Office for Disability Issues was established. In 2006 the New Zealand Sign Language Act was passed, making it an official language of Aotearoa. In 2007 Aotearoa signed the United Nations Convention of the Rights of Persons with Disabilities, ratifying it in 2008, meaning all legislation *must* adhere to the guidelines of the Convention (Office for Disability Issues, 2016). As this demonstrates, in the first decade of the 21st century, Aotearoa made significant strides toward incorporating disabled individuals as fully fledged members of society. More recent developments include calls for the appointment of a minister for disabled Pasifika groups in 2020 (Hopgood, 2020) and the creation of a new Ministry for Disabled People in 2021 (New Zealand Government, 2021). Through creating these dedicated spaces and services for disabled individuals, the government is acknowledging that the current systems are failing our disabled citizens. This acknowledgement demonstrates the leaps and bounds in Aotearoa spurred by disability activism.

Despite this progress, there are still instances, even within the last two years, where disabled individuals have not been provided with sufficient care or held in the same regard as their able-bodied counterparts. A prime example is disabled individuals' inability to access the workforce and exclusion from it (Carroll, 2021). There is a common conception that disabled

individuals are “lazy” – as one of my participants, Hera, a 21-year-old Pākehā/Māori woman, stated – and require too many accommodations to make hiring them “worth it” for employers, particularly during the pandemic (Hall, 2021; Trigger, 2021). Gray, a respondent in Carroll’s 2021 article, elaborated that there are biases attributed to the word disability in the workforce that create “roadblocks” for disabled jobseekers. These biases lead disabled jobseekers to consider whether they should disclose their disabilities during the hiring process or not. Evie, a straight-A student quoted in Trigger’s (2021) article, stated that she requires understanding for her learning disability because some things may take her longer to pick up, and that not disclosing the disability could be problematic down the road. My respondent Cyra similarly stated, “Thinking about jobs and thinking about the future and do I disclose that I have ADHD? Will that afford me accommodations, or will I not be hired? It’s terrifying.” Cyra’s fear is not misplaced. Disabled job seekers have always been overlooked and treated worse than their able-bodied counterparts, as is exemplified in Pulman’s 2020 article about a disabled woman being told that “[t]he only way [she] will get a job is if someone feels bad for [her]”. These are not merely modern problems and concerns. In 1919 a Royal Proclamation was made requesting employers to employ disabled soldiers because over 400,000 disabled men were unable to find work post-war because of their disabilities (*Auckland Star*, 15 Sep. 1919, p. 5). One of the goals of the new Ministry for Disabled People is to open the workforce and create equal opportunities for individuals with disabilities (New Zealand Government, 2021). As we can see, social issues of access that have plagued the disabled in the past continue to be a problem in the present because society continues to be dominated by ableism and ableist assumptions.

That people with disabilities experience of lower social status is further demonstrated through discriminative ableist assumptions in Aotearoa’s immigration policy. In 2020 the Equal Justice Project ran an article about the discriminatory immigration laws that prevent disabled individuals from entering Aotearoa. The language used in the 2009 Immigration Act,

that “immigration matters inherently involve different treatment on the basis of personal characteristics”, echo the sentiments expressed in the 1899 Immigration Restriction Act and the 1882 Imbecile Passengers Act – that those that do not fit the norms and are seen as a potential burden on society are not welcome in Aotearoa. Disabled individuals continue to be denied immigration and residency at an alarming rate in 2021, with the government “justifying” these individuals’ exclusion by claiming they were not of “an acceptable health standard” (Clent, 2021; Hall, 2021; Loren, 2021; Nadkarni, 2021; Tan, 2021; Truebridge, 2018) – further exemplifying that these issues of inequality have not been resolved, continuing to seep into the present because of the prevailing ableist assumptions. Section A4.15 of the Immigration New Zealand Operational Manual for 2008–2010 outlines “acceptable standard of health” as

- i. unlikely to be a danger to public health; and
- ii. unlikely to impose significant costs or demands on New Zealand’s health services during their period of intended stay in New Zealand; and
- iii. (if they are under 21 years of age and are applying for a student visa or permit) unlikely to qualify for Ongoing and Reviewable Resourcing Schemes (ORRS) funding during their period of intended stay in New Zealand. (Immigration New Zealand, 2008)

An updated definition of “acceptable standard of health”, or “good health”, as it is now termed, can be found on the Immigration New Zealand website:

- unlikely to be a danger to the health of the people already in New Zealand
 - unlikely to cost New Zealand’s health or special education services a lot of money
- able to work or study if this the reason for your visa. (Immigration New Zealand, 2021)

The perception that disabled individuals will be a burden on society and a drain on resources is the root cause for the restrictions put on the ability for disabled individuals to immigrate

(Equal Justice Project, 2020; Hall, 2021; Loren, 2021; Tan, 2021). While the government has obligations to its citizens to ensure that state-funded essential services, such as healthcare and education, do not exceed excessive costs and demands, through barring entry into the country or access to citizenship based on disability and the potential need for care, it is breaching the 1990 New Zealand Bill of Rights Act as well as the UN Convention on the Rights of Persons with Disabilities, which it has ratified (Equal Justice Project, 2020). By continuing to view disabled individuals as “vulnerable” and in need of constant care – to the point of becoming “burdens on society” – the government is setting the tone for how Aotearoa society views, thinks of, and treats disabled individuals. Rather than framing our engagement with disabled individuals as being about what they can *add* to society, they are positioned within a deficit framework that asks what they will *cost* (take away from) society. This ideology is dangerous as it flirts with the ideals of eugenics that informed and were prevalent in the passing of the 1899 Immigration Restriction Act and the 1882 Imbecile Passengers Act – again demonstrating that these events have not been concluded and that we have not made as much social, legal, or political progress as was previously thought.

Mental health activism in Aotearoa over the past 130 years

Māori views of mental health

From the archival research I conducted, it was extremely difficult to find conclusive evidence of historical Māori perspectives on mental health. Unlike disability, I was unable to locate any histories that exist today in the form of “myths and legends” that depict instances of mental health or how it was conceptualised within Māori communities – at least not overtly. There are two ways to interpret this lack of documentation: that mental health was not an issue for Māori before colonisation occurred, or that the way it was expressed and understood was different to modern notions of mental health and has thus been overlooked. For instance, Taitimu et al.

(2018:154–55) state that colonisation disrupted both Māori understandings of mental health and how they experience it culturally. As both the literature and my respondent Hermione, a 23-year-old gender-fluid Pākehā/Māori person, states, traditional Māori understandings of health were “holistic, with principles of unity, harmony and balance as central to health, culture, kinship and protocols” (Doyle, 2011:21; also see Boulton, 2005; Durie, 1985, 1997; Kopua et al., 2020; Taitimu et al., 2018). Health in Māori culture is often viewed through the image of Te Whare Tapa Whā, a house with four walls representing life’s four basic dimensions: te taha wairua (spiritual), te taha hinengaro (psychic), te taha tinana (bodily), and te taha whānau (family) (Taitimu et al., 2018:159; also see Boulton, 2005; Doyle, 2011; Durie, 1985, 1997). It is the combination of these four components that dictate health and wellbeing as they represent land, culture, and language, which connect Māori to their ancestors and ancestral history and values, as can be seen through the telling of their histories in the form of oral stories. However, because of colonisation and the enforcement of western methods and understandings of health, particularly mental health, these holistic traditional understandings and approaches to health have been largely ignored and overlooked (Doyle, 2011:22; Kopua et al., 2020; Taitimu et al., 2018).

Pākehā (European) colonisers rejected Māori cultural methods and understandings of health in favour of their “civilised” western understandings, prioritising the biomedical model of the west over what they saw as the “misinformation” and “ignorance” of Māori (Kopua et al., 2020; Taitimu et al., 2018:156). This forced imposition of a single conception of the self created internal and external tensions, leading to despair and despondency and constructing poor social determinants for Māori by taking away and invalidating their histories, language, culture, identity, and land (Boulton, 2005; Doyle, 2011:20, 22; Kopua et al., 2020:376; Taitimu et al., 2018).

Māori have been engaged in activism to reclaim their histories, culture, and mana (honour, respect and power that is handed down generationally) since they were stolen in 1840. They have been fighting to regain their understandings of health. Instances of this activism appear in the appointment of Māori practitioners who apply traditional Māori understandings of health to help Māori and Pākehā New Zealanders with their health and wellbeing, in particular their mental health. Mahi a Atua wānanga (active engagement with Māori drawing from Māori creation and histories to further learning), conceived as a way of being and engaging with whānau (family) in distress, have been implemented in recent years to encourage the empowerment of Māori and to reassert a positive association with Māori culture and identity, particularly in the health system (Kopua et al., 2020:378). Māori are significantly less likely to go to the doctor because of their systemic alienation within a westernised health system and the treatment they receive leading to poor overall health and mental health outcomes (Boulton, 2005; Kopua et al., 2020:378). To aid in understanding and respecting Māori culture and understandings of health, the taha Māori training programmes for nurses have been established; the Treaty of Waitangi is also considered when providing care for Māori, with practitioners being encouraged to ponder “how things might be done in a Māori way” (Boulton, 2005). This “return” to traditional values and understandings of health proves to strengthen cultural and ancestral identity, playing a critical role in upholding mana and wellbeing (Bolten, 2012; Durie, 1985, 1997).

Colonial views of mental health

Attitudes about mental health and the mentally ill were transported from England to Aotearoa with the missionaries and colonisers in the 1800s; as such western notions and understandings of mental health and illness have been the prevailing “school of thought” in Aotearoa, as demonstrated above. While it is difficult to find instances of mental health activism in the

historical record for the first 100 years (1840–1940) of Aotearoa’s history, a great deal of legislative and social change did occur through that period. It would stand to reason that for these changes to have occurred, there must have been some form of activism driving them. In the 1840s, the mentally ill were held in prisons, demonstrating a societal view of them as social outcasts not deserving of care (Brunton, 2018b). The first mental health legislation was the 1846 Lunatics Ordinance, which stated that a “lunatic” could be held in gaol (jail), another prison, a public hospital, or an asylum – despite Aotearoa not having any specialist asylums until 1854 (Brunton, 2018a). It was “humanitarian sentiment” – whereby “lunatics should be regarded by the state as objects of tender solicitude, and ... no pains or expense should be spared in ameliorating their condition. They wholly condemn their being treated as paupers or prisoners”, as cited by Brunton from the “Report of the Commission of Enquiry into the Constitution and Management of the Dunedin Hospital and Lunatic Asylum” – that led to the establishment of proper asylums (Brunton, 2018a). To ensure that the mentally ill were being treated fairly and humanely, the 1868 Lunatics Act was created to implement regular independent inspections (Brunton, 2018a). In 1911 the Mental Defectives Act replaced the Lunatics Act, demonstrating an evolution of the language used to refer to the mentally ill and changes in attitudes towards them, ushering in the shift from lunatic asylums to mental hospitals (O’Brien & Kydd, 2013:4; Soosay & Kydd, 2016:43). Additionally, the 1911 Act introduced “voluntary boarders” and did not require a friend or family member to initiate discharge (O’Brien & Kydd, 2013:4). Protests over the stigmatisation of the label “mentally ill” continued in 1917 as soldiers returning from the war were placed in mental hospitals to recover (*Evening Star*, May 4, 1917, p. 1). In the 1920s saw the initiation of issues of patient overcrowding and understaffing in the mental health sector, which continue to this day. However, in the 1920s two revolutionary concepts gained traction that set the precedent for how mental health is thought of today, advocated by Dr Marshall Macdonald: firstly, that

medical students should be trained in mental diseases and a chair of mental diseases appointed at Otago Medical School, and secondly, that sexual (and violent) offenders should be segregated from the rest of the mentally ill population because being mentally ill did not equate to being violent (*Gisborne Times*, July 8, 1924, p. 3). Additionally the end of the 1920s saw the beginnings of social discussions about mental health policy change. While it may not have been seen as such at the time, I believe this was one of the defining realisations in dismantling the myth that the mentally ill are all violent criminals that need to be met with force, beliefs that seem to still be prevalent in some countries in 2021. However, the calls for the sterilisation of disabled individuals and their prevention from getting married also extended to the mentally ill and were made in the hopes that this would stop the “production of defects”. However, these arguments were met with stern resistance, many refuted on the grounds that “mental defects” will not necessarily produce “mentally defective” children, just as “healthy” parents will not always produce a “healthy” child (*Ashburton Guardian*, November 18, 1929, p. 5).

The 1930s saw the ushering in of a new era in the treatment of mental illness. From working with soldiers suffering from shell shock, new techniques of care were developed, and the mentally ill were no longer considered incurable. The development of medications and these new treatments that focused on working with both the body and mind saw a change in what mental hospitals, now known as psychiatric hospitals, stood for – language again shifting to reflect changes in societal understandings and attitudes towards mental illness (*Press*, March 21, 1938, p. 7). With a new wave of soldiers in the 1940s suffering from shell shock, the focus moved more toward understanding what mental illness is, where it comes from, and what more can be done for patients (*Press*, October 21, 1944, p. 8; November 25, 1944, p. 3). Revisions of what the term “mental” encompasses began to take place. As shown above, those that were “mental” were considered criminal and placed in a gaol, before the establishment of asylums where they were considered morally ‘dirty’ and in need of “moral management” (Brunton,

2018a, 2018b). This confinement eventually shifted into actual forms of care. The world wars also facilitated a shift in social views of those that were “mental”, creating greater understanding of the cause and effects of mental illness (Brunton, 2018a, 2018b). Links between mental and physical health also became more pronounced as understandings of these causes and effects began to develop (*Auckland Star*, October 17, 1945, p. 4; Brunton, 2018a, 2018b). These changing conceptualisations led to an increase in fostering public education and understanding of mental illness (*Auckland Star*, October 17, 1945, p. 4; *Press*, October 21, 1944, p. 8; November 25, 1944, p. 3) to create a “more sensible and more tolerant attitude toward mental illness” (*Press*, November 25, 1944, p. 3), foreshadowing the implementation of a community-based model of care in 1969 with deinstitutionalisation (Brunton, 2003). Growing global mental health activism in the late 20th century saw significant policy reform. In Aotearoa by the 1990s almost all psychiatric hospitals had been closed, instead replaced by community care. The shift to this model put the onus of patient care on private providers and community networks rather than government entities. With this deinstitutionalisation, care took on a more values-based focus of putting the patients first and involving their social networks and communities in their care: “The involvement of family, friends, and/ or carers in the assessment is important” (*The Press*, Christchurch, October 6, 1999, p. 22). In 1996, following an inquiry into mental health services, the Mental Health Commission was established, demonstrating another shift in language (Ministry of Health NZ, 2021a). The primary objectives of the commission were to advise the government, facilitate research, and reduce discrimination against those with mental illness; in 1998, the Mental Health Commission Act was adopted to provide independent advice to the Ministry of Health on the state of national mental health (Ministry of Health NZ, 2021a). The commission was disestablished as a part of the Crown Entities Reform Bill in 2012; prior to that published *Blueprint II: Improving Mental Health and Wellbeing for All New Zealanders*, building on the

first blueprint from 1998 and outlining what needed to be done between 2012 and 2022 to improve mental health services (Ministry of Health NZ, 2021a).

Mental health activism today

This brings us into a discussion of what mental health activism looks like now in the 21st century. Nowadays activism exists in more overt forms, particularly over the last decade (2011–2021). Like disability activism, there has been a return to issues that plagued mental health activists of the past, the most pressing being an absence of funding and mental health staff. The mental health sector has been protesting, petitioning, and speaking out about the poor treatment of mental health workers, both from assault by patients and from overwork due to underfunded systems and understaffed facilities since 2002 (Johnston, 2002). There have been several instances of mental health workers speaking out about the poor funding and lack of support in the sector (McAllen, 2017; Pinder, 2011; Heather, 2014; Whyte, 2018). While many of the workers express wariness at “exposing” the difficulties of working in the mental health sector for fear of deterring graduates from following that career path, they also state that it is a necessary risk because “it highlights aspects of the mental health system that need to improve... it [media coverage] has some value in possibly encouraging political action” (McAllen, 2017). Mental health nurse Andy, interviewed by Jessica McAllen for RNZ, pointed out that the more media coverage, the better, saying: “It seems to be the only thing influencing change at a government level. Mental health services remain severely underfunded and it is at crisis level” (McAllen, 2017). Advocacy and activism in public forums are effective because they force engagement and have an influence on public opinion, application of social pressure, and accountability of the state (Burt, 2013:32). Public activism demonstrates to politicians what people want, and often, it gets things done. Following calls in 2018 for an “urgent transformation” of the “patchy and under-resourced” mental health system that fails those at

high risk and in serious distress (Whyte, 2018), the 2019 wellbeing budget was released dedicating 1.9 billion NZD to developing the mental health sector over the course of five years (Roy, 2021; Sutherland, 2019). Of this budget, 40 million NZD was for suicide prevention and more mental health nurses in schools and 455 million NZD for “new frontline” services for an estimated 325,000 people (Sutherland, 2019). The rest was set aside to strengthen existing services (increased funding for staff) and tackle the social determinants of poor mental health and mental illness, such as family violence, poverty, and homelessness. This budget also allowed for the re-establishment of the Mental Health and Wellbeing Commission (Roy, 2021; Sutherland, 2019). This has been viewed as a “step backwards” as it “shows how far we have not come” in failing to address the pressing and growing mental health needs of New Zealanders (Sutherland, 2019), with the new commission simply reclaiming the duties of the previous one, which were to assess and report publicly on the state of mental health and wellbeing in Aotearoa, promote alignment and communication between entities involved in aiding in mental wellbeing, monitor and advocate for the improvement of mental health systems and services, and advocate for the collective interests of those that suffer from mental distress and those that support them (Ministry of Health NZ, 2021b). Interestingly, the budget also promotes a holistic approach for the mental health care for all New Zealanders, which also happens to be the traditional Māori approach to wellbeing (Roy, 2021; Sutherland, 2019).

