"Experiences of families and professionals living/interacting with neurodivergent children while navigating the policy contexts of health, education and social services: The fight for accessible and suitable support".

A thesis

submitted in partial fulfilment

of the requirements for the degree

of

Master of Social Science – **Social Policy**

at

The University of Waikato

by

Kelly Robyns

THE UNIVERSITY OF
WAIKATO
Te Whare Wānanga o Waikato

ABSTRACT

Families of neurodivergent children often end up interacting with policy contexts of health, education, and social services on a regular basis when they have unmet needs. My research investigates these policy contexts to better understand how more accessible and suitable support can be provided to meet those needs. My research also describes the experiences of families that struggle to find or receive accessible and suitable support. I also aimed to highlight the principles of the neurodiversity paradigm to illustrate the deficit-based thinking of current systems and practice. It is natural, healthy, and valuable to have diversity among minds, both in the classroom and in society. The principles of the neurodiversity paradigm challenge the ways in which health, education, and social service systems respond to neurodivergent children. My research design included literature review, policy analysis, key informant interviews and autoethnographic reflections. Literature was drawn from academic research, but grey literature was particularly important as sometimes families of neurodivergent children at crisis point feel that they had no choice but to talk to the media. I also undertook interviews with social service professionals locally to understand their position on New Zealand provision for neurodivergent children and their families. My findings indicate that there are key limitations and problems in relation to current policy and practice. There is tension between the policy emphasis of inclusion and the real-life experiences that document the practice of exclusion. This could be due to the ways in which neurodivergent children are constructed and framed through policy language that reflects a deficit-thinking model. To ensure that the needs of neurodivergent children are met through the paradigm of neurodiversity more professional development and policy language shifts need to occur so that society can see neurological differences as a valuable part of humanity. Furthermore, greater emphasis needs to be placed on options that are accessible for families,

and suitable to the unique needs of their children. Overall, the research also demonstrates that much higher levels of transparency is needed between the siloed policy areas of health, education and social services, the professionals who work in each of these areas and most importantly between clinicians and families in relation to diagnoses, funding, and physical support. Finally, there also needs to be transparency in terms of the objectives of the neurodiversity paradigm which is to make clear the faults of the system and accept difference as the norm. The neurodiversity movement and paradigm challenge the deficit-based pathological views of neurological differences such as autism, ADHD, epilepsy and other neurodivergences. When neurodivergence is pathologized neurodivergent people are compared to a fictional norm or a 'right' way of being resulting in stigma, shame and often co-occurring mental health conditions such as anxiety and depression. These findings are important as families of neurodivergent children with unmet needs are forced to interact with policy contexts to receive support and funding. Accessible, suitable support including funding availability is essential to a neurodivergent child's well-being and inclusion within society.

ACKNOWLEDGEMENTS

He toa taku tini taku toa, Ehara te toa taki tahi

Mine is not the strength of one but the strength of many.

As with all things, it takes a village, and this thesis is no exception. There have been many people on this journey with me and I thank them all for their part. The coffee and conversation that has helped me gain clarity and knowledge on the good days and the challenging ones has been appreciated.

Special thanks go to my parents, Linda, and John, who continually support me in all my endeavours. Big or small, you are always there.

Thank you to my supervisor, Gemma Piercy-Cameron, for the many hours of conversation and wisdom. You always make time to listen and have been integral in my achievements thus far.

To my participants who gave up their time to talk to me, I thank you for your knowledge and openness.

To Riley, this is for you, even when life is more challenging than it should be, you keep going. This is our drop in the ocean to making a difference for the greater good. Keep smiling my angel, tomorrow is a new day.

CONTENTS

LIST OF FIGURES

1 INTRODUCTION

1.1 INTRODUCTION

Historically, child welfare and social services, education and health are important and vital parts of the New Zealand welfare state and are key social policy areas of development that focus on delivering social justice and equity. However, state intervention and support for neurodivergent children and their families has a mixed track record, with policy rhetoric often framing families and children in negative ways perpetuating colonisation and supporting a surveillance culture. Oftentimes neurodivergent children and their families are constructed[1] as deviant, this negative framing of families further contributes to stigma[2] creating barriers in asking for and seeking assistance from the state (Reardon, et al., 2017, p. 642). Deficit-thinking is problematic as it puts responsibility on the individual to change to fit societal expectations rather than highlighting the social structures and circumstances that encompass and constrain individuals (Davis & Museus, 2019; Valencia, 1997). As a result, families and children may be blamed for the situations in which they are caught up.