The investment into mental health services as suggested by the 2019 wellbeing budget is critical because until 2016 mentally ill individuals, who the police were called to ‘deal with’, were still being detained in police cells while awaiting psychiatric assessment because of overcrowding in hospital facilities (*Stuff*, 2016). This is despite measures being taken in 2014 to prevent the mentally ill, who have not committed a criminal offence, from being taken into temporary police care (Leask, 2014). Police are inundated with calls from the public about mentally ill individuals because they are “who people think to call when they need help”

(Leask, 2014), but they often do not have the training or the right to detain them, leading to several independent inquiries into unlawful detention of mentally ill individuals (Leask, 2014; *Stuff*, 2016). To try to prevent the mentally ill being dealt with by people not trained to do so and facilitate appropriate engagement with them, the Mental Health Interventions Team was established in 2014 along with new training at the police college, both for the safety of the mentally ill and to limit the wastage of resources (Leask, 2014). However, the mentally ill were still being “monitored” in jail cells by overrun police officers who did not have the resources to dedicate to supervising them – leading to many instances of near-deaths from suicide attempts or lack of medical care (*Stuff*, 2016). It is interesting that the default is for the mentally ill to be held by the police even if they are not suspected of having broken the law, given the history of their being housed in prisons in Aotearoa. I believe that the perception of the mentally ill as dangerous is still prevalent in the nation’s collective subconscious, and this is why the police, rather than paramedics, for example, are people’s first point of call. Given the criticisms above about the lack of progress in mental health services and mindsets in Aotearoa, this unconscious bias would not come as a surprise.

With the seemingly subconscious social biases shown above and stagnant progress of official channels, with the same ideas being revised without much tangible change, the future of mental health activism seems to lie in social media and “keyboard warriors” (Ooi et al., 2021; Sehgal, 2020). Social media has the ability to disperse information rapidly (Shifman, 2014) – as will be discussed further in Chapters Three and Four – and bring about social and political pressure to instigate change through sheer public engagement – something traditional methods have done, but never on the national and global scale that has been seen from engagement with social media (Ellis & Kent, 2015:424–25). My respondents Alexios, a 21-year-old Pilipino/New Zealand man, Sofia, a 21-year-old Pākehā/Māori woman, and Hermione (introduced above) consider themselves to be social media mental health advocates. All three

have educated themselves in various topics of mental health and illness, spoken up on mental health issues, and volunteered their time to spread mental health and illness information and promote mental health education. While they all feel that sharing official information and linking studies and statistics about mental health and illness is important, they all also focus on incorporating their own stories when they share this information. Collectively, they hold the view that people are much more likely to understand and engage with personal anecdotes over official boring jargon. As Sofia states:

If I post up one of my uni [university] assignments about different therapies, you know, people can read it, but they might not necessarily understand the language that I've used, and therefore they might not be able to connect to it as well. Whereas if I use my everyday non-academic language, they'll be like, "Oh yeah, this is a normal person, I can feel comfortable, and I can relate to it. So, I can, you know, add on me [add a comment about their experience]". I think that people are a lot more willing to read things that come from personal raw feeling, or emotion, or life experience as compared to like a five-page journal article out of *Psychology Today*.

This personalisation of content also creates a feeling of sameness and shared experiences, which makes people feel more comfortable and able to reach out to one another, something that is missing from official services, particularly when they outline specific symptoms and criteria that individuals with a mental illness do not identify with, as Cyra, a 22-year-old Indian/New Zealand woman, notes in her engagement with ADHD groups on Twitter. This type of activism helps start the conversation and cultivate safe spaces for it to grow. It only takes a spark to ignite a forest fire, and it only takes a handful of individuals willing to share their honest stories and experiences for others to feel safe to talk about theirs. The more people that openly discuss mental health and wellbeing, the better the care, understanding, and resources that will be available for them.

Conclusion

Returning to the ideas presented at the onset of this chapter, how something is remembered affects how it is presented and thought of in the present. At first sight, disability and mental health activism and rights seem progressive in Aotearoa. We have a disability ministry and a mental health and wellbeing committee. Yet upon deeper inspection, it becomes obvious that general social understandings of how disability and mental health are experienced in Aotearoa are instances of hidden histories. History is an ever-changing tale of revealed facts and interpretations that requires constant revision; we look to the past to learn for the future. But when looking at the past of disability and mental health activism, it is a sad tale of repetition. As outlined above, the same battles are being fought over and over again, demonstrating that structurally very little has changed. By allowing the structural erasure and distortion of disability and mental health histories by ableism, we are allowing for the oppression of these groups to continue. An example of this is the decommissioning of the Mental Health Commission and its subsequent recommission without any explanation as to why it was disbanded, acknowledgement of its past, or recycling of the same mandates. Social attitudes towards disability and mental health and the open discussion of them have indeed changed; they are more accepted and openly spoken about, but I question whether this is a genuine change in perception or people showing agreement in public spaces for fear of being “cancelled”. A point to note is the ways in which activist language has changed over the last 130 years. Today there must be an overt challenge, calls for change, or expression of displeasure for action to be considered activism. However, in the first century of colonised Aotearoa, it was enough to simply talk about these issues in a non-negative light because that was the social standard. So, I wonder, have things changed in name only? I do not presume to know the answers to what is next. I only know that these histories have been hidden, and I

question why. Why have we – citizens and scholars of Aotearoa – allowed them to be hidden, buried, and allowed to replicate quietly while we claim progress? Why, despite advocacy over the last 130 years, have the fundamental rights of disabled and mentally ill individuals not developed further? Why are they still seen as burdens on society rather than unique individuals who offer diverse skills, like in Māui’s tales?

The crux of the issue is that while it looks like we have come a long way since disability and mental health activism began, the issues at their core are still the same, and the rights being fought for are still very similar because the ableist foundations of society have not changed. Despite everything that has been done and achieved, the way they are viewed in society still has a long way to go. Every time slurs are thrown at individuals with disabilities or mental illness, every time they are discriminated against overtly or inadvertently, they are being systematically censored by social structures that leave me to ask: is the creation of a disability ministry and a mental health commission too little, too late? Can they bring about tangible change? In the following chapters, I explore some of the questions posed in this chapter through an examination of the politics of language used to represent disability and mental health in society and policy, the role of digital exploration and social media in advancing disability and mental health rights, and finally, the effect of the Covid-19 pandemic on the disabled and mentally ill.

Chapter Two: The Politics of Language

Language, on the surface, may not seem to be one of the most important aspects when discussing mental health and disability, but I argue that it *is* the most important because within its wider significance is the articulation of the ableist systems and assumptions embedded in legal rights, health care, and social systems (Block, 2020; Durban, 2021). As mentioned in the previous chapter, language reflects social norms and dispositions – it embodies these and further perpetuates them. It is both dangerous and key to changing attitudes towards mental health and disabilities in Aotearoa. This chapter will analyse the politics involved in disabilities and mental health language. In English several words can be used to describe any one idea, each with their own social implications and historical meanings and biases (Morgan, 2004:9). Words chosen hold power and meaning: along with the spoken meaning there are sub-textual meanings, resonances, and implications derived from the choice of one word over another to express the same idea, stressing the importance of society and culture in the creation and understanding of language (Ardener, 1971; Bucholtz & Hall, 2004; Duranti, 2004; Duranti et al., 2003; Eckert & Wenger, 2005; Grillo, 1989; Kroskrity, 2004; Morgan, 2004; Philips, 2004; Reyes, 2014; Woolard, 2004). An example would be modern policy using the language of *handicap* rather than *disability*, demonstrating a continual struggle for language that is seen as inclusive, accurate, and non-judgemental. The language used in policy and by government officials is of particular importance because it reveals the underlying motivations and social attitudes towards a topic. Understanding youth participation in online communication around mental health and disability is contingent on understanding the nature of these distinctive hidden attitudes informing our language (Bucholz & Hall, 2004:376). Furthermore, language reveals elements of identity and is a key component of cultural performance and understanding (Ardener, 1971; Austin, 1962; Boyer & Yurchak, 2010; Bucholtz & Hall, 2004; Crowley, 2003;

P. Davison, 2012; Duranti, 2004; Duranti et al., 2003; Eckert & Wenger, 2005; Egbert & Keating, 2011; Goodwin & Goodwin, 2004; Grillo, 1989; Keating & Egbert, 2004; Kroskrity, 2004; Kulick & Schieffelin, 2004; Lambek, 2010; Mayr, 2008; McCormack et al., 1979; Morgan, 2004; Philips, 2004; Reyes, 2014; Shifman, 2014; Suchman, 1994; Thomas & Wareing, 1999; Wilce, 2004; Woolard, 2004).

Languages of disability and mental illness

When asked what a disability is, my respondents typically focused on the disabling effects of something, rather than on impairment itself. This focus on the disabling effects rather than on the impairment reflects the difference between official ableist-based discourse and grassroots disabled voices. For instance, Cyra, a 22-year-old-woman studying at university who suffers from anxiety and depression and is seeking a diagnosis of ADHD, states that if something

disables you and prevents you from being productive in whatever capitalist, neoliberal way [...] then it is a disability.

Similarly, Leda, a 20-year-old-female Pākehā/Māori university student, says,

Disability is something that regularly and consistently impacts your life and prevents you from doing what is, I guess, expected of you to do. Or [...] to what you would assume to be the best of your ability. [...] it prevents you from doing what you want to do, how you want to do it.

Demas, a 22-year-old Pākehā man, continues this focus on the “normative” body, stating,

[If something is] encroaching on your life and how you normally do day-to-day [activities], I would say that is a disability.

Cyra, Leda, and Demas focus their understandings of disability on what is expected of a “normal” and “healthy” body in western capitalist societies. Others stressed the inaccessibility of society. Athina, a 19-year-old Pākehā/Māori woman and university student who is a part of

the National Disabled Students' Association (NDSA), explains this as an incompatibility of one's physical body with their environment:

[Y]our physical circumstances or your accommodation needs vary from your environment. [...] in this sort of world it means you face barriers.

Melissa, a 22-year-old Pākehā woman, also comments on this incompatibility:

Disability is the] inability to control your own environment. Like doing everyday things gets a bit harder than it *should* be.

Phaedra, a 21-year-old Pākehā/Māori woman and university student, expands further on the notion that environments construct disability, saying:

[W]ider-world influences and ingrained obstacles maintained by society affect someone's lived experience in navigating the world with a disability.

As these statements suggest, for them, disability thus entails expectations of the body and how it should perform, the social barriers it faces and the social space that creates disability. If a body is unable to function or meet the expectations of society, then it is *disabled* – out of action or broken.

Interestingly, Sofia begins to consider who is thought of as disabled, what they look like, and where these notions come from:

[A]ll throughout my life it has been ingrained into me from society that disabled people, you know, are physically disabled. They *look* it, they need extra things to help them. [...] if you were to go out to the street and ask any random person, oh, can you tell me what a disabled person looks like? They'll be like, oh, you're in a wheelchair or crutches or something like that.

In this account, Sofia demonstrates the ingrained societal expectations of what disability is, and by extension, what it is not. A disability, by these standards, is a physical condition that limits an individual's mobility. While my participants and the literature acknowledge the role

of impairments in disabling an individual, they tend to focus on the roles of society and language in constructing the narratives of disability, thus placing the responsibility for the disabling factors onto the barriers created by society (Aneshensel et al., 2013; Alvermann, 2004; Ellis et al., 2019; Ginsburg & Rapp, 2020; Hartblay, 2020; Inhorn & Wentzell, 2012; World Health Organization, 2011). This is further exemplified by Adriani, a 22-year-old Pākehā woman and mental health nurse, who states that disability is defined by the way “it affects you negatively” socially: these effects do not affect impairments on the same “level” but rather each involves a different set of obstacles and barriers, creating “different levels of hardness to life”.

In Section Two of the New Zealand Mental Health (Compulsory Assessment and Treatment) Act 1992, there is no use of the terms mental wellbeing, mental illness, or mental health in relation to individuals. Instead, the document uses the dated language of “mental(ly) disorder(ed)”. The Act states:

Mental disorder, in relation to any person, means an abnormal state of mind (whether of a continuous or an intermittent nature), characterised by delusions, or by disorders of mood or perception or volition or cognition, if such a degree that it (a) poses a serious danger to the health or safety of that person or of others; or (b) seriously diminishes the capacity of that person to take care of himself or herself. (Mental Health (Compulsory Assessment and Treatment) Act 1992: section 2)³

However, there are calls to repeal and replace the Mental Health Act. These calls began in 2019 but have since intensified in the context of Covid-19. The review report (*He Ara Oranga*) into the state of the Mental Health Act concluded that the Act “has not kept pace” with the shift to

³ <https://www.legislation.govt.nz/act/public/1992/0046/latest/DLM262181.html>

human-rights-based models of care which focus on recovery and wellbeing (Government Inquiry into Mental Health and Addiction, 2018). There are two prominent factors driving this overhaul of the Act. The first is to address the “technical drafting issues” of the Act. The second is to remove the sunset clause (the date the Act automatically expires; Kenton, 2020) for the technical and audio-visual link amendments made by the Covid-19 Response (Further Management Measures) Legislation Act 2020 (Little, 2021). The first of these issues is blatant in the outdated language used in the Act, as seen above. The Act does not acknowledge the nuances of mental health, mental wellbeing, and mental illness and instead uses the stigmatising language of mental disorder.

I argue that in these revisions we need to consider mental illness as a disability (cf. Mulvany, 2000:584), because disability is a social construction, encompassing the perceived limitations and stigmas surrounding an impairment – an impairment being a difference in a person’s body structure or function or mental functioning (CDC, 2020). By applying disability theories to analyses of mental illness, a complex and multilayered framework of social restrictions, disadvantages, oppression, and stigma begins to emerge where a clinical medicalised view of disability and impairment used to be. This shift to a “process of social oppression, discrimination, and exclusion” leads to questions raised by Foucault’s biopolitics, which he defines as government regulation of populations through biopower – the application and impact of political power on all aspects of life (Foucault et al., 2008:6) – which encapsulates instances of institutional oppression, wherein social barriers deny those with “psychiatric disabilities” their rights of citizenship (Mulvany, 2000:582, 585).

Similarly, as shown above when defining disability, my participants talked about the disabling effects of mental illness and how it constrains an individual from living their normal day-to-day existence. Sofia speaks about the intersection of disability and mental illness:

I'm mentally not functioning the same as anyone else. That makes me disabled in a sense, because I can't do my everyday tasks the same as someone else. I can't... like, get out of bed and be a happy, normal, functioning human without taking 150 milligrams of sertraline [a common anti-depressant] every day.

Interestingly, the only time any of my respondents outright used the language of disability rather than disabling was regarding mental health. Whenever mental illness was mentioned, they always referred to it as disabling, but made the point that they do not believe it is a disability. Alexios, Sofia, Leda, and Cyra offer an explanation as to why this is. They state that the key difference between disability and mental illness is the term *illness*. An illness can typically be “fixed” or “cured”: it is not a permanent state, whereas a disability, despite the fluctuations in its intensity and impact from day to day and second to second, is not “fixable”. As Melissa states, the distinction is not black and white. My respondents are clear about this distinction so as to neither romanticise mental illness by classifying it as a disability (something someone “just lives with and deals with”) nor diminish the experiences of impaired individuals. They stressed this because of the romanticising of mental illness previously seen in digital spaces, most notably on Tumblr. This romanticising of mental illness tended to encourage escalations and unhealthy behaviours – such as anorexia and self-harm.

While I agree that it is important to not romanticise mental illness, I wish to illustrate the parallels that exist between the language and experiences of mental illness and those of impairment. Firstly, I purposefully employ the term *impaired* here as opposed to *disabled* because, as discussed above, disability is a socially constructed barrier which affects people and prevents them from engaging to their fullest abilities. This definition applies to both impairment and mental illness. Just as impairment and its effects can vary from day to day and from minute to minute, so too can the severity of mental illness. Like chronic illness, mental illness causes serious long-term functional impairments with lasting impacts over an

individual's life course, especially when it first appears in adolescence (Groce, 2004:15; McGorry et al., 2007:S5; McGorry et al., 2013: S30). Just as impairments can become chronic and disabling, so too can mental illnesses as they continue to manifest with varying severity across an individual's lifespan (Dashiff et al., 2009; Groce, 2004; McGorry, 2007; McGorry, Bates, & Birchwood, 2013; McGorry, Purcell et al., 2007; Webb et al., 2008; Zaffar, 2021; Zito et al., 2001). Interview participant Hermaphroditus, a 16-year-old, non-binary British/Pākehā high school student, describes defining mental health and mental illness as disabilities in terms of their *permanence*. They claim,

They [the effects of mental health] are not disabilities, in the same way that having an injury isn't a disability. Mental health is the same, in my mind, the same level as like physical injuries. [...] I believe if [mental illness] is a permanent sort of injury of mental psych or whatever, then it would be classed as a disability in my mind. To me... disabilities are more of the permanent ones.

It is interesting that Hermaphroditus inverts what the other respondents said regarding disabling effects versus disability. Hermaphroditus claims, like the literature, that because mental illness is a permanent state that can fluctuate over one's life, that makes it a disability. On the flip side, Hermaphroditus's claim implies that mental health is more of a temporary fluctuation based on temporary environmental factors and inputs. To put this example of permanent and temporary injury into context, mental illnesses, such as depression or PTSD, are *permanent injuries*, and their severity fluctuates over the course of an individual's lifetime due to environmental triggers. Mental illnesses, then, are disabilities because they are permanent impairments which can only be *treated* and not *cured*. A stressful week at work, which can decrease mood and an individual's overall mental wellbeing, is a *temporary injury* because it will resolve once the environmental factor (a stressful week at work) is removed.

Language in practice

Above I outlined the language used to describe disability and mental illness and claimed that understanding the use of this language is important to understanding the socio-cultural dispositions towards disability and mental illness. These socio-cultural dispositions are revealed through John Austin's concept of linguistic phenomenology – the analysis of concepts and expressions in everyday language (Austin, 1962). Speech act theory examines the “recurrent patterns of communication in which language provides the coordination between actions” (Flores et al., 1988, quoted in Suchman, 1994:179) – or, as Austin (1962) states, the combination of speech acts. Language is a performative action. When language is seen as an action, it is clear that the utterance has specific intent, a purpose it is meant to fulfil, although this intent may not match the impact and interpreted meanings of the utterance. Language is therefore a social action and utterances moments of social interaction. The understanding of language as social action, coupled with the notion of communities of practice – the conferring and exercising of power in day-to-day linguistic practices (Eckert & Wenger, 2005:582) – sets the stage for the development of more recent conceptions of *speaker* and *hearer(s)* (Austin, 1962; Crowley, 2003; Goodwin & Goodwin, 2004; Keating & Egbert, 2004; Kulick & Schieffelin, 2004; Suchman, 1994; Woolard, 2004).

Understanding the power relations within and behind the social action of language is important to understanding discussions about disability and mental health in online spaces. The language choices of online activists, everyday users, disabled users, users with mental illness, and political entities all reflect and affect the social norms and understandings concerning these issues. For instance, ableism dominates our understandings of language and creates a gatekeeping effect. This is exemplified by interlocutor Cyra, a 22-year-old New Zealand Indian woman studying at university, who has experienced mental illness and identifies as disabled. Cyra outlines an interaction with her therapist where she is told, “You're not disabled, you're

neurodiverse”, to which Cyra responds, “No, I mean disabled – I am disabled”. In this exchange Cyra’s experiences and expression of her experiences are being ignored and altered by ableist frameworks and thought in the form of her therapist. Another example of this is the new Ministry for Disabled People. There have been debates over the choice of using “disabled people” over “people with disabilities”. An example of this can be seen on the post “Government announces new Ministry for Disabled People and accessibility law” in the “newzealand” subreddit. In the comment section of this post user A asked, “Do you care how it’s phrased?” in reference to the difference between using “disabled people” or “people with disabilities”. Many people responded that person-first language (people with disabilities) is preferred as it is more polite. User B explains,

Loads of us don’t really care (unless it’s obvious the person is being a turd and defining us by our disability), but a large majority of us prefer person first. [...] It’s worth noting that people with really intense life changing disabilities tend to have more of a preference for person first language [...]. The real no is not even referencing personhood. Like calling someone ‘a disabled/insertslurhere’.

User D replied that “‘people with disabilities’ starts by specifying [that] they are people”, which is what makes it more courteous language. User C, meanwhile, argued that “The term disabled people is social model language. [...] I prefer this language since it implies that it is society that had something wrong with it, not me”. User B follows up stating,

I personally don’t care what people default to, and I feel people should understand that neither is *intended* to be offensive [...]. [But person-first language] is usually the best use case for official policies.

This example demonstrates the complex conflicts and relationships between language, meaning, and people. In this instance, for the disabled community it appears to come down to what is more important – a person being seen outside their impairment, or disability being seen as a problem with society rather than with the person.

Discourse is a product of knowledge endowed with the performative power to bring into reality what it describes; it is the idea of culture as text (Duranti et al., 2003:329; Morgan, 2004:17). It *means* something and it *does* something which is linked to the context of use (Mayr, 2008:3, 7; Morgan, 2004:17). In order to understand or decode what the speaker wants to say – what they are *doing* through discourse – one must examine the context in which the discourse resides because it will have differing encoded meanings in interpersonal, institutional, socio-cultural, and material contexts (Mayr, 2008:7). Therefore, institutions are shaped by and themselves shape the discourse of their “subjects”. It is those with social and political power that create this cycle of creating, using, and spreading discourse (Mayr, 2008:1; Thomas & Wareing, 1999:11). Mayr (2008) claims that institutions, through imposing ideology-filled discourses upon their subjects, seek to legitimise their own interests and existence. Weber et al. (2004) asserts that the institution’s power must be legitimised and justified in order to be accepted socially (Mayr, 2008:2–3, 5). Furthermore, Eckert and Wenger (2005:586) claim that this consensual hierarchy is born through status within the institution and the ideologies of control which afford individuals power and status. Discourse *is* social practice, which represents and (re)produces social realities grounded in institutional status and power (Austin, 1962; Bourdieu & Nice, 1977, 2010; Boyer & Yurchak, 2010; Mayr, 2008; Morgan, 2004); it is what constructs the disabled and mentally ill as the Other. This Othering reflects the “markedness model” – the social power dynamics within society that assign markedness to any social categories that oppose the default status, the *unmarked* – straight, white, able-bodied and so on (Bucholtz & Hall, 2004:372; Thomas & Wareing, 1999:87; Woolard, 2004). Hegemonic identities are unmarked, denoting their social power; they are the unspoken standards for social reproduction and reinscription. They challenge the marked and their identities and language – the language and structures that differ from the “norm” (Bucholtz & Hall, 2004:372). Bucholtz and Hall (2004:372–73) claim that markedness is used

to justify instances of social inequality, constructed through language and discourse. Unmarked discourse tries to erase the marked, and those that cannot be erased are depicted as socially deficient, as I demonstrated in the previous chapter. Philips (2004:474) supports this point, noting that “[a]t the heart of the relationship between language and social inequality is the idea that some expressions of language are valued more than others, in a way that is associated with some people being more valued than others and some ideas expressed by people through language being more valued than others”. The power dynamics between the speaker and the hearer that are embedded in this concept of markedness demonstrate anthropologist Ralph Grillo’s claim that “questions of language are basically questions of power” (Grillo, 1989:2). I explore these ideas further in Chapter Three, where I investigate the voices of youth with disabilities and mental illness in digital spaces.

Questions of who belongs and who is valued also arise within the concept of the *speech community* (Ardener, 1971; Boyer & Yurchak, 2010; Bucholtz & Hall, 2004; Crowley, 2003; Duranti et al., 2003; Grillo, 1989; Keating & Egbert, 2004; Kroskrity, 2004; Lambek, 2010; Morgan, 2004; Philips, 2004). Morgan (2004:3) defines speech community as “the product of prolonged interaction among those who operate within shared beliefs and value systems regarding their own culture, society, and history as well as their communication with others”. Each have their own unique languages and histories; historian and anthropologist Daniel Crowley states that “language is ‘the living and speaking witness of the whole history of human beings’ [...] A language has within itself the history of a nation. [It] is ‘full of instruction, because it is the embodiment, the incarnation [...] of the feelings and thoughts and experiences of a nation’” (Crowley, 2003:56, 58, quoting Müller, 1862 and Trench, 1851). For instance, historical queer subculture has its own language, Polari. These historical imprints of language are seen in how groups interact internally but also with those outside of their speech community. For instance, where the same word is used by multiple groups but with different

meanings and connotations, language is the carrier of social categories (Bucholtz & Hall, 2004:370; Crowley, 2003:56, 58, 83; Grillo, 1989:4–9; Morgan, 2004). This is demonstrated by the recent reclaiming of the term “special needs” by some of the disabled community, as demonstrated by a post made on January 18, 2021, in the Facebook group Disability Connections New Zealand, wherein some members commented on the post claiming the term because “we” are “special people”. The “reclaiming” of terms by speech communities is important because it demonstrates the power embedded in language as a social product, bearing the marks of past and present history (Crowley 2003:229; McCormack et al., 1979), as well as language’s status as a political object (Grillo 1989:8).

From about the age of 10 or 11, I can remember repeatedly hearing the phrase “everything is too damn PC [politically correct]” from family, and friends my age. At the time I did not really understand what this meant, but like any child I replicated the language and ideas of those around me. By the time I was about 15 or 16 the term PC had lost some of its steam in everyday language, and in the five years since leaving high school (I am now 23), I can count on both hands the number of times I have heard the term said in conversation. I am under no illusion that this is because people have stopped complaining about how “PC everything has become”: rather, through becoming a self-thinking and reflexive individual I no longer engage with people who peddle these views, because when someone says that everything is too PC, what they really mean is that they can no longer throw slurs at minorities without social judgement. A more recent term with similar connotations is “woke”. However, rather than being used by (typically) politically conservative individuals, as the term PC was, it is utilised by (typically) politically liberal individuals. Wikström (2016:165) demonstrates that the aversion to PC language is because it prevents people from being bigoted and rude. In “example 5” (Wikström, 2016:165) Twitter user A shares a quote stating “I will speak the truth regardless of what media and the PC police say”, and user B replies sarcastically “Because

there is no politically correct manner in which wapo [the *Washington Post*] knows how to present truth?” A common critique is that PC language has gone “too far”, to the point of being ridiculous and ineffective (Moss & O’Connor, 2020; O’Neill, 2011), and to an extent I agree. For instance, as is demonstrated by Caplan (2008:14), the language used to describe disabilities has seen significant “corrections” over the years from “crippled” to “handicapped”, “disabled”, “physically challenged”, and finally “differently abled”; the latter two terms she states (in 2008) as having become the common ones. However, a majority of the disabled community dislike “physically challenged” and absolutely loathe “differently abled”. On Reddit, a post titled “Using the term ‘Differently Abled’ in reference to someone with physical disabilities is not acceptable and is not empowering to be referred to as such. It is degrading and demeaning” is an excellent example of this. The author’s primary point is that these terms were not chosen *by* disabled individuals but rather *for* them, demonstrating the systems of ableism within which disability exists.

This increasingly popular term of “Differently Abled” did not come from disabled people trying to change how we were seen, the term was started by perfectly able bodied people that didnt like the sound of handicapped and disabled or the very realistic cripple.

User D comments:

Disabled people have made it clear they find this term demeaning and unacceptable. The question is are people listening?

To which user E replied:

Yes I agree. People should look to the group they are referring to and ask what they would like to be called. It’s similar to how people using latinx to refer to latino people, when the vast majority don’t want to be referred to as latinx. If the group has a term for themselves (in this case physically disabled or disabled) and

they are using it in professional settings, it's generally better to refer to the term the group uses rather than come up with something you think is better.

The only way in which to achieve the desired effect of PC language – to impose “either explicit or implicit restrictions on acceptable language for public discourse” in order to replace minority-demeaning language with language that creates equality and respect (Caplan 2008:13) – is to listen to and respect the language these groups use rather than telling them they are wrong for using that language. If the language that communities want to use is ignored because it is seen as not being PC then those trying to be PC end up creating the environment they are trying to prevent. Ignoring a group's preferred terms is the same as ignoring someone's pronouns. It is an action through language that tells someone that you do not respect them, will not be inclusive of them, and in the harshest terms do not want them in “your” society/community as they are.

Application of social discourse and language

The consequences of language and society being irrevocably intertwined is a theme that emerged from my interviews, even in instances wherein participants did not draw direct parallels between the two concepts. They all talked about the social power that frames the treatment of and stigmas directed at people with mental illness and disabilities, and the prioritisation of profit over human life and wellbeing. There is a consensus that the language New Zealanders use perpetuates socio-cultural expectations and presentations of identity, culminating in social standards. These standards often isolate people from the services available for mental health and disability because, when deviation from these norms occur, such as cases of “classic” Kiwi blokes seeking help for mental illness, social ridicule and discrimination can occur, such as in the past being called a “fag” (a derogatory term for a gay man) or told to “toughen up and take a concrete pill”. For instance, Adriani, explains how some people within her local community in the South Island do not feel as though it is socially

acceptable for them to access these services. This is because these individuals are perceived to be “failing as men” in the sense that they are not adhering to the still-hegemonic socio-cultural masculinity expectations of their communities. Such mentalities and cultures are extremely detrimental to the mental health of those individuals subjected to these behaviours and adversely affect others who do not seek help for fear of similar treatment and dismissal (Ministry of Health Manatū Hauora 2018, 2019). These behaviours are also dangerous because they create unobtainable standards of what a specific aspect of identity ought to be (Aneshensel et al., 2013:357): for instance, that a man is never emotional, never suffers from mental illness, and cannot be overtly feminine (Johnston, 2021). These false narratives exacerbate worsening mental health and increase the rates of mental illness that go undiagnosed and lead to instances of suicide or harm to others (Johnston, 2021). Other expressions – such as “she’ll be right”, a Kiwi phrase used to express a belief that everything will be all right with time (Cryer, 2018), and “toughen up” and “take a concrete pill”, or “harden the fuck up” (GCR Staff, 2018) – also contribute to this macho narrative of the emotionally controlled man. Both the cultures of “toughen up” and “she’ll be right” are blamed by grieving families for “killing us” and “costing lives” due to their contribution to toxic masculine and feminine ideologies surrounding emotional vulnerability, being the “perfect” man or woman, and openness about mental distress (Cryer, 2018; GCR Staff, 2018; McCool, 2017; Weber, 2017). For instance, in Weber’s (2017) news article, Bary Neal, the father of Matt, a victim of suicide, stated, “That age group is the age group where they’re cool, they’re tough. They don’t want to sit there and tell other people what their problems are, they prefer to try and nut it out themselves, but that kind of culture, the ‘toughen up’ culture, is costing a lot of lives.” These terms and perceptions are not limited to men. Women, like men, are affected by stereotypical traditional gender roles, social expectations left over from British colonisation, and continued perpetuation in mass media of the idea that they should be “seen and not heard” (Davison & Huntington 2010; MacDonald,

2020; World Health Organization, 2011). Women “learn” to smile and present an external façade disjointed from their conflicted internal world (Davison & Huntington 2010:241, 244, 246). They, like men, are socialised by gender roles and powerful but often “out-of-sight” influences on socially acceptable forms of self-expression and how people are treated if they do not conform (Davison & Huntington 2010:246). Women are the carers of society, taught to put others’ needs above their own feelings, emotions, and needs, causing them to internalise their mental illnesses (p. 246). This is manifested in the “hidden statistics” in which women have higher instances of self-harm where men have higher rates of completed suicide (Weber, 2017).

The mental health of Aotearoa women is significantly unnoticed unless it is in relation to the mental health of men – to the extent of becoming a hidden history in its own right. Women’s mental health is generally only discussed when linked to men’s self and social repression, denial of mental illness, and declining mental health leading to domestic violence, alcoholism, and drug abuse (American Psychological Association, 2011; Swarbrick, 2018; World Health Organization, 2011). Leda drew links between rates of domestic violence and the social determinants of gender, race, and socio-economic status and socio-cultural expectations. Historian Nancy Swarbrick supports this claim in an entry she published in *The Encyclopaedia of New Zealand* about domestic violence, stating that it often occurs in families where extenuating social determinants such as poverty, substance abuse, or mental health issues are prevalent (Swarbrick, 2018). Leda, in discussing the “she’ll be right” and “toughen up” culture surrounding mental health, noted how the repression and denial of declining mental health or mental illness can affect domestic violence rates:

I mean, a lot of men, even in my own family’s history, they were dealing with their own issues. But because they didn’t know how to deal with it, they had to internalise it. They took it out on the woman in their lives. Which obviously has the knock-on effect to our domestic violence rates. [...] I think it needs to change,

but I don't think enough is being done to change it, especially on a government level.

These claims of men repressing their own issues can be seen in the statistical data. In 2016, 553 people committed suicide, of whom 412 (74.5%) were men compared to 141 (25.5%) women (as it is not stated I assume that these categories refer to biological sex rather than gender). That same year, 171,033 people used mental health and addiction services, 89,379 of which were male (52.3%) (Ministry of Health Manatū Hauora, 2018, 2019). The toll of toxic masculinity on both men's mental health and domestic violence rates is explored in a media article, "Boys (Still) Don't Cry" (K. Johnston, 2021). In the article, University of Auckland psychology professor and specialist in gender violence Nicola Gavey is quoted as saying, "It is so widely globally acknowledged how damaging that ... [the repression of emotions] is, both to ... [men], and to the women in their lives... what that does to the psyche, if you can't show emotion or hurt or disappointment – that gets turned into anger and violence, and self-harm." The article lists restrictive masculine ideals that confine men to the "man box": "Be strong. Provide for your family. Pay for meals. Don't knit or do the gardening. Play rugby. Go to the gym. Drink beer. Don't show emotion. Don't watch television shows about emotions. Don't listen to songs about emotions. Certainly, don't listen to John Mayer.³ You could probably wear pink, occasionally. But never wear a dress. And don't cry. In fact, don't even think about crying, because that's acting like a girl. And if you want to be a man, you can't act like a girl, ever."

The "man box" prevents men from acting authentically and forces them to conform to behavioural expectations that are detrimental to their mental health, but also potentially to the physical and mental health of those around them (K. Johnston, 2021). This article, citing a recent study on "the rules of New Zealand manhood, as told to University of Auckland

³ An American singer-songwriter who tends to produce "emotional" songs such as "Slow Dancing in a Burning Room".

researchers by teenage boys”, validates Leda’s claims about the linkages between the repression of mental health due to masculinity stereotypes and violence towards women in Aotearoa. This study, conducted by Nicola Gavey, and draws on the works of Australian sociologist Michael Flood, who has been working in the space of gender and domestic abuse for almost two decades (cf. Flood & Pease 2009; Jewkes et al., 2015; Johnston, M., 2021).

Not only is the denial of men’s mental illness killing Kiwi men, but as stated above it is also leading cause in declines in women’s mental health due to men’s abusive behaviours that are associated with the repression of these emotions. In Aotearoa there is a bias towards discussing men’s mental health because we see women as being “emotionally free” to express their mental decline. None of my interview participants brought up how women’s mental health is discussed online or what the social perceptions of it are, nor did I, at the time, think to explore this. I think this is in part because Kiwi women’s mental health has never been presented as the crisis that Kiwi men’s has been by the media. Additionally, the demographics of online support groups is overwhelmingly female, indicating that women feel more open about talking about and seeking help for their mental health (MacDonald, 2020; World Health Organization, 2011).

The performative act of these utterances by society is to control people by applying outdated ideals of masculinity and femininity. These two attitudes have aided in constructing the damaging stigmas around mental health and being vulnerable enough to ask for or accept help for our mental health, leading to the deaths of many New Zealanders (McCool, 2017; Weber, 2017). For instance, according to the WHO (World Health Organization, 2003):

Communication between health workers and women patients is extremely authoritarian in many countries, making women’s disclosure of psychological and emotional distress difficult, and often stigmatized. When women dare to disclose their problems, many health workers tend to have gender biases which lead to them to either over-treat or under-treat women.

Since 2007, men have been consistently 2.5 to 3 times more likely than women to complete suicide in Aotearoa (Coronial Services of New Zealand, 2020:1). The highest rates of suicide occur for men in the age groups 25–29 (33.9/100,000) and 30–34 (32.88/100,000) years old, according to a Coronial Services review. Comparatively the female rates for these age groups were 9.33/100,000 and 6.57/100,000, respectively (Coronial Services of New Zealand, 2020:2). Interestingly, for women the age brackets her higher suicide rates are different: highest is 15–19 (14.97/100,000), followed by 80–84 (12.93/100,000), then 20–24 (12.23/100,000) years old (Coronial Services of New Zealand, 2020:2). This discrepancy highlights the significant damaging effects that the Kiwi bloke image and the “toughen up” and “she’ll be right” attitudes have because men feel less able to access the resources available; aiding in creating Aotearoa’s mental health epidemic. This is further demonstrated in participant Adriani’s claims that it is not only the historical socio-cultural stigmas surrounding mental health or the subsequent cultural and gender expectations (for both men and women) that dissuades individuals from seeking or accepting help but also the inaccessibility and off-puttingness of the clinical language that is used in inpatient services acting as a further barrier. She postulates that it may be because people do not understand or trust this politically and institutionally charged language. Cyra offers a deeper perspective into the significance of the issue of official/clinical versus non-clinical language, stating that the language found in official discourse does not represent her experience or those of others with anxiety, depression, or ADHD in her online communities:

[Online groups are] where I find comfort in the language to explain my experiences, whereas if I try to google a symptoms list for ADHD, none of [my symptoms] come up. It’s like “do you get up in situations where you’re expected to sit still?”, and I’m like, “NO!?!”. Of course I wouldn’t, are you kidding me? I would never! But that’s what, that’s on every check list I’ve had to fill out at the psychiatrist, it’s on every quiz I’ve done online, it’s – it’s just not at all within

the community that's been given that label. And is actually benefiting the most from talking about their experience and the language they use helps me. Not this official [discourse]. And just like googling, "the overlap between anxiety and ADHD" there's maybe one or a couple of Venn diagrams or whatever, but the main information about how these things present and the language to use around that comes from online community.