This kind of deficit-thinking also reinforces wider stigma about mental health disorders and disability (Lewis, 2022; MHF, 2022; WHO, 2021). Neurodivergent children and their families are caught between the goals of equity and social justice on the one hand and stigma and deficit-based blame on the other. The term neurodivergence was coined by Kassiane Asasumasu (Walker, 2021, p. 39), and terms such as neurodiverse, neurodivergent and neurodiversity are increasingly being used to characterise a range of neurological differences.

---

[1] Framing theory suggests that the way information is presented influences the choices people make when hearing such information. While 'framing' is an abstract concept it works to structure meaning (Arowolo, 2017). The meaning that is constructed for neurodivergent children is that they are deviant, challenging and/or difficult, this reinforces deficit-thinking.

[2] Stigma; mark of disgrace. Shame or dishonour (Collins, 2009).

These terms are part of a social movement and a shift in paradigms. Walker (2021) argues that these terms are quite different in terms of meaning and can be used inappropriately, as such it is important to have a clear understanding of such terms.

Neurodivergent individuals are people who could be but not limited to autistic[3], epileptic[4], dyslexic[5], ADHD[6], and others. A neurodivergent person could be dyslexic with no other co-occurring divergences, or the person could be autistic, epileptic and ADHD. When you read 'neurodivergent' throughout this thesis it is important to consider how many variations and combinations of neuro-difference there are, and therefore, how complex conditions can be made more complex by co-occurrences. Anxiety[7] and depression[8] can often be common mental health conditions that also co-occur due to the challenges of everyday tasks that neurodivergent individuals can face (Lewis, 2022).

Some neurodivergent individuals and their families can access the services they need or are able to access sufficient resources privately therefore passing within the mainstream population as successful or integrated. However, some families with neurodivergent children need support from the state through the publicly funded health, education, and social service systems. The focus of this research is to explore and make more visible the stories of these families. The research seeks to highlight the challenges many of them face when seeking to

---

[3] Autism (ASD) is a neurodevelopmental condition which affects how people interpret and interact with the world. There are many ways in which autism can present, it is a spectrum (Autism, 2022).

[4] Epilepsy is a seizure condition whereby increased electrical activity in the brain causes altered movements. There are many types of seizure (Epilepsy.org, 2022).

[5] "Dyslexic individuals tend to think in pictures rather than words, receiving and retrieving information in a different part of the brain to neurotypical, word-based thinkers" (DFNZ, 2023).

[6] Attention deficit hyperactivity disorder is considered to be an underdeveloped prefrontal cortex. The prefrontal cortex is responsible for attention, behaviour, emotion, executive functioning among other things. Due to the neurodevelopment delay control over these things can be hindered (ADHD, 2022).

[7] Anxiety is categorised by extreme fears or worries that impact a person's everyday function, symptoms last longer than 6 months (APA, 2015).

[8] Depression is deeply felt worthlessness or hopelessness and impacts daily function. Diagnosis is dependent on length and types of symptoms (APA, 2015).

access the scarce and pressured state-based resources available to support families with neurodivergent children.

1.2 Research context

As a parent of a neurodivergent child, I have met many other parents with similar (but different) children experiencing similar (but different) scenarios. These scenarios include a range of experiences with our children at home, at schools, extracurricular activities, and involvement with social support agencies. Some scenarios include feelings of joy and validation, and others can bring blame and frustration. Parenting in general is a rollercoaster yet when your child sits outside of what society deems as typical or expected it can be like being on a rollercoaster blindfolded, with more twists and turns than you can imagine. My experience of the rollercoaster is only an individual observation and the experiences of similar groups of parents are difficult to generalise, but research, statistics and public reporting indicates that New Zealand has many neurodivergent children and families unable to access support services (Cardwell, 2021; Crawshaw, 2022; Doocey, 2022; Ridout, 2023). There are families unable to send their child to their preferred school (Gerritsen, 2022), widespread/extensive numbers of involvements with Oranga Tamariki (OT), involvements with mental health services and sometimes with the justice system.

Extensive involvement with school, OT, the police, and justice system can be connected to poor long-term outcomes beyond the walls of our homes and consulting rooms and are a real social concern (Baistow, 2003). For example, New Zealand has one of the highest teenage (aged 15-19) suicide rates in the OECD, suicide being the "act of commission or omission on the part of a person resulting in that person's death" (Pierson & Thomas, 2010, p. 506).