She claims that this is a common feeling amongst individuals in mental health and disabled communities. Furthermore, it is the language of the community and how they talk about ADHD (in her case) that puts her at ease, makes her feel seen, and validates her experience to the extent that she feels accepted and related to. There is a strong sense of needing to find a place to belong.

This need to have an experience validated through language and through a similarity of experience highlights the importance of having a commonality of understanding, which can be achieved through a shared language and semiotic tools (Danesi, 2019). In the case of language, this means that there needs to be a collective understanding of words and their socio-cultural connotations – as occurs in a speech community (Crowley 2003; Bucholtz & Hall 2004; Ardener 1971; Duranti et al. 2003; Grillo 1989; Keating & Egbert 2004; Kroskrity 2004; Lambek 2010; Boyer & Yurchak 2010; Morgan 2004; Philips 2004). This is critical because as a person and their knowledge base grows, so too does their vocabulary and the language they use to articulate what it is they are feeling. For instance, Sofia, a university student, posts on social media about her experiences with mental illness, simultaneously promoting official services. She states that she began to get a grasp on her own anxiety and depression through diagnosis and using government resources, such as depression.co.nz. Explorations of the official mental health discourses and engaging with more people online led Sofia to learn about a variety of mental illnesses:

I expanded my horizons, if you will, about the different kinds of mental health issues. Like I've started to talk about like BPD [borderline personality disorder], like my mum, but also like schizophrenia... um and just like different types of personality disorders, about learning disorders, and I think that's probably what changed the most is it wasn't that my language changed about it, it was that the knowledge that I knew just got expanded. And so I started to share that knowledge too.

Similarly, as briefly described above, Cyra's language began to change as she "found her people" among ADHD communities. She began adopting the language used in those groups to articulate her own experience:

I've been playing life on "hard mode", which is a metaphor that I've picked up through online community [...]. So the language is like hyper-focus, which is something I found from [the] community [...] the other day I posted something like "I don't know if my inability to stop working is perfectionism, internalised neoliberalism, hyper-focus, or inability to switch tasks, or executive dysfunction or whatever." All that language comes from online activism. Disability activism, ADHD activism, specifically, but also just generally discourse on Twitter, that is how I got access to a lot of that language.

Cyra's adaptation of her vocabulary from the dialects of online communities, when talking about ADHD, signals her inauguration into the ADHD subculture and speech communities. She now possesses the necessary capital to understand and embody the community's semiotics and distinct lexicon. This change in language is not only about the terms with which she expresses her experience but also represents a shift in mindset. Both Cyra and Adriani note that the language and position of official clinical discourse is quite different to that of unofficial online discourses. For instance, Cyra claims that in the official diagnosis criteria for ADHD and in her experiences with medical professionals, ADHD is diagnosed through the lens of deficit framing. This may be because in the medicalised understanding, disabilities are

diagnosed through focusing on the differences that cause “suffering” or “struggles” within mainstream society. However, Cyra claims that this shouldn’t be the primary focus of ADHD or disabilities descriptions. While it can be helpful from a diagnostic point of view, the continued focus on deficit frames disabilities and people with disabilities as “wanting”. Cyra states that there is so much more to ADHD than the “negatives”; having ADHD is what gives her excellent pattern-seeking abilities and makes her a good friend in terms of empathy and emotional capacity. Furthermore, she sees the tendency of individuals with ADHD to hyper-focus as an ability to fully invest themselves in and be enthusiastic about something – the language she and the community use conveys the traits of ADHD as positives, rather than as negatives, as in the diagnostic process. By contrast, the use of negative instead of positive language in official discourse no doubt adversely affects people with ADHD, as well as those with other disabilities, because it demonstrates a systemic disabling form of ableism that is ingrained into every form of discourse and must be unlearned by those who are disabled. They need to overcome internalised ableism and the thoughts of “I always knew there was something wrong with me” that accompany having invisible disabilities. As Cyra phrases it:

I always knew I was fucked up somehow. I always knew I was less than everyone else around me, and this [diagnosis] is confirmation of that.

This again demonstrates that rather than focusing on the negatives of an impairment, the question of what special skills and insights people with impairments can offer should be asked.

Conclusion

Language is imbued with social meanings. The type of language one uses changes how something is seen because, among the many words that say the same thing, those we choose to use reflect our unconscious social bias. The problem therefore is not the words but the social meanings they carry; as Cyra puts it, “the problem isn’t actually the word *disability* but [...]

people seeing it as a negative thing”. The essence of this chapter was to demonstrate how, given that language is such a significant element in constructing the reality we live in (Ardener, 1971; Bucholtz & Hall, 2004; Caplan, 2008:13; Morgan, 2004), commonplace and specialist languages profoundly, and often adversely, construct the worlds of disability and mental illness in Aotearoa. Language is a powerful tool for conveying understanding, but also for confusing it. Language and communication are a political field in which our habitus is entangled. While there are many words and combinations of words that can be used to convey the same idea, they all have varying social, cultural, and historical meanings and connotations that must be considered. My interlocutors were profoundly aware of this, having been repeatedly disabled, and sometimes enabled, by their experiences of local and specialist linguistic practices.

As this suggests, as academics, as engaged citizens, as marginalised people affected by words and their hidden meanings, we need to be more aware of our language choices and those of those around us. What ideals and historical, societal, and cultural notions are they reflecting? Who and what is being prioritised? As stated at the beginning of this chapter, language is the key to understanding; it is both powerful and dangerous. It sets and maintains social attitudes and norms, and if there is any hope of progressing mental health and disability discourse then we must examine the language used and how it is used.

Chapter Three: Lives Online

Disability and Mental Illness in Digital Spaces

Social media powerfully informs and influences how we communicate (Loh & Lim, 2019). Digital space and social media, for better or worse, allow us to curate and present a particular image of ourselves online for others to consume (Barendregt, 2020; Boellstorff, 2015; Miller, 2021; Scott, 2019). Digital media has created new local and global cultures in which information is exchanged and new identities are formed through a crafting of experience and participation in online spaces (Cohen & Salazar, 2005; Jayadi & Abduh, 2020).

Social media and digital technologies are complex cultural entities which are neither solely good nor solely bad; they exist in a state of duality. Using observational and participant interview data from across several social media platforms – Reddit, Tumblr, Facebook, Instagram, and YouTube – I show how social media, is a critical tool for communication, identity formation, and activism for individuals with disabilities and mental illnesses. Such online spaces are particularly useful for those with disabilities and mental illnesses because they afford a range of anonymity and the opportunity to be seen as more than their disabilities. The spaces allow marginalised voices and discussions of taboo topics to be articulated and noted. However, I also argue that because social media is imbued with social norms, there are accessibility constraints, limiting participation for some. Furthermore, the curated nature of social media can be detrimental to youths’ mental health because it presents a filtered version of people’s lives, supporting the notion that “mental illnesses are the chronic diseases of the young” (McGorry et al., 2007:S5) because they are the most prominent users and consumers of social media.

Disability presentation online

Online expression of disabled identity is complex. Some post with pride, claiming their disabled status in an “open disclosure approach”; others hide their disabled status, only disclosing in secure “disabled-only” spaces, enacting a “secure disclosure approach”, or by private messages, in a “limited disclosure approach” (Furr et al., 2016:1359, 1360, 1362). All three disclosure types centre on control over when and how disability status is disclosed; the type of disclosure an individual chooses depends on how they intend to participate online. All three types of disclosure are wrapped in elements of “impression management” – the choice of what information is disclosed due to the possibilities of visual anonymity and the general freedoms of digital spaces (Huang, 2014:417). Those who openly reveal having a disability, particularly if the disability was the result of an accident, used it to “come out”, accept themselves, and take control over their disability narratives, pushing back against assumptions made about their disability (Furr et al., 2016:1360). Both open and secure disclosures offer disabled individuals the chance to explore and claim their disabled identity, expressing their expert knowledge and pushing back against ableist assumptions, and often leading to activism in the form of self-advocacy (Buckingham, 2007:7; Ellis & Kent, 2016:52; Ginsburg, 2020:102-105 Horst & Miller, 2020:105; Rothenbuhler & Coman, 2005; Sweet et al., 2020:5; Underberg & Zorn, 2013:8).

However, as Ellis and Kent state, “Disability is activated differently online compared to the analogue world and has uneven effects on different impairments” (2016:4). Some disabled individuals are capable of “passing” as able-bodied in online space (Boellstorff, 2015; Ginsburg, 2020:107), allowing them to feel like “everyone else” when they are engaging online (Sweet et al., 2020:3) – a potentially intoxicating feeling for someone who faces stigma and social and physical barriers in their everyday lives (Furr et al., 2016; Salzmann-Erikson & Hiçdurmaz, 2017; Sweet et al., 2020:2). Having a “digital” or “virtual” social identity that is

not defined by disability, impairment, or bodily appearance – their “actual social identity” – has a levelling effect, allowing disabled individuals to show and be defined by their personalities and abilities (Ellis & Kent, 2016; Schüll, 2021:293; Sweet et al., 2020:5) and offering them a chance at participation in an environment and interactions over which they have control (Ginsburg, 2020:130). This bodiless participation challenges the social discrimination towards disabled individuals, often leading to disbelief when they later disclose their disabled status (p. 130). This levelling effect is also evident in instances of physical manifestation of mental illness. When someone is in a digital space no one can see the scars of depression and suicide attempts, and they aren’t beholden to the shame and guilt that others’ lingering glances evoke. Engaging online is perceived as a liberating space which decreases social judgement based on physical characteristics. This perceived freedom is alluring for anyone who does not conform to mainstream physical “norms” because it allows them to be seen beyond their scars or ailments.

In not sharing one’s disability status the toxic practice of “inspiration porn” can also be avoided (Ellis & Kent, 2016:41, 46; Schüll, 2021:137). Inspiration porn is the practice of elevating a disabled individual, often a child, for doing something completely ordinary and framing it as extraordinary because they are disabled. This action is accompanied by a caption along the lines of “your excuses are invalid” or “before you quit, try” (Ellis & Kent 2016:41). Inspiration porn is typically the practice of able-bodied individuals claiming someone’s (disabled or able-bodied) reason for not doing something as “invalid” because a(nother) disabled person is doing it (Ellis & Kent 2016:46) – forcing all disabled individuals together to conform to an arbitrary standard, regardless of the type or degree of their impairments.

Digital spaces facilitate the formation of new cultural communities that offer support, collegiality, and comradeship, which are key drivers of digital participation for those with disabilities (Attrill & Fullwood, 2016; Ellis & Kent, 2016; Inhorn & Wentzell, 2012;

Salzmann-Erikson & Hiçdurmaz, 2017; Sweet et al., 2020). Who disabled individuals talk to, particularly those with mobility impairments, is no longer limited to those in their physical proximity. Online participation allows them to engage with people around the globe that often share elements of their experiences; as Athina explains, people seek out groups that centre around the specific elements of their identity that they wish to discuss. The ability to relate to other experiences is a vital drive for sharing stories: a commonality of experiences forges a bond between people, allowing them to feel more connected to others, less alone in their experiences, and supported. The comment section on every social media site plays a vital role in this connection: it “not only provides the posters with cherishing comments and supporting comments but also enables them to mirror their experience with others” (Salzmann-Erikson & Hiçdurmaz, 2017:290). These communal spaces offer more than just a form of connection, a shared experience, or people that “get it”: they are sites of expert knowledge and information sharing (Attrill & Fullwood, 2016:110–11; Ellis & Kent, 2016:162, 291–93; Inhorn & Wentzell, 2012:3–4). This flow of knowledge further develops feelings of belonging and deeper connections and increases rates of participation because people feel safe to engage (Rothenbuhler & Coman, 2005; Underberg & Zorn, 2013). However, this is dependent on sufficient access to computing and other resources, as will be discussed in depth below.

Politics of design

The design of digital technologies and social media are embedded with socially normative ableist assumptions which create barriers to participation (Barendregt, 2020; Ellis & Kent, 2016; Ginsburg, 2020; Knox, 2021; Horst & Miller, 2020; Sweet et al., 2020). These barriers appear predominantly in three forms: coding, collaboration, and expense. Firstly, technology is encoded with the presumptions, judgements, and social biases of the programmers. A well-documented example of this is in the hidden racial bias of face recognition software

(Barendregt, 2020:206; Rhodes et al., 2009; Yucer et al., 2021). What is shown or promoted on social media sites is determined by powerful algorithms (Knox, 2021:184), which, as Cyra notes, “marginalise particular voices and prioritise certain ones [...] working against [and] censor[ing] certain accounts over others”. The design of digital spaces has tended to assume a “universal design” without the ability to edit or alter accessibility elements, such as text size, colour inversion, text to audio, live or closed captions, and so on (Ginsburg, 2020:115; Knox, 2021:183–84; Snyder, 2021).

While programming for particular brands and devices make these accessibility options more available – for example, Apple offering a host of accessibility features across their devices, such as conversion of selected text to audio, colour correction for colour blindness, and safe audio – very few social media sites offer such options. In my observations I have found that Tumblr and Reddit are the only major social media sites to offer colour inversion and different backlighting to accommodate those with visual impairments. The systematic exclusion of certain disabilities and impairments from these spaces demonstrates the “digital denial”, which reproduces in digital spaces social patterns seen as normal and logical (Barendregt, 2020:206; Ellis & Kent, 2016:52; Knox, 2021:183–84).

This relative neglect of accessibility features stems from the social biases mentioned above, biases that could be mitigated if developers were to consult with disabled individuals with a range of impairments in the development process (Ellis & Kent, 2016:101, 111–12). As in physical society, in online environments some disabilities and impairments are more severely affected by ableist norms than others, creating the inequities of what Horst and Miller (2020:103) term the uneven expansion of “disability media worlds”. Sweet et al. (2020:7) and Snyder (2021) expand on Horst and Miller’s analysis, using the term “digital divide” to explain the disparities within disabled communities and between disabled and able-bodied users. This dual intra/inter-conflict was exemplified during Snyder’s presentation at the 2021 Disabilities

Conference in Auckland, which I attended. It focused on detailed audio description allowing blind individuals to “see”. However, because the presentation lacked consistent closed captions, deaf audience members were unable to “hear” or participate in the presentation – a perfect illustration of the conflicts within the disabled community wherein disability worlds are expanding unevenly and sometimes exclude other impairments completely.

This inequality extends to accessibility and affordability of devices. Disabled individuals are more likely to have lower incomes than their able-bodied counterparts and as such face the additional barrier of possibly not even being in a position of obtaining a device to access these social media sites – particularly if they require additional devices in order to engage in these spaces because of their disabilities (Sweet et al., 2020:7). As this research was based online, those without any or stable access to these devices were inadvertently excluded from participating in this research.

Filtered lives: Mental health online

The process of filtering our lives for online consumption is harmful because it sets unrealistic and unobtainable standards and expectations, leading to poorer mental health and wellbeing outcomes. Only sharing the good moments online, especially when behind the scenes they are entangled with hard or painful moments, as demonstrated by the growing trend of revealing the “true story” behind most liked photos and moments (Gasaitytė, 2021; Ritschel, 2021; Fishwick, 2017), perpetuates the drive to achieve unrealistic and unobtainable lives/bodies, which leads to declines in mental health and illness. However, anonymous online groups can offer a respite from this behaviour. Through anonymising the pressures to present a perfect façade are lifted and more honest conversations can be had.

Huang’s (2014) notion of impression management is critical in understanding the effects of social media on youths’ mental health. Impression management is in essence an

online “filtering” of real life whereby people only post the best parts of life, embellishing where they can. For instance, Miller (2021:92–93) states that “low-income people don’t post photos on Facebook about where they really live [...]. They post photos posed next to swimming pools or near the gym [...]. Life portrayed online [is] a more conservative version than what could be seen offline”. Hermione explains that online filtering is a fake, curated version of life, highlighting only the “rainbows and sunshine” while ignoring the nitty gritty of life. From our conversation it was clear that she knew this filtering can and often does worsen mental illness because these curated moments – presented as a representation of the poster’s life all the time – are not what “normal” people experience day to day. It is the action of filtering our lives on social media, in order to achieve the ‘perfection’ of the lives we compare our imperfect ones to, that can worsen mental illness for ourselves and others; we must take a closer look at why people engage in this filtering.

But what is the catalyst that prompts people to filter their lives online? I argue that it lies in the transference of gender norms, imposed social rules, and expectations into online spaces where people have more control over their impression management and how they are portrayed to others (Aziz, 2017; Franchina & Lo Coco, 2018; Herring & Kapidzic, 2015; Nowotny et al., 2015; Perloff, 2014; Seserman, 2021; Siibak, 2010; Tamplin et al., 2018; Vuong et al., 2021). Men and women “perform” the interpretations of gender taught as culturally correct (heteronormative) (Siibak 2010:407). The social regulation of gendered behaviours and physical appearance through cultural teachings and stereotyping has been proven detrimental to mental health, even increasing rates of suicide (Nowotny et al., 2015:115).

Furthermore, youth, who are in the process of identity development, are more at risk from constant exposure to these stereotypes in media and online, which increases the internalisation of unrealistic and toxic beauty and behaviour standards (Aziz, 2017:19; Perloff,

2014; Tamplin et al., 2018:30; Vuong et al., 2021:9). Both men and women can be victims of body dissatisfaction and dysphoria, with women internalising the thinness-based idealised female beauty, which can lead to the development or worsening of mental illnesses such as eating disorders, bulimia, anxiety, and depression (Franchina & Lo Coco 2018:9–10; Nowotny et al., 2015; Perloff, 2014:364; Tamplin et al., 2018; Vuong et al., 2021), and men the ideal of the tall, lean, muscular body (Franchina & Lo Coco, 2018:9–10; Herring & Kapidzic, 2015:4–5; Perloff, 2014:371). The social pressures to conform to group masculinity or femininity norms, even if these norms do not represent them, are high, increasing suicide rates from both performing an inauthentic identity and fear of social retribution, such as ridicule (Nowotny et al., 2015:117) – a phenomenon prevalent among the transgender community because of expectations placed on their assigned gender at birth (AGAB) and then expectations to ‘pass’ as they transition (Bergero-Miguel et al., 2016; Peterson et al., 2017; van der Miesen et al., 2020).

An example of the problematic reproduction of gender stereotypes and ideals online in Aotearoa are evident in how the ‘Kiwi bloke’, discussed in the previous chapter, should behave and express emotions. The Kiwi bloke has long been portrayed as a staunch and hardy farmer who is strong but emotionally distant (Herring & Kapidzic, 2015:5). While the social-cultural views and expectations of what ‘manhood’ is are evolving and disseminating throughout Aotearoa society, outdated social expectations are still prevalent, creating instances of discrimination and prejudice when these opposing expectation of being a ‘man’ collide (Ministry of Health Manatū Hauora 2018, 2019). For the Kiwi bloke this means not being ‘effeminate’ or emotional and not struggling with mental health and illness, effectively silencing men from discussing their feelings and calling out these destructive behaviours (Jacobson, 2021). Adriani describes this silencing in terms of who qualifies for and feels welcome in mental health programs and services, particularly in small rural communities and

in the South Island (Angermeyer & Matschinger, 2003; Browne-Yung et al., 2013; Corrigan et al., 2014; Obst & Stafurik, 2010; Zito et al., 2001). As will be examined further below and is discussed by Adriani and Demas, social media, particularly sites that offer greater anonymity, such as Reddit, are excellent outlets and spaces of exploration for those suffering from mental illness or declining mental health but do not feel that they can express this in their everyday lives to those around them or use/have access to services.

It is social expectations that dictate what we should post and how we should present our lives online – as Hermione says, “it’s not social media that’s making us depressed, it’s society that’s making us depressed”. Society negatively affects mental health because of the social standards set for how people ‘should’ act; these are based on their age, gender, ethnicity, sexual orientation and so on. These social standards and expectations influence how people filter their image online. Social media and digital technologies are not inherently detrimental to youths’ mental health; it is how they are used and what is portrayed in these spaces that can lead to poorer mental health and increases in the occurrence and severity of mental illness.

Disability and mental illness online: Determinants of youth participation

The previous two sections described the inherited socio-cultural biases and social standards that continue to be detrimental to people’s mental wellbeing both online and offline. There are three primary elements of online engagement that youth with mental illness find advantageous, particularly if they are also disabled and online engagement increases their ability to participate in society. These are anonymity, community, and voice.

Anonymity allows people to act as and say things they ‘shouldn’t’. It offers them the chance to be who they are and express socially taboo thoughts without fear or repercussions (De Choudhury & De, 2014:71; Pavalanathan & De Choudhury, 2015:320). In online spaces the anonymity of “throwaway accounts”, as are seen on Reddit, allow for ‘candid discourse’

of self-disclosure and disinhibition (De Choudhury & De, 2014; Horgan & Sweeney, 2010; Kummervold et al., 2002; Pavalanathan & De Choudhury, 2015; Prescott et al., 2017). People feel as though they can be honest because they have a sense of control over what is being disclosed, but more importantly there is a sense of security and safety in that these anonymous throwaway accounts cannot be linked to their offline lives (De Choudhury & De, 2014; Horgan & Sweeney, 2010; Kummervold et al., 2002; Prescott et al., 2017). This digital anonymity thus provides a security blanket for people to feel like they can express their feelings uninhibitedly and discuss sensitive topics that are unsuitable for mainstream consumption, without fear of judgement or burdening those in their lives and at the same time being provided with more effective emotional support from the members of online communities seeing their posts (Attrill & Fullwood, 2016:113; De Choudhury & De, 2014:71). Leda and Demas describe this security of digital anonymity in their use of Reddit as opposed to other social media sites like Facebook. Leda states that with her personal Facebook account she avoids stigmatised topics, even censoring what she posts in private groups, which are not anonymised, posting “nothing that [she] wouldn’t want to come back to [her]” in case someone she knows ends up joining these groups. In contrast, Demas prefers face-to-face engagement with professionals; he notes that these online spaces are helpful when there is no other alternative for him. He uses Reddit for the anonymity it offers as well as the separation from his offline life and affiliations so as to not expose himself or burden those around him – a common feeling for those with disabilities and mental illness (Kummervold et al., 2002:62). Furthermore, anonymity overrides personal differences (Prescott et al., 2017:2). Anonymity allows people to engage without any biases or assumptions being directed at them based on their profile, allowing impression management and more open equitable discussions, particularly for disabled individuals and other marginalised groups (Ginsburg, 2020:130; Meier, 2021; Prescott et al., 2017:2). As Hera explains,

I think that the social media does make things a little bit more equitable, especially the anonymous forms. Or maybe like in an article, if there isn't necessarily a bio, for example, or there isn't a picture of the person, you just kinda have to read what they're saying and go oh, okay, I assume that they have the authority to be making these statements. Whereas if you can see that person you can see how they function; there may be this opportunity to assume their ability as well.

Athina continues, stating that anonymity is freeing:

Like you could be who you wanted to be. I don't mean it like you could fake your identity and pretend that you're like Prince Harry, but like if you were closeted [LGBTQ+] then it was very easy for you to, you know, present the way you wanted to present, you know.

Online communities have always been a critical motivator for online engagement because they offer connection through a shared sense of being (Muir, 2020:29–30, 38) in the form of peer support, which is integral to improving the quality of life for those with disabilities and mental illnesses that access these spaces (Attrill & Fullwood, 2016; Kavanagh et al., 2015; Prescott et al., 2017). This peer support and sense of connection and community are critical to healing for several reasons. Firstly, it is an example of “mood management theory” in action – the theory that people use specific forms of media to subconsciously regulate their emotional states (such as anxiety and loneliness) and achieve more positive moods (Cauberghe et al., 2021:251). Secondly, online community offers a connection, validation, and understanding of shared experiences that may be missing from individuals' offline lives in which they feel lonely and misunderstood (Attrill & Fullwood, 2016:6, 109, 110–11; Cauberghe et al., 2021; De Choudhury & De, 2014; Horgan & Sweeney, 2010; Horst & Miller, 2020:105, 130, 226; Johnson., M, 2021; Kavanagh et al., 2015; Meier, 2021; Muir, 2020; Pavalanathan & De Choudhury, 2015; Prescott et al., 2017; Webb et al., 2008:16–25). Johnson M. (2021) explains

loneliness as reflecting an “unmet social need” which we try to correct through relationships, and notes that society is facing a “loneliness epidemic”. As I have noted, humans are incredibly social creatures who need and crave physical and emotional connection with others. When these needs are not met for an extended period, according to Johnson, we go into a state of withdrawal, leading to adverse physical and mental health effects that ultimately increase our mortality rates (Johnson., M, 2021).

While participation in online forums and on social media cannot replace physical connection, it nonetheless allows people to develop and retain social connections and a sense of community, as will be explored further in Chapter Four. While these community spaces are often centred on particular topics, for instance the subreddits “Anxiety” and “disability”, discussions of non-forum topics develop as people form a sense of belonging, connection, and community (Prescott et al., 2017:2–3). Such discussions often begin in the comments section of posts but can also be the topic of main posts. An example of this is someone asking for area-specific advice on disability services, which leads to comment conversations about events in that area, people in that area, possible catchups, and so on.

Finally, these online spaces which have been carved out by and for people with mental illness and disabilities allow for engagement in ways never available before. For the first time, anyone can express their voice and have it be heard at any time, allowing people to not only be produced by culture and society but also to engage with it and become producers of culture and society themselves (Alvermann, 2004:79; Buckingham, 2007:ix, 7, 14; Horst & Miller, 2020:102–3, 167–68, 225–26, 228–29; Kent & Ellis, 2015:424–45; Literat et al., 2018:262–63; Pertierra, 2018:93–94; Rothenbuhler & Coman, 2005:319–20; Underberg & Zorn, 2013:8). These forms of engagement are constituted by the concept of voice, the right to expression and the agentive authority to represent oneself, which can aid in empowerment, self-advocacy, and the reduction of stigma (Horst & Miller, 2020; Kummervold et al., 2002; Prescott et al., 2017).

However, because of their positioning as socially marginalised and stigmatised, the disabled and mentally ill as a group experience voice poverty in traditional spaces of engagement.

Voice, or lack thereof, is critical to understanding the embodied marginalised experience and to the stripping and reclaiming of personhood, as demonstrated through Horst and Miller's (2020) exploration of Amanda Baggs Youtube video "In My Language". Amanda, a non-verbal autistic individual, explores feelings of social alienation and her personhood and citizenship being devalued:

It is only when I type something in your language that you refer to me as having communication. [...] It is not enough to look and listen and taste and smell and feel, I have to do those to the right things, such as look at books, and fail to do them to the wrong things, or else people doubt that I am a thinking being, and since their definition of thought defines their definition of personhood so ridiculously much, they doubt that I am a real person as well. (Horst & Miller, 2020:101).

Amanda's frustrations at the denial of her personhood is replicated by other disabled individuals. For instance, Hartblay's (2020:S28–S29) respondent Anya, a Russian woman in her 30s with a progressive muscular disorder that confines her in an electric wheelchair, tells a tale wherein she asserts her own sense of personhood through the refusal of assumptive embarrassment, pity, and charity of uneducated able-bodied individuals who are "just trying to help" (Hartblay, 2020:S31). In these examples, both Amanda and Anya experience the "clueless other" – an able-bodied person who (often inadvertently) denies personhood and voice by asserting assumptive authority over an individual with disabilities about whose abilities and needs they are clueless (Kasnitz, 2020:S19). The clueless other, while often trying to 'help', enforces disability by creating an environment wherein impairments are 'felt' not only by impaired individuals but also those around them. However, voice poverty does not affect every disabled or mentally ill person equally. Because I often present as able-bodied, am

white, and in certain instances pass as a man, I experience dramatically less voice poverty than Amanda or Anya. This is because of the ‘severity’ of their disabilities and the intersection of marginalised identities, creating several social levels where they must fight for their voices to be heard (Aneshensel et al., 2013; Ellis et al., 2019; Ginsburg & Rapp, 2020; Inhorn & Wentzell, 2012; Kasnitz, 2020).

In the subreddit “newzealand” a user comments: “This [the new Ministry for Disabled People] is probably going to create slightly more awareness for wheelchair access and every vaguely invisible disability will be even more overshadowed.” This comment illustrates the inequity of voice poverty within the disabled community (Ellis et al., 2019; Ginsburg & Rapp, 2020). This occurs because of what Appadurai terms the “gravest lacks” of the poor: that is, of those who do not possess the correct social and cultural capitals or resources that would give them a voice (Appadurai, 1990, 2004:63). This exclusion of the intersecting elements of marginalised identities sets to (re)produce the societal norms of silencing marginalised voices (Bowker & Tuffin, 2002:330), as professed by my participant Cyra, whose embodied experience of being an Indian woman with ADHD was ignored by her therapist and in the online support groups, as explored previously. The elimination of these intersecting voices and experiences allows for the perpetuation of particular narratives and versions of reality, such as the trope that Indian women do not have ADHD. Such erasures of diverse experiences further empowers the dominant versions of ‘reality’ and demonstrates how language both reflects and constructs reality, as discussed in Chapter Two (Austin, 1962; Bowker & Tuffin, 2002). The prioritising of mainstream ableist conceptions of the disabled experience over others is the reason online engagement is critical to marginalised activism: it allows for the subversion of these ableist assumptions through a collective voice and expertise of disabled individuals (Horst & Miller, 2020:200).

Anthropologists Eric Rothenbuhler and Mihai Coman (2005:325) explore the parameters of voice, stating that “people do not merely reproduce the thoughts and perspectives of the media – they respond and react to them as well”. An example of this comes with the announcement of the new Ministry for Disabled People. Many remain cautiously optimistic that this ministry will be a milestone that gives way to disabled voices being more widely integrated in social planning. One Reddit user in the subreddit “newzealand” states, “Cautiously optimistic, but I wonder how long it will take for us to see real change in our experiences. Soon would be nice because it’s a fucken shit show at the moment.” Another comments: “Exactly! I’m hopeful. The govt is saying and making the right moves. But I want to see that translate into reality and improved access to services for everyone in NZ with disabilities.” Yet there are many who do not believe that the implementation of this new ministry will have any measurable impact, especially with the appointment of a non-disabled person – Dr Justine Cornwall – as the executive director of the Establishment Unit (Kauaeroa, 2021). Many leaders in the disabled community are “gravely concerned” by this appointment and the timing of it, occurring on December 23, before New Zealand’s traditionally long Christmas and summer break, a factor in many believing it was “designed to slip past disabled people” (Kauaeroa, 2021).

In essence, digital cultures are providing mechanisms for youth and the marginalised to “challenge traditional conceptions of civic participation, for example by expressing skepticism towards traditional politics or valuing other forms of engagement over it” (Literat et al., 2018:262–63). Only time will tell whether the voices of disability groups will be listened to and elevated by the appointment of a qualified and disabled head for the Ministry for Disabled People, because the impact of voice is as much about the mainstream being prepared to listen as it is to enact change (Horst & Miller, 2020:20).

Conclusion

Digital media is a critical component of our daily lives in the 21st century. It is ingrained in everything that we do and to an extent who we are. Our presentation in online spaces is just as important as our presentation in the physical: it reveals aspects of who we are, who we want to be, and who we can be. This freedom in presentation of identity is particularly relevant for those with disabilities and mental illness. Part of this freedom involves feeling that there is a space where one belongs alongside others who understand. However, impression management does not just provide freedoms for the disabled and mentally ill; it also aids in the perpetuation of societal norms and the drive to present the ‘perfect’ life – creating significant declines in mental health. Despite how integral digital media is, it is not designed with diverse needs in mind, because diverse people are not a part of the design process yet, something that the implementation of the Ministry for Disabled People will hopefully aid in rectifying. Social media and digital technologies reflect societal norms, and we must create significant and lasting change in how the disabled and the mentally ill are perceived and engaged with in Aotearoa society offline to then see greater inclusion online.

While this was the case in a pre-pandemic world, Covid-19 has had a significant impact on digital engagement, particularly for those with disabilities and mental illnesses. In the next chapter, I explore how the pandemic has shined a light on the systemic prejudices against disabled individuals. But more importantly, I discuss what Covid-19 has given us as a society and the hope for a more inclusive and diverse future.

Chapter Four: Sociality during Covid-19

An analysis of Covid-19 and the pandemic is critical because the issues described in earlier chapters have been exacerbated by the Covid-19 crisis which has had a profound effect on everyone, forcing us all to change how we live our lives to some degree. There cultural, social, and economic impacts of the pandemic will continue to ripple for years to come. Even the legions who engaged online prior to the pandemic have felt and seen the sociocultural consequences of the pandemic on their online communities. The pandemic has altered their frequency and manner of engagement online, as was demonstrated throughout my interviews and observational data, and not always in the ways that might have been expected. It has also forced a shift in how political leaders engage with their citizens, with more and more leaders doing so through Facebook, Instagram, or Twitter, facilitating a greater flow of ideas and citizen engagement whilst building a sense of community.

The consequences of physical distancing mandates have been detrimental to the mental health and overall wellbeing of many individuals globally. As Fuentes (2020:24) says, “humans [have] evolved as beings whose needs to touch and be touched, to converse, debate, and laugh together, to smile and flirt with one another, and to interact in groups are central to healthy lives” (also see Pillay, 2021:3). Without these overt and nuanced physical interactions, we begin to decline. Yet, despite the physical distance between New Zealanders, the pandemic has brought us together in a manner I have not seen before. A sense of nationalism is fundamental to international sporting endeavours, such as the Rugby World Cup or the Olympics, but this is different. Covid-19 has created something new. The pandemic has given New Zealanders something that I think has been declining for many years now: a greater trust and faith in our fellow citizens as well as an empathy for what disabled and mentally ill citizens experience. More open discussions of mental illness and disabled experiences have created a greater sense

of legitimacy of these experiences. Covid-19 has forced us to re-learn how to connect with one another, both online and unplugged with those around us. Covid-19 has fostered temporally and experientially unique experiences that will continue to have lasting effects on how we engage with one another and how we think about issues of public health, citizenship, rights to participation, and so on. Because the social consequences of Covid-19 are just as drastic as the physical ones, I propose that we need to think about what I term long social Covid – our shared Covid consciousness – because Covid-19 ravages not just the bodies of those infected but also the cultural experiences, mental health, and navigations of social space of everyone. The main question is, do the positive consequences of this re-learning outweigh the negatives, and which will prevail?

To investigate these experiences and their outcomes I now examine the duality of social media and digital technologies during the Covid-19 pandemic. What are the positives and negatives of using digital technologies to communicate with people, work, and learn? Secondly, I examine the roles of ‘civic duty’ and nationalism in keeping the virus at bay in Aotearoa. Thirdly, what was the disabled experience(s) during the pandemic, and what, if any, effect was had on the ableist assumptions in our society? Finally, what is the current effect of Covid-19 on mental health and illness, and what does this mean for the future as its effects continue to unfold in the years to come?