Suspected suicide data is released by Te Whatu Ora and the Chief coroner. Te Whatu Ora can only publish confirmed suicides once enough information has been gathered to eventually confirm intentional self-harm (TeWhatuOra, 2022). The table below shows confirmed and suspected suicide data for specific age groups within that calendar year.

Number of suicide deaths across 10-14, 15-19, 20-24 age groups, 2009–2021

Data status	Age group	2009	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020	2021
Confirmed	10-14	10	6	6	11	S	6	9	8	8	6	-	-	-
Confirmed	15-19	55	51	60	75	55	38	57	44	48	54	-	-	-
Confirmed	20-24	61	60	71	73	56	51	54	68	78	79	-	-	-
Suspected	10-14	11	8	8	11	S	6	9	10	10	8	9	12	11
Suspected	15-19	57	52	64	71	58	41	55	42	49	56	65	47	48
Suspected	20-24	61	64	68	72	60	56	56	68	81	80	75	60	68

Source: New Zealand Mortality Collection (confirmed suicides); Ministry of Justice's case management system (suspected suicides).
Cells for which confirmed suicide data are not yet available are denoted with a hyphen (-).

(TeWhatuOra, Suicide Web Tool, 2022)

Not all these children and teenagers would have been classified as neurodivergent and not all of them would have had a mental health diagnosis, but research suggests that suicide is more frequent in this part of the population. A UK study found that 66% of autistic adults had considered committing suicide with a significant number of people who had committed suicide having autistic traits. More evidence is needed to determine an accurate number of suicides within the autistic and wider neurodivergent community worldwide (Brown, 2022).

Both locally and globally there are children and families struggling to get help and support to create better lives for their families. In New Zealand millions of dollars are being poured into mental health and education sectors, yet the pressure on the health system is immense with many media commentators stating it is at breaking point (Cardwell, 2021; Doocey, 2022; Witton, 2022).

There have been reports of "extraordinarily long" wait times for New Zealand children in crisis trying to access social services and in Australia, there are reports of wait-times up to two years for assessments relating to autism and ADHD diagnosis (Cardwell, 2021; Pillar & Whitehouse, 2023). Dr Brian Betty noted in a recent interview that it is "more than wait times, it is a total lack of capacity" - referrals keep being rejected due to lack of capacity therefore people do not even have a wait time (Betty, 2023). There are other contributing factors for the rise in need for social services including lack of diagnosis, parental blaming, and issues within the education system. These problems coincide with a rise in policy that emphasises inclusion, yet many neurodivergent children are continually let down by systems that are designed to help rather than hinder (Freeman, 2019; Williams, 2021).

1.3 RESEARCH AIMS

The aims of this research are linked to my research positionality and context, concisely they are,

- to draw attention to neurodivergence and neurodiversity as a paradigm that highlights deficit-framing with the current state services and wider society,
- to contribute to policy development by highlighting how the neurodiversity paradigm empowers neurodivergent children and their families, and that understanding neurodivergence is imperative as part of inclusive policy promotion,
- to bring attention to the validity of personal stories through literature-based research,
- to give voice to professionals 'on the ground' that encounter parents of neurodivergent children.
- A contribution to existing literature on the tension between policy that emphasises inclusion and the exclusionary practice of schools and healthcare systems that

neurodivergent children experience when they interact with these systems regularly and simultaneously.

1.4 RESEARCH QUESTIONS

- What are the challenges and/or opportunities for families of neurodivergent children when accessing social services?
- How have policies for neurodivergent children and their families evolved?
- What are the perspectives and experiences of some professionals within social services who interact with neurodivergent children and their families?

1.5 THESIS OUTLINE

The thesis comprises of eight chapters. This chapter has provided context for the thesis including research context, aims, and questions. Chapter two provides understanding of the methodological approaches and the methods that I have used to undertake this research. It also contextualises my position as both a parent and researcher and outlines why this research and my dual position is so important.

Chapter three grounds the thesis in theories of health and neurodiversity; outlining the models of health that exist within society and defines polypharmacy. It is important to situate neurodiversity within the current systems of health that neurodivergent people must interact with. This chapter conceptualises disability and considers some of the challenges associated

with ableism. It defines and discusses the importance of the language of the neurodiversity paradigm.

Chapters four and five consist of literature-based research with chapter four contextualising policies of disability, mental health, education, and child social service. This is to better understand the legacy of difficulty that many neurodivergent children and their families face when they try to access suitable support. Chapter five discusses a range of international empirical research on parental experience of living with a neurodivergent child and/or within a neurodiverse household. This chapter explores how neurodivergent children are framed throughout literature and policy and the potential challenges that deficit framing can bring. This chapter also draws on news media items and includes a case study of a Waikato family and their experience of living with a neurodivergent child, the challenges they face and the raw reality of interactions with multiple agencies.

Chapter six presents the stories of my key informant's experiences and perspectives of working within social service provision and their observations and recommendations for further support for neurodivergent children.

Chapter seven discusses my research, combining literature with personal accounts to build a bigger picture of accessibility within the neurominority[9] community.

---

[9] Neurominority – a neurominority is a population of neurodivergent people that share a similar type of neurodivergence, the form of neurodivergence is largely innate and the shared form of neurodivergence is subject to some form of adversity from the neurotypical population (Walker, 2021).

Chapter 8 concludes the thesis by succinctly answering the research questions along with highlighting the limitations of the research, this chapter also includes suggestions for further research.

2   METHODOLOGY

"No man is an island, entire of itself" (John Donne)

2.1   INTRODUCTION

I do not come to this research as an unexperienced or unknowledgeable single entity, I come with experience that has shaped my beliefs that will guide my actions through this research. While the above quote sits within the *principles of social policy* it also resonates with the ethnographic insight that "your own lived experiences, beliefs, and values influence your observations and interpretations" (Bochner & Ellis, 2016; Drake, 2001) The perspectives and practices of feminism, social constructionism, and autoethnography underpin and shape my research, and are part of the qualitative research methodology that aligns with the interpretive methods I have employed.

Qualitative methods are seen to be a richer experience and present a truer a picture of what goes on compared to only using statistics (Haralambos, Holburn, & Heald, 2000). Denzin and Lincoln describe qualitative research as "a situated activity" meaning that the researcher is located within the realm of their study. Qualitative research is interpretive and through a series of representations has the possibility to "transform the world". Representations in qualitative research include field notes, conversations, transcriptions, and photos all of which set out to make meaning or make sense of the world around them. Qualitative research can be observational, and visual but also statistical; no single method is given status over another but rather all methods work to complement each other. Researchers understand that reality is socially constructed, and importance is given to *how* peoples social experiences are given meaning (Denzin & Lincoln, 2000).

2.1.1   Social constructionism

This thesis operates from the view that reality is constructed by language and the way in which language is interpreted gives meaning to interactions within society. Social constructionism is also concerned with the power relations within those interactions and why some are given more power than others (Burr & Dick, 2017). Within the social constructionist view there is no single "truth", instead there are multiple perspectives and meanings given to a single event. As knowledge is given meaning through the construction of human interaction, any definitive 'truth' should not only be questioned but also evaluated differently (Burr & Dick, 2017; White R. , 2004).

Language, power, and the construction of knowledge is particularly important within the medical and psychological realm of diagnosis and treatment. The heart of medical knowledge reflects ideals and 'truths' in the society of which it functions. Within the medical model of health dis/ease is presented as fact or truth based on a positivist view of the natural sciences (White K. , 2009), whereas a social constructionist approach disrupts 'truth'. As discussed in the following chapters, the concept of normality provides room for critique as literature suggests dis/ease is a social product rather than biological (White K. , 2009). Ludwik Fleck focussed his work on medical knowledge being a social product, this preceded Foucault and his work on coercive collective knowledge.

Foucault developed his work on humans becoming subjects within science as something to be controlled. Labelling and constructing certain conditions as dis/ease that need to be treated or cured is a form of social control (Collyer & Scambler, 2015). What and how a condition is defined is a production of what the society deems normal or not (White K. , 2009), or as some would say, medicine is "becoming a vehicle for societies values" (Freidson, 2001). By

employing Becker's work on deviance, and Foucault's work on control we can understand that labelling something as different from the ableist[10] norm can be used as a form of social control (Haralambos, Holburn, & Heald, 2000).

Howard Becker's labelling theory suggests that by labelling something makes it so, or part of the world (Haralambos, Holburn, & Heald, 2000). The construction of language is how we make sense of and understand the world therefore, when a behaviour is labelled as 'challenging'[11] then a further language connection is constructed between the label and an autistic person, feelings of inferiority and undesirability can be internalised (Wilde, 2023). By labelling a behaviour as challenging and then further connecting it to a group of people can promote a dominant view about behaviours of all autistic people due to way it is framed.