Duality of social media in Covid-19

Social media and digital technologies have the potential to be both beneficial and harmful to individuals and their mental health (Attrill & Fullwood, 2016:11, 67–68, 78, 115; Horst & Miller, 2020:227; Miller et al., 2021:50). These effects are determined by how technologies are used and the perspective of the people using them. Several of my interview respondents referred to this duality of social media and digital technologies. For instance, Hermione spoke

about how social media negatively affects people’s mental health because it is “not done in a way that is real” (referring to filtered lives) since people tend to only post their good moments, which can be disheartening for those struggling, as explored in the previous chapter. She goes on to say that it is not social media that makes people depressed but rather society. From the context of our conversation, I interpreted this to mean the social expectations placed on the parts of our lives that we share. An excellent example of this is when the prominent American model Chrissy Teigen uploaded a series of photographs of herself and singer John Legend in 2020 depicting the raw emotion of having had a miscarriage at 20 weeks. This drew much criticism of her for sharing such a personal and emotional event. I believe some of this criticism came from the expectation that we do not/should not post about negative life events online. However, there was also an outpouring of support, and thanks to Teigen, many individuals, who had previously felt it was unacceptable to do so, began to share their own stories of miscarriage. This is a fantastic example of how social media can be a “tool to alleviate [mental suffering]” and of the “good social media can do from being true”, as Hermione says. Hermione’s own accounts illustrate the duality within which social media can exist. If we shared the difficulties of life as well as our triumphs, it becomes a complex but healthy space, one not dominated by toxic positivity, which creates a mask, from which true feelings cannot be expressed; or by toxic negativity, where people only post their worst feelings and neg one another on, causing their mental wellbeing to decline further. Social media and digital technologies, particularly during Covid-19, have played a positive role in allowing people to remain connected and “sane”, as Sofia says. However, online spaces and digital technologies as sources of connection and forms of community are nothing new: many people have been using these spaces for many years to engage with in-person as well as internet friends with similar interests (Muir, 2020; Webb et al., 2008:16–25). The continued use of digital spaces during Covid-19 is a testament to the “valuable sources of emotional support, [...] relief or

escape [from the] constraints [of] everyday [life] by using phones to access networks of support” (Pertierra, 2018:110) that these spaces offer. Many of my respondents comment on using digital technologies to escape their physical spaces and expand out into the world through digital means. Hermaphroditus sums this experience up when they say, “[We are] more on the internet, more dependent on escaping through the internet, instead of escaping outwards into the world”. As Leda and Hermione point out, Covid-19 and the need for support has prompted some who did not previously use these platforms for community engagement to do so – as is demonstrated by the creation of Facebook support groups at the beginning of and during the pandemic as spaces for people to gather and foster a sense of connection and community. For instance, the Facebook group Disability Connections New Zealand was created in March 2020 when Aotearoa first went into lockdown. Once Aotearoa was out of higher alert level lockdown protocol in mid to late 2020 this group held a poll asking its members if they wanted the group to remain active. All members that responded indicated that they did, while also suggesting offline events as a chance to socialise more directly in person with one another. This demonstrates, as Martí et al. (2017:192) state, that social support is multidimensional: there are times in which, as human beings, we need more physically involved interaction and other times where online support and community are what we need (Attrill & Fullwood, 2016; Webb, et al., 2008; Martí et al., 2017). The balance of these mediums of support will differ for each person. By inferring from what my interview participants have said and the level of activity in the digital forums during periods in and out of lockdown, it becomes clear that during lockdowns – which are necessary periods of isolation – digital social support tend to increase (Webb et al., 2008:109). This increase can be in the form of engagement in groups or within private social circles and messages. Then once people were out of a lockdown situation they returned to more offline social engagement. As shown with the Facebook poll, people were wanting to see one another, to connect and re-connect in a physical sense, having been deprived

of it against their will for an extended period. This is because a majority of people require a balanced ratio of physical to online contact to have optimal wellbeing and mental health outcomes (Long, 2020:249).

These online groups are often informational as well as supportive social spaces (Thelwall & Levitt, 2020:2) – another instance of the duality that they offer. As I discussed in earlier chapters, online groups are spaces where people can feel validated through a commonality of experience. They also provide opportunities for discussion that involve giving and receiving advice (Attrill & Fullwood, 2016:115). This dual use of online groups for social support and information-seeking demonstrate how these digital and online platforms can perform as what Long (2020:250) calls “vital technologies of care”. These technologies of care possess the capacity to sustain relationships and wellbeing, something not just limited to the pandemic, disability, or mental illness. These technologies can offer advice on vast topics such as: relationships, fashion, makeup, and so on. Online there are spaces for giving and receiving advice on anything and everything, even if that is not the primary focus of a group (Muir, 2020). Interview respondent Rea, a 24-year-old Pākehā woman, states:

I think that if you are having issues, then it can be very helpful to know that you are not alone and that there are people who support you, even if they’re strangers.

These spaces are a means of finding support, compassion, and commonality, again invoking Long’s notion of technologies of care. While there is still division within these spaces and beyond in the form of blaming, xenophobic, racist, sexist, and homophobic remarks, and many more, every country *is* suffering from the impacts of Covid-19 – even if unequally. Aotearoa’s Prime Minister Jacinda Ardern calls for *unity* against Covid-19, using the phrase “team of 5 million” as a rallying call when discussing lockdowns and working towards stamping out community spread of Covid-19 (Long et al., 2020; Spoonley et al., 2020; Trnka et al., 2021).

Despite these calls for teamwork and unity, the ways in which marginalised communities are overlooked have been exacerbated during the Covid-19 crisis. An example is the targeted vaccination campaigns towards Māori, Pasifika, and disabled “at-risk” communities that were necessary because vaccination processes were not made accessible to them during the initial vaccination process (RNZ News, 2021; Scotcher, 2021; Whitehead et al., 2021). With the introduction of vaccination passes, those most at risk and unable to get the vaccine were also further isolated and discriminated against because of the failure of ableist systems to consider them. While “temporary medical exemption” vaccine passes were available that do not disclose exemption status, the criteria to access these was highly stringent and exclude many people who may not be able to get or may not feel safe getting the vaccine while in altered health, such as pregnant individuals, those that have severe adverse reactions to vaccines, and disabled individuals who do not have “adequate resources to support safe delivery” (Ministry of Health NZ, 2022). This process infantilised these individuals; because they were viewed as society’s “most vulnerable”, the risks to their health through having the vaccine was ignored. It is particularly interesting that pregnant individuals were not included in temporary medical exemptions. I have a friend who received her first vaccination and was set to get her second when she found out she was pregnant. Not wanting to risk the health of her child, as she is a high-risk pregnancy due to her disabilities, she decided to wait until her baby was born to get her remaining vaccinations. This policy does not account for individuals, like my friend, who have pre-existing conditions that cause adverse reactions to vaccines and temporary altered health due to other factors such as a high-risk pregnancy. Once again, through trying to protect our “most vulnerable” they are excluded from the decision-making process, their voices ignored, and placing them at greater risk.

As I mentioned above, there are still hateful and toxic environments online. Both Cyra and Hermione explain that “social media reflects society structures”, and Buckingham

(2007:ix) also states that digital media takes the forms it does because of these existing social and cultural structures. Social structures are reproduced in online spaces in the form of social standing and social hierarchy (Shore, 2017). This means that those lower in the hierarchy, such as being women or disabled, face worse health outcomes due to various socioeconomic factors. This is exemplified in the male-to-female and other ratios in online forums as well as among my interview respondents. To this end I also point out that one of the men is Pilipino and the other suffers from severe mental illness, two things which place Alexios and Demas – and men generally with less social capital – lower on the social hierarchy.

For instance, there are Aotearoa-specific groups on Facebook that centre on mental health complaints, but even in groups that do not, complaints are often an integral part of discussion. People are going into these spaces seeking advice on what doctors they can go to that will actually listen to them and on what to do when they feel like their care has not been adequate – as is the experience of many of my respondents, but particularly Crya, Hera, and Nasia, and disabled individuals in my online observation groups – and to complain about the treatment of disabled individuals in the media not getting the same attention as “pretty white ones”, as one user writes in reference to a Stuff article titled “Where’s the social media outrage and march for Lena Zhang Harrap?”, a disabled Asian woman murdered in Aotearoa in August 2021.

Covid-19 further exposed the social structures that set to prioritise some citizens over others in myriad ways. Firstly, there has always been a need for remote learning and working, particularly for the disabled community. This is something disabled individuals have been asking for years, only to be told that the infrastructure was not available for this to happen. However, once a global pandemic hit and abled-bodied individuals required these services, great pains were made to shift all operations online (Campoamor, 2020). As Danni, a respondent quoted by Campoamor (2020) in their article, states in reference to remote learning,

“the fact that it suddenly becomes possible when it wasn’t before is disheartening. This simply proves that the barriers to an inclusive education [and workspaces] are not insurmountable problems that cannot be overcome.” These comments reflect the opinions of scholars and disability rights activists that attended the three-day hybrid disability conference held in July 2021 in Auckland. Of note is Aspen Lillywhite’s presentation, “Knowledge production of disabled undergraduate students: Perspectives of disabled students”, which demonstrated that the students in her study made the same observations. This example highlights the systemic exclusion of disabled individuals and others who needed to engage remotely with educational institutions, employment opportunities, and active participation in society before the pandemic forced everyone to adopt these practices.

Furthermore, disabled individuals have been significantly disadvantaged due to the lack of access to care, particularly during the Delta outbreak that began on August 18, 2021. While access to care seems to have always been a point of contention within disabled communities, the Delta lockdown saw an increase in disabled individuals suffering. They were unable to seek adequate care, unable to go to specialist appointments or even the dentist, for eight weeks and counting, as was disability activist Huhana Hickey’s experience, leading to a decline in health because of a detriment of care. I myself was unable to see a specialist for progressive carpal tunnel during this time. This meant I was unable to get the support and aids required to prevent permanent damage and rapid decline from this condition. This was a familiar tale for many with chronic conditions: the aids required for management were not available during the lockdowns. Furthermore, once lockdown restrictions were eased and disabled individuals were able to receive medical treatment, a backlog had developed, which created an additional several-month waiting period for care; causing further health decline.

Further inequities that were exacerbated by Covid-19 and lockdown were the inequalities of access to digital technologies and online capacities, shining a light on the

“digital divide” that exists within Aotearoa communities (Attrill & Fullwood, 2016:227; Kenny, 2021). The lockdown revealed socio-economic disparities between students and employees who were now having to work and study from home when they would have usually been able to use on-campus and work resources. As shown above, this is another instance of where lockdown further disadvantages already disadvantaged individuals and communities because of pre-existing systemic issues creating a state of inequality (Beeby, 2020; Harris, 2020; Kenny, 2021) – something that is particularly relevant for Māori, Pasifika, low socio-economic groups, and individuals in public or rural housing (Beeby, 2020). Workplaces, the government, and learning institutions provided disadvantaged individuals with equipment to ensure they could engage within this new landscape. However, this is only a temporary measure that does not get to the root of the issue or begin to explore how we can use these experiences to tackle these systemic issues and the inequities that many of our citizens face not just in lockdown situations but every day.

Detrimental online behaviours

While social media can provide connection and an escape from the loneliness and social isolation of a pandemic, behaviours in engaging with it are sometimes harmful. Doomscrolling, fake news, cyberbullying, and troll activity are the primary factors cited by interview participants and in the observational research of the potentially detrimental effects of social media and digital technologies on mental wellbeing. Doomscrolling, also known as doomsurfing or tragedy porn, is not a new term specific to the Covid-19 pandemic. However, the number of people and frequency of engagement in doomscrolling behaviours has significantly increased during Covid-19 as people find themselves scrolling through bad news continuously without the ability to stop or step back (Merriam-Webster Dictionary, 2020; Savić, 2021). An explanation for this inability to stop scrolling is that it triggers the brain’s

amygdala and danger response (Chaffin, 2021:26). Chaffin explains that when there is perceived danger our attention is drawn towards it, consuming as much information as we can get in order to respond accordingly, thus creating the obsessive behaviours of doomscrolling (Chaffin, 2021:26–27). Although the term doomscrolling first emerged on Twitter in October 2018, the phenomenon is as old as the internet or even the dawn of news reporting (Jennings, 2020; Klein, 2021). The difference between digital and analogue doomscrolling is that with a newspaper you are limited to the reports within the physical artefact, whereas with the internet you can keep going on and on and on by endlessly scrolling through curated content presented by algorithms: it is addictive, and it is dangerous to one’s mental wellbeing. Doomscrolling is stated to be akin to ogling a car accident: it is simultaneously horrifying and mesmerising, and the viewer finds it irresistible (Klein, 2021). The negative nature of doomscrolling has been linked to increased levels of depression and anxiety. Instances of fake news – the knowing or unknowing spreading of misinformation on a mass scale by prominent figures – encountered in doomscrolling causes further harm (Carrion-Alvarez & Tijerina-Salina, 2020:290). Fake news and doomscrolling are a dangerous combination because while doomscrolling in theory is a behaviour meant to “soothe” our fears and put our minds at ease in a search for answers, endless consumption of content, particularly fake content and the need to constantly fact-check content, makes the world appear very bleak (Klein, 2021).

However, I do not believe that this is the only explanation as to why people engage in doomscrolling behaviours. Hermaphroditus describes the behaviour of doomscrolling and talks about the inability in lockdown to do anything but go on the internet to escape the four walls within which you are confined. Constantly doing so means that there will be consumption of negative content over and over again, contributing to a decline in mental wellbeing. But even though these behaviours continually expose people to negative world news, it remains one of their primary forms of escape. People will thus repeat this behaviour despite the negative

impacts it can have on their mental wellbeing. From my interviews I surmise that there is a sense of numbness when doomscrolling which enables the behaviour to continue even when it becomes harmful (Chaffin, 2021; Markham, 2020). The media is “punching people in the face”, and people are being so overwhelmed by tragedy and fear that they become numb to the suffering of others (Chaffin, 2021:168; also see Markham, 2020:914) and unable to offer themselves respite from the emotional toll that consuming this content creates. Alternatively, there has been a significant decline in users’ regular online engagement because of the influx of negative content and messages and correspondingly greater demand on emotional/mental bandwidth.

This lack of mental capacity for online engagement provokes an interesting examination of activism and *the activist*. There seems to be a social narrative that activism is the product of a linear process leading to people achieving “enlightenment” to look beyond their own situations and become politically active, transforming them into *an activist*. However, in learning of the experiences of Nasia, Hera, Phaedra, Sofia, Alexios, Hermione, and Cyra I discovered that this may not be the case. The purpose of engagement in online communities is different for everyone and does not necessarily develop into activist participation, nor does it need to. Similarly, those who do engage in activism do not always remain activists. Instead of a linear chronological shift from first engagement in online communities to activist, I suggest that it is rather a fluctuating spectrum that is both contextual and situational. For instance, my respondent Nasia outlined that over 2020 and 2021 her engagement in online communities, let alone in activism, significantly declined because:

I’m knackered all the time, [...] I’ve had a few other health issues go on, so it [engaging online] has been really difficult [...]. I had to take a step back. It [activism and community engagement] was just getting too much for me. I think you’ve gotta really put in your boundaries and really practice self-care when it comes to it [activism].

Nasia's position as activist has shifted: situationally, she no longer possesses the capacity to engage in community or activism because all of her limited energy is being placed into self-care. This will likely change in the future once her health is in a more manageable state and she has the reserve mental and emotional capacities to resume community and activist engagement. What it means to become an activist is contextual and determined by the individual. To some activism involves grand protests, digital petitions, being publicly outspoken, and to others it is as simple as advocating for themselves, their care, and how they should be treated. Hermione and Cyra engage in community groups to create a better understanding of their conditions through the knowledge and experiences of their peers, knowledge they use to talk to their doctors and in their self-care. This to them is activism because they are advocating for themselves. What this shows is that there is no one way to be *the activist* and it is not a continuous and linear process; it is both contextual and situational based on an individual's needs and capacities.

Furthermore, my participants noted that negativity that exists within communities can drain one's willingness to participate beyond focusing on their own care and wellbeing. Hera explains that many become discouraged by the negativity and hierarchy that exist within and outside of these groups,

I'd say there's a lot of differences between the younger and the older generations of disabled and disability advocacy. I think that having an invisible disability can make it harder for people to actually listen. Because they see you and they think you look fine, therefore you must not be a valid disabled voice. Within the disability community there can be a bit of oh, but I'm worse off than you, so my voice should be projected above yours. And I think that people with invisible disabilities are often seen as better off. And so [in] the disability community, some people, not everyone obviously, tr[y] to institutionalise this hierarchy of voices. [...] I think [this behaviour] can be quite disheartening. And I think that

there is a generation of advocates and potential advocates who see that and who decide that it's not worth the trouble and the stress.

This behaviour saw a decline in mental health and a decrease in active participation online, but due to the pandemic an increase in passive time spent online. This has caused a rise in negativity and cyberbullying during lockdowns compared to before Covid-19 (Barlett et al., 2021). Cyberbullying is defined as “repeated harm delivered through electronic means” (Barlett et al., 2021:408). Trolling, an aspect of cyberbullying, is defined as the deliberate, deceptive, and mischievous attempt to provoke reactions (Golf-Papez & Veer 2017). As shown above, façades of perfection cultivate toxic environments of criticism and bullying. Moreover, cyberbullying, like in-person bullying, also seems to be centred on difference. If someone is different, the difference is picked at, for example the bullying of the openly queer individuals in Cyra’s ADHD group. The group was not accepting of this element of these individuals’ identity. People often bully others because they feel insecure, are having troubles, or for a sense of power or control (New Zealand Ministry of Education, n.d.; Nittle, 2021). As well as people spending more time online during the pandemic, the motives behind bullying behaviours may also explain their increase during the pandemic. For many the pandemic has caused economic insecurity, turmoil in home life, and a loss of control. For these same reasons, as well as due to the scope it can reach, cyberbullying has been extremely detrimental to people’s mental health. As tensions rise, as they did during the August 2021 lockdown, people engaged in acts of cyberbullying, perhaps without even realising it. Comment sections on social media sites got heated, particularly regarding the duration of the lockdown and opinions on the government. Disabled and other high-risk groups were again thrown aside because people wanted their “freedoms” back, as evidenced by the post “#3762 Complacency is toxic” from the Facebook page “UoA: meaningful confessions”:

I know there are vulnerable people out there that are scared of this virus and I am acting selfish because I am young and healthy but let's be honest, the 99% of the population can't lock themselves out for the 1%.

This demonstrates that the pandemic has forced people to change how and where they engage with one another. The social responsibility to remain inside one's household bubble to protect the wider community against the threat and spread of Covid-19 was immense (Trnka et al., 2021). The restriction of movement and external face-to-face socialisation forced a migration to and intensification of digital engagement both in Aotearoa and globally. Evidence of this trend appears through the creation of groups specifically to cope and communicate during the period of the first Covid-19 lockdowns in Aotearoa, as well as a global shift to Zoom – a video conferencing software – in what has been termed “Zoomism” (Estévez, 2021:19). The immobility and seclusion of our bodies in lockdowns limits external socialisation to the projection of online avatars in digital spaces, redefining perceptions of the time and space of socialisation. These online spaces aided in bridging the gaps left in instances of social and physical distancing (Usher et al., 2020).