Framing is another tool used by policymakers to control how an issue is perceived and responded to. The way in which an issue is framed has implications on how the audience organises their thought processes on that issue (Chong & Druckman, 2007, p. 106). Through the construction of language, the way neurodivergent people are labelled throughout policy impacts the way policy comes to life in education and health settings. Policy documents are a form of communication, frames in communication are significant as these influence attitudes and behaviour of the reader and audience (Chong & Druckman, 2007, p. 106). The media have specific ways in framing autistic people, and this can have a significant effect on attitudes and beliefs about and towards autistic people every day. Jones and Harwood (2009)

---

[10] Ableism is the way in which certain abilities are favoured and desired in society such as cognition and physicality – negative responses can be shown towards people who do not have such qualities (Goodley D. , 2014).

[11] 'Challenging behaviour' can be defined as behaviour that poses a threat to the individual or others around them. Lanovaz et al (2017) identify three areas of behaviour that could be considered challenging, these are self-injurious behaviour, aggressive and destructive and/or repetitive behaviours (Lanovaz, Rapp, Gendron, Prefontaine, & Turgeon, 2017).

undertook an extensive study of the framing of autism within Australian media, consistently they noticed that having an autistic child is portrayed as negative. Media coverage portrayed autistic children in two ways; uncontrollable, aggressive, and violent individuals that caused much stress to the people around them or unhappy and poorly treated by both the system and their families. There are few positive frames of autistic children and adults (Jones & Harwood, 2009, pp. 5-18).

2.1.2   Feminist epistemology

"Personal is political" (Hannam, 2014)

Carol Hanish's above quote is one of the most coined phrases of the women's liberation movement of the 1960's (Hannam, 2014; Schuster, 2017). This statement highlights the inevitable relationship between the private and public aspects of life (Schuster, 2017, pp. 647-659). The liberation movement saw groups of women at a grass roots level formed to continually reject the hierarchies within society, this was known as consciousness raising (Hannam, 2014). Consciousness raising is attributed to Brazilian educator Paulo Freire and his theory on Critical Consciousness. Critical consciousness uses elements of critical reflection, critical motivation, and critical action to understand relationships of the oppressed within society (Diemer, Rapa, Voight, & McWhirter, 2016, p. 216). Critical reflection is used to discover the possibility of change and transformation (Morley, Ablett, & Noble, 2020, p. 11).

C Wright Mills' (1959), Sociological Imagination embodied the 'personal is political' with his distinction between private troubles and public issues. He observed that *troubles* are to do

with the self, within the individual and their direct relation with others. A trouble is considered a private matter whereby the individual feels their values have been threatened. Whereas an *issue* transcends that of the individual and is concerned with the organisation and interconnectedness of society as a whole (Mills, 1959, pp. 3-24).

While the family was seen as a key place of women's oppression, radical feminists were determined to find other ways of categorising women in relation to men. Second wave feminism was not just focussed on the family but on the wider patriarchal discourse within society that continues to oppress women through social control on many levels, including "violence, heterosexuality, and reproduction" (Hannam, 2014).

Language is key to dismantling the deeply embedded patriarchal views and systems of what it means to be woman (and man) within society. Constructions of femininity and masculinity through "media, advertising and everyday language" had to be challenged so that the next generations of women had a different start in life (Hannam, 2014). As the second wave feminist movement began to dwindle in the 1980's, other ways of thinking began to develop. Postmodernism, with a focus on the construction of language and how language shapes our understanding of reality was rising at this time. Postmodern feminists critiqued that experience alone could not be linked to political activity in a linear way (Hannam, 2014), especially when language to describe experience is a male dominated discourse (Haralambos, Holburn, & Heald, 2000). Yet Day (2012) would argue that "experiential accounts have been an important source of knowledge" especially when objective knowledge is often impossible as well as undesirable in certain situations (Day, 2012, p. 62). Masculine knowledge is seen as the dominant, objective discourse with speech being defined by Helene Cixous as "governed by the phallus" (Cixous, 1976, p. 881; Haralambos, Holburn, & Heald, 2000).

Cixous emphasises that it is women through their speech and writing, "from and toward women" that patriarchal governance can be countered. At no point should woman sit in, lest accept, the margins. It is by listening to a woman's voice that challenges phallocentric discourse and "makes possible" (Cixous, 1976, p. 898). Cixous did believe that change was possible and that all – men and women – would benefit (Haralambos, Holburn, & Heald, 2000).

My adoption of these feminist ideals is represented in my activist stance. Runswick-Cole and Ryan (2019) describe a moral responsibility that some mother activists take on as they realise that it is not their child that needs fixing but society. I am a mother who is actively using my experience to further understand social service provision for neurodivergent children in the wider policy context. We must illuminate the additional labour that (mostly) mothers take on in balancing motherhood, activism and sometimes academia. Parents of neurodivergent children can be propelled into a complex world of specialists, clinicians, educators, and therapists (Good, et al., 2017, p. 108). As we live through our parental experiences of raising neurodivergent children in neoliberal ableist times, the responsibility is greater than the happenings of our individual homes and instead about recognition of humanity and equity for all neurodivergent children (Goodley D. , 2014; Runswick-Cole & Ryan, 2019, p. 1129). Runswick-Cole and Ryan (2019) suggest that "telling stories is not enough to bring about change" (p.1131), autoethnography is a way to combat that, autoethnography is a way of demonstrating that personal troubles are public issues (Mills, 1959, pp. 3-24).

2.1.3 Autoethnography

"All knowledge is situated" (Brabazon, 2022)

Though not always explicit, I will be drawing on my personal experience of parenting a neurodivergent child with co-occurring mental health challenges, therefore it is important to outline how my subjective insights fit within the wider methodology of my research. Ethnography gives the research a 'personal' aspect in opposition to the 'professional'. Not to say that my participants conversations were not personal – they absolutely were – but they hold positions in society that give them professional jurisdiction, being a parent does not hold the same kudos. Autoethnography is a way to connect the two; there is a back and forth between personal experience on a micro level yet constantly looking outwards to the social and cultural aspects at a macro level. Spending time in this liminal space to create wider understanding of the social and cultural through "action, feeling, thought, and language" (Ellis & Bochner, 2000).

Ellis (2016) discusses the importance of diary keeping in autoethnographic writing as a reflective tool when writing about her experiences with illness and grief. When I was most engaged with social services, I too kept a diary, not only for appointments but also attempts at finding common denominators between events, medication, and behaviour. I can empathise with Ellis in that diaries become "field notes" and by writing you make (some) sense of the crisis you experience sometimes daily (Bochner & Ellis, 2016). Not knowing at the time how useful it would be, it is now a source of knowledge, documentation, and reflexivity. While autoethnographies will often be about the writers themselves and events surrounding them, autoethnography can also be a call for social justice (Bochner & Ellis, 2016). This social justice call is why an autoethnographic lens is key to my research, it fits with feminist

epistemology bringing the personal into the political realm and highlights how narratives of neurodivergent children and their families are socially constructed.

Like feminist epistemology, autoethnography is an approach that acknowledges "subjectivity, emotionality and the researchers influence on the research", rather than make out they do not exist (Ellis, Adams, & Bochner, 2011). My use of specific personal moments will add "depth, emotionality, nuance and coherence" to my research (Christians, 2000) yet when I choose not to add any of my story, this is also very specific. While my story and experience with social services is relevant it does not need to be explicit to enhance the research.

2.1.4   Positionality

"I am not what happened to me, I am what I choose to become". (Carl Gustav Jung)

How did I come to be here, writing a thesis about neurodivergent children, their families, services that are available to them, and what might happen if and when those services fail them? I arrived in New Zealand in 2005, I was 21 years-old, and fresh off the boat from England. I had gained my first BA in Drama and Theatre and had many life experiences. For the first 3 1/2 years in New Zealand, I was a business owner of a café in a busy city, and I loved it, I cooked, baked, talked, laughed, and cried for all that time. I used to describe each day as a different play as you never knew who was going to walk in the door at any given time and what stories they came with; you never knew where the conversation was going to take you. I sold the café at 6 months pregnant and was more than ready for him to arrive, I used to say, "how difficult can a single human be when I'm used to feeding 100's a day, a hundred different meals!". Little did I know. The first year was without comment despite

finding myself as a single parent early in the journey but I've realised over the years, I approached becoming a parent and a single parent like I do most things; I write lists, I talk to myself, I plan for every eventuality and just get on with it because there is simply no other option.