The need for these modes of engagement were nothing new to long-distance friends, partners, and family members (Dainton & Aylor, 2002; Sahlstein, 2004). But the knowledge that they no longer had the agency and freedom to travel and be together was a new and frightening sensation, as observed online and within my own family trying to get to Australia from Aotearoa and move within Australia to say goodbye to my dying aunt during 2020. Covid-19 and the subsequent inability to move around due to border closures and household bubble measures created an atmosphere of severe physical separation, such as in cases of long-distance relations, despite the actual distance between friends and family being no more than usual.

This new atmosphere forced a heightened presence online and a greater use of digital technologies for people and situations accustomed to in-person engagement. Heightened digital engagement and the sense of connection it fostered between people, enabling them to remain

ethical and responsible citizens fulfilling their moral obligation to comply with lockdown restrictions; thus also developing a new sense of social cohesion between citizens (Long, 2020; Long et al., 2020; Hulse & Stone, 2007; Spoonley et al., 2020; Trnka & Trundle, 2017; Trnka et al., 2021; Shore, 2017). Society migrating online proved positive for the disabled community. Online environments allowed them – particularly those with mobility and social impairments – to form connections and communities (Attrill & Fullwood, 2016:6) that are useful, particularly in times of crisis as well as participate in areas of society which in ‘normal’ circumstances exclude them.

Pseudo-nationalism and civic duty in Covid-19

In Aotearoa, nationalist discourse was a vital instrument in the government’s Covid-19 response during the 2020 and 2021 lockdown measures. New Zealanders were told to “follow the rules” to protect one another from the threat of Covid-19. This led to instances of self-surveillance, but also an increase in the policing of others’ behaviours through moral surveillance (Setel et al., 2020; Manokha, 2018) – something that was at times encouraged by the prime minister (PM) and other government figures. In examining the success of nationalist discourse presented by the New Zealand government over the course of the Covid-19 pandemic in 2020 and 2021, changes in governmentality, responsabilisation, and social surveillance have emerged (Manokha, 2018; Muir, 2020; Setel et al., 2020; Trnka & Trundle, 2017).

Nationalism is ideology that centres around concerns for and promotion of the nation through imagined communities, invented traditions, and construction of the Other (Sturm et al., 2021:2020). Governmentality refers to the ways in which power is diffused and productive, “often guided by expert knowledges that seek to monitor, observe, measure, and normalize individuals and populations” (Clarke et al., 2003:165; see also Foucault, 1979, 1991; Foucault et al., 1988). Responsibilisation is the bridge between governmentality and modern social

surveillance; it is both a political project and mode of governing that sets the individual, rather than the state, to be responsible for their own care, as well as that of others (Trnka & Trundle, 2017:2). Social surveillance, particularly during Covid-19 restrictions, draws on the notion of responsible care of the self and others extending to moral care through monitoring and policing appropriate behaviours (Manokha, 2018; Muir, 2020; Setel et al., 2020). The fear of constant social monitoring produces (self-)policing of perceived “immoral” behaviours (Foucault, 2008; Manokha, 2018; Muir, 2020; RNZ News, 2021a; Roy, 2020; Setel et al., 2020). This social policing was encouraged by the government, framed as “vigilance”, in which the PM urges everyone to “call out” people who are not following the rules – that is, committing unethical behaviours – by saying, “Do it with kindness, but do it” (RNZ News, 2021a). However, while the PM called for kindness, compliance was often accomplished through bullying, social humiliation, and collective punishment (cf. Muir, 2020; Leask, 2020).

Community policing occurred in several ways during the 2020 level 4 and 3 lockdowns. The first mode of this policing is in-person verbal abuse. In one such example, a woman out for a walk during level 4 with her husband and three sons – all a household bubble – recorded a man yelling at them saying, “You need to stay in your bubble! You’re putting everyone at risk” (Leask, 2020). In this example the “name and shame” technique was used on individuals perceived to be breaking the rules and giving those “complying” the feeling that they *can* be aggressive in their policing of these individuals. Similarly, in attempts to make fellow citizens “toe the line”, community Facebook groups saw a dramatic increase in abuse and threats during the 2020 level 4 lockdowns aimed at cowing people into submission (Roy, 2020). These forms of policing, while not kind and therefore not endorsed by the government, are still accepted by it. In early 2021, when there were breaches in the managed isolation facilities, this statement was released by the PM: “[N]o one is accepting that these breaches are okay. They were not. Clearly, everyone is paying the price” (RNZ News, 2021a). While the PM’s statement is not

as harsh as the man screaming at a young family or Facebook users hurling abuse and threats, it is still a strong statement from the government. This governmental stance, like that of these community members, attempts to shame people into following the “rules” by invoking the idea that in not doing so they are harming the collective good of the nation (Leask, 2020). It is in the court of public opinion that these individuals are judged and their moral value as citizens is determined.

The reports of lockdown infractions became so numerous that the government created a website dedicated to these reports, which crashed several times due to the quantity being filed – most not actually turning out to be lockdown infractions. The implications of these ideologies raises questions about what and who is a moral citizen. Ethical citizens in these circumstances are those who abide by the mandates for physical distancing, shelter in place, and stay within their bubble –those who follow the rules for the good of the collective (Strong et al., 2021). A moral citizen in these circumstances then becomes one who monitors and polices themselves and others in order to protect the collective – enacting ethical proximities (Strong et al., 2021:346).

Yet, despite these social vectors of control, some flaunt the rules without fear of consequences. There has been anti-lockdown protesting in Auckland both in 2020 and 2021, as well as numerous people refusing to wear masks or maintain proper physical distance while out in public during lockdowns. The August 2021 lockdown saw the supermarket chain Countdown release a series of statements invoking self-surveillance and surveillance of others for the good of the collective as the primary mode of compliance. One statement said:

[W]e are hoping people comply [with mask-wearing policies] and we are going to make it as easy as we can [...]. It is not our job to enforce it. If customers become aggressive and refuse to wear a mask, the advice from the NZ Police is that our supermarket team members should not enforce this as it is simply too dangerous. (*New Zealand Herald*, 2021)

The statement goes on to say that Countdown is providing masks for those who forget their own. Yet people are still observed shopping without masks. Reddit users agree that everyone should be wearing masks, but they also agree that it is not the responsibility of Countdown employees to police this and possibly put themselves in danger. Official exemptions for mask-wearing in public settings are available for a range of health conditions, including mental health conditions such as anxiety and PTSD. There were numerous news reports of people with such exemptions being harassed or barred entry, sometimes multiple times. These actions are compounded by confusion created by government officials, with both Ardern and director-general of health Ashley Bloomfield publicly stating that disabled individuals who do not need to wear masks must carry documentation of their exemption, while at the same time the Ministry of Business, Innovation and Employment (MBIE), which oversees exemptions, clearly stated on their website that this is not necessary (Henry, 2021); “Wearing a face covering may be unsuitable for some people due to a disability or health condition, so they are not required to wear one. These people can get an exemption card but are not required to carry it or show it” (Ministry of Business, Innovation and Employment, 2021). Heated disputes and increased social division have occurred through those intent upon “doing it right” by the “team of five million” attempting to enforce mask wearing even when someone has a government-granted waiver (Pearse, 2021). These feelings of division created through the enforcement of social morality and responsibility indiscriminately were seen during the First World War with the Order of the White Feather – a group of women who handed out white feathers to men as a mark of their cowardice for not going to war, despite many of these men being exempt (Imperial War Museums, n.d.).

While New Zealanders have always expressed a sense of nationalism in sporting endeavours, we are still a largely individualist society in terms of government (state) responsibility and personal responsibility, something that fluctuates depending on the

governing political party (Ashton & Tenbenschel, 2010; Berg & Roche, 1997; Manokha, 2018; Setel et al., 2020; Shulruf et al., 2011; Skilling, 2010). Sturm et al. (2021: 2020–22) propose the term “pseudo-nationalism” to understand the invocation of the imagined community and idealised citizens that nationalism presents. Pseudo-nationalism encompasses the moments, such as sporting endeavours, where collective messaging about “us the nation” versus an outside force is prevalent, but tends to disappear in instances of communal responsibility of care (Ashton & Tenbenschel, 2010; Berg & Roche, 1997; Setel et al., 2020; Sturm et al., 2021; Yong & Martin, 2016). These forms of pseudo-nationalism also became apparent during Covid-19. In the first lockdown in March 2020, there seemed to be a shift into the mindset of pseudo-nationalism that is usually reserved for sporting and world events. The narrative of nationhood perpetuated through government messaging emphasised the collectivism of ‘us’ (Aotearoa as a nation) against Covid-19. This language invokes notions of defence and civic duty. By employing the collective *we*, the PM positioned combatting Covid-19 as not an individual fight but a collective one in which no one would be left behind, demonstrated by the use of “team of five million” (Chen et al., 2020; Pillay, 2021). The PM’s daily updates when in lockdown and her personal live Facebook posts exemplify Rothenbuhler & Coman’s (2005:290–91) assertion that:

If we want people to sense connectedness, to participate in community, to care about the world, and to assume some responsibility, then someone needs to help empower citizens with the ability to respond. That means making accessible the information and insights people need to participate.

The PM fostered this sense of connectedness in her references to Aotearoa citizens as the “team of five million” during periods of lockdown. With each resurgence of Covid-19 in the community the collective is reminded of what *we* have achieved and what *we* can achieve again. When there was a resurgence of Covid-19 in the Auckland community in 2020, this is the message the PM conveyed: “Together we have got rid of Covid before. We have been

world-leading in our Covid response. We can do all of that again. 1.4 million New Zealanders are carrying the load for our team of 5 million right now” (RNZ News, 2020). This collective responsibility, despite geographic separation (particularly between the North and South Island), was invoked again in 2021 with the emergence of the Delta variant in the community. At the press conference announcing the level 4 lockdown on August 18, 2021 (after six months of free movement), Dr. Bloomfield said, “It requires us all to be part of the response. Hard work across the country will help us get on top of this outbreak” (McClure, 2021). Government officials, in their language and messaging, convey that it is our duty to do everything we can (staying home) to protect the community from further spread, but also from death. A common slogan used by the government to enforce this point was, “Stay home, save lives” (McClure, 2021; RNZ News, 2020).

However, despite the government’s best attempts and seeming success in cultivating a sense of the collective during the 2020 lockdowns and even the early 2021 lockdown, by the time the August 18, 2021, lockdown restrictions came into effect these previous feelings of unity seemed to be forgotten, particularly when the lockdown restrictions dragged on for months. This fracturing is particularly concerning for those most at risk – such as my research participants – because the majority no longer cares enough to maintain the restrictions, enforcing the pseudo-sense of care felt by the disability communality because of the disconnect between “protecting our most vulnerable” and the ableism of “returning to normal”. These instances of ableism and ableist structures became extremely overt during the pandemic.

Disability experience in Covid-19

Covid-19 demonstrated that the inadequacy of facilities and services in normal circumstances, such as those for disabilities and mental illness, can be deadly during a crisis (cf. Kent & Ellis, 2015:423). Those with disabilities have always been disproportionately represented as

casualties in times of disaster or crisis because of these inadequacies (Fjord & Manderson, 2009; Kent & Ellis, 2015:426; Malpass et al., 2019), and Covid-19 has proven to be no exception, as medical services elsewhere have been overwhelmed, resulting in hospitals turning people away, essentially choosing who is and who is not worthy of care, and possibly of life. While, at the time of writing, Aotearoa has not had to face these decisions, disability advocates and medical professionals have expressed great concern and anxiety regarding the fate of disabled individuals if our medical services were to become overrun, invoking concerns similar to those cited against the euthanasia bill (Bateman & Bracewell-Worrall, 2019; Hayden, 2020; Martin, 2020; Hickey, 2020). Decisions about disabled citizens' 'worth' is a significant concern for disability advocates. As explored in earlier chapters, the social narrative is that disabled citizens are financial burdens on society and are not 'good productive citizens' (Yellowhorse, 2021). These violently ableist value politics are of particular concern in times of scarce resources when disabled individuals may be denied treatment because their lives are assigned less value than those of the able-bodied (Kent & Ellis, 2015:426; Thelwall & Levitt, 2020:3; Yellowhorse, 2021).

Countless examples around the world demonstrate the moral and ethical dilemmas Aotearoa would have faced, and the likely outcomes, had Covid-19 overrun our medical services. While disabled individuals may not necessarily be at higher risk of contracting Covid-19, they are more at risk of suffering from neglect if they do contract it (Sabatello et al., 2020:1523–25). For instance, in Italy, there was a 'rationing of care' from the outset of the outbreak which discriminated against those with greater health needs – the disabled and elderly (Ne'eman, 2020). These measures which devalue the lives of disabled citizens saw a surge in other countries, such as the USA, when Covid-19 overran the medical system, as is shown by the death of Michael Hickson (Cha, 2020). Hickson, a quadriplegic black man from Texas who contracted Covid-19, was denied lifesaving treatments because it was determined by medical

staff that he would not have “quality of life” and that it was “not worth” wasting resources on him (Cha, 2020). This is why disabled activism and voice is crucial: without it we would be sacrificed and there would be no contemplation about what Aotearoa considers “normal”.

Disability and Covid-19

Navigating public spaces, the social Othering, and accessing sufficient medical care has always been a significant challenge for disabled people in Aotearoa. Entire fields of study have been dedicated to understanding disabled individuals’ movements and the constraints on these movements in public spaces (Gleeson, 1999; Morrison et al., 2020; Smith et al., 2021). Disabled individuals’ “embodied belonging” has always been limited in public (ableist) spaces because of how these spaces are designed and used, with many seeing their own bodies as not belonging or “out of place” (Morrison et al., 2020; Smith et al., 2021:8). While there are legislation and rules for infrastructure to be mobility inclusive, these are rarely fulfilled to the standard and functionality that a disabled person would need, such as the provision of Braille and sound indicators for those with vision impairments, alternatives to steps and stairs for those with mobility aids, and so on. Given that public spaces during ‘normal’ conditions are exclusionary and often inaccessible to disabled individuals, what have the effects of pandemic-related restrictions on movement, contact, and accessibility to public spaces meant for disabled New Zealanders?

I have found several significant barriers encountered by disabled New Zealanders during the Covid-19 lockdowns. First, as described above, is the policing of entry to public spaces and negative assumptions made about those who cannot wear masks. Second is the use of public transport, a significant issue for wheelchair users and those requiring buses that can “kneel” (Hickman, 2021; Jacobson, 2021). To protect drivers Auckland Transport (AT) mandated that passengers must enter and exit through the rear door, saying that exemptions

would be granted for those requiring the kneeling function and wheelchair access (Jacobson, 2021). This, unfortunately, was not the experience of many mobility-impaired individuals, who were often meet with hostility by drivers, with some even refusing to stop if they saw a patron in a wheelchair waiting at a bus stop (Jacobson, 2021). Members of the Facebook group Disability Connections also commented on the cordoning off of disabled parking to make room for social distancing lines without providing new spaces for disabled patrons to park. These are just two examples of how those with disabilities have been barred from public space through seemingly insignificant changes. Lockdowns have highlighted the areas in which disability access to space and the embodied belonging of disabled individuals is lacking in our public spaces.

The pandemic presented the world with the unique opportunity to temporarily experience life from the perspective of many people with disabilities, forcing able-bodied individuals to change how they live in/use public space and to inhabit something like the “embodied belonging” of disabled individuals; from having to work from home, having a designated person to go to the shops, and having their ability to move around in space limited. As demonstrated above, those who were perceived to not be following the lockdown restrictions were socially Othered, something those with disabilities, particularly those that are young or have invisible disabilities, face daily. With restrictions to medical care able-bodied individuals further faced the frustrations and trials many with disabilities face in ‘normal’ conditions when trying access medical care. The pandemic *has* forced able-bodied individuals to experience how limiting ‘normal’ is for those with disabilities. It is my hope that these experiences will lead to greater allyship, giving more credence to disabled voices and experiences and leading to tangible revisions and drastic social change of what is considered ‘normal’.

Mental health and Covid-19

“[A] silent pandemic of psychological distress” is how Thomas (2020) describes the current state of youths’ mental health in Aotearoa. This was already cause for concern before Covid-19, with one in five people aged 15 years and older experiencing medium- to high-level mental distress. These levels are climbing quickly: in 2011, 5 percent of those 15–24 experienced high mental distress, rising to 15 percent in 2019 (Te Hiringa Hauora, Health Promotion Agency, 2020). It is likely that the level of high mental distress significantly increased during 2020 and 2021 as the effects of the pandemic were felt (Thomas, 2020), as suggested by recent data from France and Italy showing instances of depression and anxiety at double the normal levels (Cohen, 2021). Covid-19 was termed an “acute chronic crisis” with physical manifestations of declining mental health, with those already afflicted by mental illness being severely impacted (Power et al., 2020).

Hermione claims that this acute crisis has caused a shift in the social perspectives of mental health and mental illness. From the discussions online, the topics of articles being published, and even comments at the Covid-19 press conferences, Aotearoa is more acutely aware of how our overall wellbeing, specifically our mental health, has been harmed or, in many cases, further harmed by the pandemic. For instance, Leda explains that she mentally struggled trying to do her studies online, but it was

once things started opening up again, I think it was around September, October when we were just coming out of that level three again and I was going back to uni and all that. Yeah, that’s when it [anxiety] started getting quite bad and I had to go to the doctor, so... yeah. I guess it would be, I guess it would be connected to Covid, but I also think it was a long time coming.

There was also a consensus among my interviewees that the pandemic, through worsening many disabled individuals’ physical health, also worsened their mental health because the two are related. As Hera put it, “when you’re not feeling right mentally, you don’t end up feeling

right physically. And when you don't feel right physically, you don't feel right mentally.” – another example of the holistic way of understanding the interrelatedness of hauora for Māori and the importance of reintegrating this approach into social thinking as the effects of physical isolation that many people endured during the pandemic exacerbating pre-existing mental illnesses and cause mental health decline.