What I did not know in 2008 was that my son would acquire many letters after his name including, ADHD, ASD, SPD[12], along with asthma, epilepsy, and anxiety; things that I had never dealt with as an adult or a child. I remember one or two kids at school that would need an inhaler when they were running and that was the extent of my experience with asthma, the rest was a mystery. I was introduced to the world of medical and mental health within the first 2 years of my son's life, and it is still a major feature in our lives. I have engaged with many social services including but not limited to, Ministry of Education, schools, churches, youth groups, sports clubs, Child, and adolescent mental health services (CAMHS)[13], Oranga Tamariki (OT), STAND, police, therapists, psychologists, psychiatrists, doctors, and nurses. I'm happy to say that my son is now home-schooled full time, and we have a great (small) team of people including a General Practitioner (GP), paediatrician and psychologist that listen to both him and me, that care immensely and are focussed on his wellbeing, both mental and physical. But it wasn't always like that or rather, it didn't always feel like that.

Separately, I have written an autoethnographic account of my experience parenting a neurodivergent child through a mental health crisis including many of the interactions I experienced with multiple agencies. I considered every word that hit the page and continually

---

[12] Sensory processing disorder – people who have sensory processing differences have trouble receiving and processing information due to sensory overwhelm. They may react excessively to something seemingly small or vice versa (Childmind, 2022).
[13] CAMHS are a mental health service responsible for the psychological wellbeing of children and adolescents up to the age of 17, they are multidisciplinary and can consist of nurses, psychologists, occupational therapists and others (Pierson & Thomas, 2010, p. 78).

asked myself, do I want to share this publicly? By writing that account separately it has allowed me to be more objective and reflexive when choosing which parts of my story to access. It was never designed to be a finished account; it will be an ongoing piece of work that may someday be published in its own right as a whole or in many parts but for the purpose of this thesis I was very specific about what was published. Tullis notes that once we publish our stories, they become permanent records of our thoughts and feelings and, who knows where they will end up; wheels put in motion that I will never be able to stop (Tullis, 2022, p. 103). My experience of being a parent of a neurodivergent child who has struggled immensely with his mental wellbeing will always be with me and will always influence how I approach a situation, so while I set out to tell my story, I realised that I did not have to do that explicitly to achieve my aims. Bochner and Ellis (2016) describe one of the goals of autoethnography is to "put meanings into motion" and I can create meaning and motion by navigating my story through this thesis without always being explicit (Bochner & Ellis, 2016). The stories of parents (predominantly mothers) are easily accessible and published widely, although Runswick-Cole and Ryan (2019) acknowledge that telling stories is not enough to bring about change. That is not to say that our stories are not valid, yet we must be specific about the change we want and explicit in how to achieve it (Runswick-Cole & Ryan, 2019, p. 1131).

In terms of my position within this research my story illustrates how there is an intersection of identities and stances from which I see, interpret, and analyse things. Before 2008 I was female, woman, daughter, sister, student, business owner, and then I was mother, I am mum and for me, that transcends any other identity. As the years went by, I continued to be all things, whether it's wiping the tears from a scrapped knee to watching them physically struggle to stay in this world every single day because some days it is just too hard to be here.

That seems like a big jump in scenario but knowing what I know now; they aren't, and I think that jump only amplifies the unpredictability of parenting a neurodivergent child.

However, while I am the parent of a neurodivergent child, and I acknowledge this affects how I read and interpret the findings, I am not carrying out this research *as* a parent but rather someone with a deep-rooted sense of moral responsibility to continue the narration of situated experience of neurodivergence. Lorna Hallahan articulates this point when referencing her own work, "I am not my cause, I am brought to my cause due to my own experience and share solidarity with people" (Lohmeyer & Hallahan, 2021). Holding this unique position enables me to "study a particular issue in depth and with special knowledge about the issue" (Costley, 2010, p. 3). As a researcher I critically reflect on my own experience as a parent and that adds the critical nature of humanity to my research. The process of reflexivity is central to my chosen methodologies and will facilitate a critical examination of my insider status.

This thesis will take you on a journey of neurodiversity, mental health, physical health, heartbreak and triumph through storytelling and academia. It is impossible to separate as I am only human; I am both Mother and writer, therefore all chapters have an autoethnographic lens, but some more than others will be rooted in literature and policy. I invite you to experience my experience as both writer and Mother, to inspire you to continue the dialogue of mental health and neurodivergence, and to put meaning into motion long after this is published.

2.2 METHODS

By exploring the experiences of professionals working in social services and understanding how neurodivergent children are framed within literature and policy, we can better understand how neurodivergent children and their families currently experience social services. Such understanding can be used to challenge policy settings so these families and their neurodivergent children can prosper in their communities. In this sense my research contributes to the wider mission of social science research being "enabling community life to prosper" (Christians, 2000). The methods I used in this research included literature review, policy analysis and key-informant interviews. A key feature of gaining ethics approval was ensuring that participants that were known/unknown to me was 50/50.