New Zealanders seem to hide behind humour in order to discuss hard topics, and mental health is no exception to this, especially among young people. The use of memes is the most popular online medium for discussing the mental strains the pandemic. Memes are an important aspect of digital dialects and information diffusion, because they are always culturally relevant and transformative (Danesi, 2019; Davison, 2012; Shifman, 2014). Memes *must* be suited to the sociocultural environment in order to “spread” successfully (Shifman, 2014:9). Shifman (2014:14–15) defines internet memes as “(post)modern folklore, in which shared norms and values are constructed through cultural artifacts such as Photoshopped images or urban legends” (also see Suchman, 1994:183). Internet memes are denoted by rapid transmission and uptake, where they are unique in that they can capture “memeable” reactions and snapshots of society and culture in the form of transmittable imagery and language, creating relatable and editable content. This content becomes folklore due to the way it is remembered and transmitted within and between communities (Danesi, 2019; Davison, 2012; Shifman, 2014:13). Political and social commentary memes are a prominent example of this phenomenon (Danesi, 2019:7, 15, 39, 40; Davison, 2012:131; Shifman, 2014:15, 33, 119–50). Memes, through their nature, have a hypermemetic logic, assuming a further meaning than that from the culture the meme first appears in. Memes have a multidimensional presence, leaving them open to interpretation and to encoding and decoding according to the needs of the individual “reading” them, expressing both a uniqueness and a connectivity among people (Shifman, 2014:26, 31). “Memes have always played an important role as venues for

expressing opinions and subverting established order” (Shifman, 2014:149); they function as a conduit to persuade and provide political advocacy through grassroots action, and to facilitate public expression and discussion – highlighting power dynamics and empowering citizens’ engagement in collective action (Shifman, 2014:128–29; Thomas & Wareing, 1999:10). In this sense, memes and online spaces are cultivating critical arenas for discourse and policy-generated forms of resistance. This is why they are extremely popular as mediums to discuss socially difficult topics, such as mental health, illness, and disability.

Memes are also a conduit for humour, a positive coping strategy for stress and as a mode to relieve boredom (Akram et al., 2021; Nepul Raj & Jayaprakash, 2021; Plester, 2009). This is evident in the countless groups dedicated to memes targeted at mental wellbeing; for instance, the Facebook groups Memes Are Cheaper Than Therapy and Therapy Memes. Memes offer a safe space to discuss issues of mental health, illness, and wellbeing because they frame these through a humorous relatability. Humour and laughter are also common trauma responses that offer a sense of dissociation and separation from traumatic events, allowing individuals to “cope” with them in less confronting and triggering ways (Spearman, 2021). Covid-19 has created a phenomenon of cultural trauma (shared trauma that is attached to a group of people) that anyone who has experienced it can relate to in some way; this has caused an explosion of Covid-19-related memes to be passed around groups that would normally not feature memes or mental health content, such as disability-based groups, because the experiences attached to the pandemic are relatable to those in these groups. Because these memes offer relatable experience and humour as a safety net, as Leda and Athina state, they normalise discussions of more serious content (Akram et al., 2021; Nepul Raj & Jayaprakash, 2021). Leda comments that this normalisation has the potential of glorifying harmful behaviours through the idea that “other people[s] experience this, so it is okay”, rather than promoting healthy and productive means of processing. While affirming behaviours have the

potential to become toxic, they also aid in bridging the social gaps created through isolating at home and in increasing wellbeing while simultaneously normalising discussions of mental health and alleviating boredom (Kumar & Nayar, 2021; Moore & March, 2020; Pillay, 2021; Usher et al., 2020; Zaffar, 2021). These behaviours also provide a cathartic outlet and socialisation for the boredom Hermaphroditus and Melissa discuss having experienced from being in lockdown. With the vast dispersal and consumption of mental health memes I hope that the world in general, but Aotearoa specifically, places more importance on youth mental health and the maintenance of mental health. However, given the public and political agitation that emerged with the continued restrictions and regulations the further marginalisation of the already marginalised, among who we can number those with disabilities and mental illnesses, is inevitable.

People or profit: What matters more?

As explored previously, financial pressures are a common cause of decreased mental health and manifestation of mental illness, with “widespread adverse mental health and substance use outcomes [...] likely to occur, both directly from the pandemic and indirectly from the related economic downturn” (Vigo et al., 2020:681). Systematic social barriers persist in neoliberal capitalist societies, perpetuating financial barriers which worsen in times of crisis, as is exemplified by the differential care given based on bodily status. Lockdowns have hit the global economy hard, leaving many without jobs and increased financial anxieties (Baloran, 2020; Cullen et al., 2020; Pettinicchio et al., 2021; Vigo et al., 2020). In Aotearoa a wage subsidy was offered first from March 27 to June 9, 2020 (Work and Income, n.d.a), then again from August 18 to December 9, 2021 (Work and Income, n.d.b) to businesses experiencing a 40 percent or more loss of revenue during the level 4 and 3 lockdowns (Unite against COVID-19, 2021). The aim of this government-funded scheme was to keep businesses running and

people in jobs during the lockdowns, while also ensuring compliance with public health measures. Compliance protects everyone from the spread of Covid-19 while avoiding overt Othering of “at-risk” citizens.

Despite these economic packages the government has seen a lot of criticism from the Opposition (the National Party). While the National Party has never expressly stated that at-risk lives are worth less than businesses, their rhetoric criticising the government’s handling of the pandemic implies this (Graham-McLay, 2020; Manch, 2021; 1News [Breakfast], 2021). Simon Bridges, the Leader of the Opposition in 2020, stated, “I now worry that the harm of staying in lockdown will be greater than if we were to come out” (Graham-McLay, 2020). This statement in effect is saying that the economic cost of lockdown is more important than the human cost. Similarly, in September 2021 Judith Collins, who replaced Bridges as Leader of the Opposition, described National’s Covid-19 response plan, which included opening national borders at 80–85 percent vaccination rates with public health measures (Covid tracing app, mask mandates, sanitisation and so on). When asked if the figures projected by the Shaun Hendy model (referenced throughout the plan) of 4,300 deaths and 36,000 hospitalisations per year were “acceptable”, Collins avoided the question, before stating, “Small businesses failing, people losing their jobs [...] that is more important” (1News [Breakfast], 2021). There are many more examples of the Opposition prioritising business and the economy over human life, suggesting that had they been in power at the time of the pandemic Aotearoa would likely have faced a similar response and death rates and rampant spread of Covid-19 in the community as other countries did, like the UK and USA (Tankersley et al., 2020; Vinopal, 2021).

Social isolation and loneliness were significant factors in declining mental wellbeing and mental illness during Covid-19, particularly during lockdown situations wherein people *must* remain physically isolated from one another (Kumar & Nayar, 2021; Moore & March, 2020; Pillay, 2021; Usher et al., 2020; Vigo et al., 2020). Themes of loneliness and increased

social anxiety when around people permeated my interviews. My interview participants discussed attempts to connect with others online, for their experiences to be validated, and to not feel so alone both before and during lockdown. Alexios outlines the importance of loneliness as a lockdown experience that caused feelings of depression, anxiety, and PTSD, to name a few: “Loneliness and missing each other [is] something I think a lot of people can relate to when recalling that time [lockdown].” It has been well documented that loneliness and physical separation has been a leading cause of suicides. Aotearoa’s rural communities, particularly farmers, are most at risk; indeed Adriani and Leda both said in their interviews that rural communities are far more at risk of mental illness and suicide partially due to their isolation from other people (Kumar & Nayar, 2021:1), something that was discussed in the Seven Sharp segment “A farmer teaches us isolation 101” when the hosts conducted interviews with farmers (Seven Sharp, 2021). Isolation from others is just one part of the equation, as Alexios states, and it was through forms of escapism such as online gaming, video calls, phone calls, and simply knowing he was not alone in the experience that he got through the lockdowns.

The constant barrage of death, suffering, and isolation the pandemic has caused has led to what psychologist Stanley Rachman termed “fear acquisition” wherein parental and media fear is being transmitted to youth, significantly informing their fears (Radanović et al., 2021:7); resulting in increases in social anxiety, desensitisation, and emotional “numbness” (Akram et al., 2021; Al-Balushi & Essa, 2020; Chaffin, 2021; Nearchou et al., 2020; Singh et al., 2020; Thompson et al., 2021). Covid-19 has worsened social anxieties, as Sofia discusses, because of the overload of continuous and increasingly sensationalised news cycles about risks of transmission and death, focusing particularly on the risk of young and healthy citizens infecting the old and vulnerable (Akram et al., 2021:2; Chaffin, 2021:27, 81; Nearchou et al., 2020; Thompson et al., 2021:2058).

Fear acquisition is a part of the shared Covid consciousness, imprinting Covid-anxiety behaviours such as avoiding contact with unvaccinated or single-dose-vaccinated individuals, avoiding crowded public spaces such as schools, and other modifications to daily lives and routines, creating the experience of long social Covid. These feelings of constant anxiety and fearfulness, intensified by doomscrolling, cultivate into compassion fatigue, a state of emotional and physical exhaustion (Chaffin, 2021:74). Compassion fatigue evolves into desensitisation and numbness when our expectations of care are not in alignment with the resources available for care, leading to disillusionment. This forces decisions about compassion capacities and where the most important and impactful change can occur (Chaffin, 2021:74–75, 78).

The mental fatigue caused by the implications of long social Covid leaves individuals vulnerable to exacerbated mental distress. For instance, Leda ruminates on the role Covid-19 played in her mental health and mental illness breakdowns. Upon reflection during our interview, she postulates that the trials and tribulations of Covid-19 tipped her over the edge, but that this breakdown was a long time coming.

Conclusion

The pandemic potentiated a social awakening to what it can be like to live in what is considered “normal” under disabling conditions. Certainly, it demonstrated the inequity of normal conditions and that the idea of returning to normal – a ableist system – needs to be discarded. Rather, we need to put our energies into advocating for our government and society to seize the opportunity the pandemic has given us to restructure our conceptions of normal. This would not be an instantaneous process, but it would be a worthwhile one. The lessons learnt about and empathy developed towards the realities of living with disabilities and mental illness cannot be allowed to be forgotten. These changes cannot be pioneered and enacted by disabled

and mental health activists alone; it is tiring and unsustainable, and effecting change will take a willingness and engagement from Aotearoa as a whole.

Digital engagement has been an important aspect of our lives for many years, but the pandemic sparked an evaluation of how, why, and when we use social media. The importance of online literacies, such as meme culture, in expressing and evaluating social experiences and emotions became undeniable as the effects of long social covid started to disseminate. The effects (physical, mental, economic, and social) of this pandemic will be felt for years and even decades to come, but we have the chance to institute positive and productive changes from these experiences. I hope our society will continue to move to being more open, knowledgeable, and accepting of mental illness, disability, and the things required to maintain mental wellbeing. There are so many lessons that can be taken away and applied: the possibilities are open. I only hope we rise to the occasion and keep these issues in the light rather than pushing them back down, as New Zealanders and society at large are known to do.

Conclusion

As this project was completed in conjunction with a Marsden research project on the topics of youth, mental health, and digital engagement, these focuses were selected from the get-go. But I discussed with my supervisor, Susanna Trnka, the need to bring something else in, another angle that would make the project mine. While I brainstormed a series of ideas, my first, and the one I kept returning to, was disability. But why? From the outset of this project that has been the question asked countless times: “Why disability? Why the combination of disability, mental health, youth, and digital technologies?” and “Why are they important?” These questions came out of the subconscious ableist socio-cultural norms, expectations, and assumptions that are prevalent within Aotearoa. These questions demonstrated an ignorance and indifference towards these issues. If someone is asking why you consider something important the inference is that they, in that moment, do not, and therefore it is vital to articulate its importance. This is how this question always came across to me. If my being disabled came up in these conversations it was usually met with “oh, that makes sense”, itself a form of dismissal that, by reducing my research to a matter of personal interests, reinforced the sense that it was not of great significance outside of myself. This reminded me of the old anthropology notions that only “women do women’s studies, queer people do queer studies” and so on. As I noted in the introduction, researchers *are* driven by our own interests, which themselves are inflected by embodied experiences and curiosities, but this does not make these issues any less socially significant. And while this was a significant motivation for me, it is insufficient to judge the value of my project solely on the grounds that I am disabled. Disability, youth, and mental health are vital social issues that deserve discussion regardless of who is raising them.

Despite being a part of the disabled community, I did not “know” anything going into this project because I was not an active member of these digital communities. I did not previously have the language I employ in this thesis to describe my embodied experiences; these are things I learned from the literature, my participants, and observations. Based on my personal experiences and my early preliminary readings, I developed hypotheses about what I might uncover. These hypotheses were driven by the notion that we exist in a society dominated by ableist assumptions that disable people through not consulting them or considering them in its design. This notion of ableism is what drove my research. I wanted to hear from the Othered – youth with impairments – about how they exist in a society that is not cultivated with them in mind, therefore forcing them to face “invisible” barriers. The more I uncovered about the treatment and experiences of youth with disabilities and mental illnesses, the more impassioned I became about the project. With each stone that I turned new questions arose. The shape of this project has been in constant revision. The power and politics that language holds are a critical aspect of this project; the language used by governments, in policy, by the communities, and by the rest of society all hold different intents and meanings even if they use the same word. These meanings that shift temporally and spatially were what drove my interest in the histories of disabled and mental health activism, two of Aotearoa’s hidden histories. Going into this project I knew I would be discussing Covid-19 and its impact because no matter how you look at it, Covid-19 has affected how everyone has engaged in digital space, mental health, and even the disabled experience for the last two years, and will likely have rippling effects on all of these for years to come.

This research represents a particular subset of disabled youth who engage in discussions of disability and mental health online. People in these groups tend to be community- and information-oriented individuals who are active participants in their own care, to the point of often being self-advocates. These self-selected individuals are also people who want to talk

about disability and/or mental health for an hour, to share their knowledge, thoughts, and concerns. This is not to say this research is not applicable in a general sense to the common experiences of youth with disabilities in Aotearoa. Self-advocacy, community engagement, and information sharing require a set of knowledges and practices that are particular to these communities and that have been developed because of the histories of neglect. These knowledges and practices open up questions about how society and its institutions enable these individuals to be active (responsible) agents in their care. Through participating in this research I would argue that these individuals have unlocked another stage of *the activist* through sharing their voices and experiences with me.

Voice, or more accurately voice poverty, were driving motivations for the topics investigated throughout this thesis. In the instance of Covid-19, disabled individuals were framed by society as the “vulnerable” in need of protection, but they were never spoken *with* about these protections and whether they were indeed being helped and protected. Assumptions of what they needed were made, and these often harmed these individuals in myriad ways, which they were talking and posting about. Official messaging about vaccinations was that we needed to protect our most vulnerable and that the vulnerable that could get vaccinated would be prioritised. But accessible vaccination centres and alternative options for those that couldn’t leave their homes were not thought of until the community raised them as problems. Similarly, there seemed to be no thought given to the restrictions on “essential services” during the lockdown alert levels in terms of disability care, leaving many medical professionals, care staff, and individuals with disabilities with the ethical dilemma of breaking lockdown protocol or seeing their health rapidly decline. If not for digital spaces, these stories, these voices would not be heard, or they would be assumed to be isolated incidents and not instances of systemic ignorance because of the inherent ableism in government policy. Covid-19 drove able-bodied

individuals into the online disability worlds, forcing them to see and hopefully reflect on these issues.

A big part of voice is humour. Outside of well-known advocates the names that come to mind when people are asked about people that speak on disability and mental health topics are comedians or celebrities. Disabled individuals express their pain and daily struggles through humour, and online this often takes the form of memes. These are disseminated into groups and spaces they were not initially intended for because people can now relate to them due to the lockdowns. Humour and memes offer these groups a transmittable and relatable mode of voice that is less confrontational and, in my opinion, easier for able-bodied individuals to swallow than being told “society has been constructed to exclude me”.

When people are calling for a “return to normal” they are coming from an ableist perspective because the disabled, the voiceless, do not want a return to the “normal” of being ignored, overlooked, and spoken over. I hope with the establishment of the new Ministry for Disabled People the harmfulness of “normal” will be addressed and individuals with impairments will begin to be seen as fully capable citizens that have a right to experience the same embodied belonging in public space as able-bodied citizen. I also hope that the experiences and insights about disabled lives created by the pandemic do not get forgotten in favour of this mystical “normal”.

The disabled communities only want people to understand and through that understanding foster the social attitude of change. They are not their impairments, and they are not the things that society has said makes them less-than, but rather they have unique insights, experiences, and ideas because of the impairments they live with. There will always be people who are angry at the system, at the barriers, and at others that do not “get it”, but anger breeds anger. All my respondents shared a sense of frustration with how disability and mental health are presented and understood in Aotearoa, but they also expressed a hope that things can change

because youth are more open about these aspects of life and discuss them more freely. The old saying of “youth are the future” rings true: it is the youth that can see these issues, and with the help of others, it is youth who will be the catalyst that forges social change.

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Appendix

Interview respondent biographic data:

- Melissa, a 22-year-old Pākehā woman from Auckland that has experienced mental illness and identifies as being disabled
- Sofia, a 21-year-old Māori/Pākehā woman studying psychology at university in Auckland who has experienced mental illness and identifies as being disabled
- Cyra, a 22-year-old New Zealand Indian woman studying at university in Auckland who has experienced mental illness and mental disabilities and identifies as being disabled
- Leda, a 21-year-old Māori/Pākehā woman from Auckland who experiences mental illness
- Adriani, a 22-year-old Pākehā woman and registered mental health nurse in a small town in the South Island who has experienced mental illness and has physical disabilities
- Alexios, a 21-year-old New Zealand Pilipino man and university student in Auckland who has experienced mental illness
- Demas, a 22-year-old Pākehā man who suffers from mental illness and identifies as being disabled
- Hermaphroditus, a 16-year-old Pākehā non-binary person and high school student in Auckland who has experienced mental illness
- Phaedra, a 21-year-old Pākehā woman and disabilities rights activist from Wellington who has experienced mental illness and has physical disabilities
- Rea, a 24-year-old Pākehā woman from Auckland who has experience with mental illness
- Athina, a 19-year-old Māori/Pākehā non-binary feminine person and university student in Christchurch who has experienced mental illness and identifies as disabled
- Avra, a 20-year-old New Zealand Ukrainian trans-feminine/non-binary feminine person and university student in Auckland who has experienced mental illness and has physical and mental disabilities
- Hermione, a 23-year-old Māori/Pākehā gender fluid woman from Wellington who has experienced mental illness
- Nasia, a 24-year-old Pākehā woman from Hamilton who has experienced mental illness and has physical disabilities
- Hera, a 21-year-old Māori/Pākehā woman and disabilities rights activist from Auckland who has experienced mental illness and is physically disabled.