2.2.1 Literature review

Literature based research spans two chapters; the policy context of health, education, and care services and literature describing parental experiences of neurodivergence while interacting with those policy contexts. It was important to contextualise my research historically to better understand the legacy of deficit thinking, stigma, and exclusion. I then examined the lived experiences of parents who have experienced the challenges of stigma and exclusion among other things whilst interacting with health, education, and social services. These experiences are represented by parents globally.

The literature review consisted of journal articles, textbook chapters, and grey literature (newspaper articles, documentaries, podcasts, government reports and websites). Grey literature has been particularly important for my research as some parents of neurodivergent children have felt that they have no other option than to go to the media to share their stories

in the hope of better access and support. These accounts are vivid, personal, and relevant to understanding the specific challenges parents face when trying to access suitable support for their neurodivergent children.

2.2.2 Policy analysis

Policy documentation and analysis was carried out to outline the evolution of disability, mental health, education, and child welfare policies. While each of these areas of policy are interconnected, their structures exist independently. Enactment of multiple policies can be confusing when parents of neurodivergent children encounter multiple agencies such as the Ministry of Education, Ministry of Health and possibly the police and Oranga Tamariki. Understanding how they work individually and together is critical to better support for neurodivergent children and their families. While policies have been re-worded over time to promote inclusivity, the legacies of stigma, blame, and exclusion are still a lived reality for many neurodivergent children and their families.

2.2.3 Interviews

Participants across different areas of service provision were invited to take part in a semi-structured interview, held at a venue suited to them and a time that was appropriate, there were four participants in total. Three participants worked in the Tauranga area and one in Auckland, two participants were known to me as professionals that I had engaged with on a personal level and two were not. This 50/50 ratio of participants being known to me was a way of dealing with my insider bias. Their roles in service provision were within New Zealand Police, social work, and education; one was still engaged with employment, one had left their position and was speaking retrospectively and two were in private practice. The

interviews took place across a range of locations, the police station, the University of Waikato – Tauranga campus, a private home and over Zoom. There were three female participants and one male.

Interviews took between 55-75 minutes to complete, they were recorded on a personal device and transcribed by myself. While transcription was a long process it was beneficial to hear every facet of the conversations over again, by doing this I was able to re-discover themes and correlate them across interviews. Once I had identified the themes of similarity and difference, I was able to attribute certain quotes that I wished to use. Each participant received a full transcript of their interview and a separate document specifying which quotes I wished to use as per the consent form, the participants had multiple opportunities to decline at various stages of the process.

Through these interviews participants were invited to share their experience of interacting with neurodivergent children and their families. Participants benefited by being able to voice their experience and have a forum to discuss what provisions they believe are available for neurodivergent children. By taking part in a semi-structured interview for a qualitative study this gives participants an opportunity to, "provide a narrative of their experience" (Healey, 2016). Participants also had the opportunity to give recommendations on what they believed could make things easier, if anything, for neurodivergent children, their families, and within the social service provision that they belonged. Feminist researcher Ann Oakley identified that by being collaborative, you can break down the barriers between interviewer and interviewee for a richer experience which she found preferable than the scientific masculine style (Haralambos, Holburn, & Heald, 2000; Oakley, 1981). Semi-structured interviews allowed for a collaborative approach.

2.2.4 Ethical considerations

Ethical approval was gained on 21 September 2022 by the University of Waikato ethics committee, approval number FS2022-46 (for the ethics form, see appendix B). Ethical concerns ranged from personal harm to the harm of my participants and anyone else who could have been mentioned and identified during the time of writing and further publication. As part of the approval process, it was stipulated that there must be a 50/50 ratio of participants known/not known to me to ensure a measure of impartiality. All my participants were given pseudonyms and their workplaces were not mentioned therefore further removing them from being identified. 'Kate' and 'Lydia' were unknown to me and were recruited from; one, a workshop I attended where 'Kate' was the host and two, 'Lydia' was mentioned in a previous interview. I googled her company, enquired about her practice and I was able to tell her about my research and then further ask her if she would like to participate.

Each participant had the opportunity to read the information sheet (appendix C), and the consent form (appendix D) as part of the informed consent process. Consent was also obtained at the beginning of each recorded interview. Due to the nature of semi-structured interviews, I proposed a list of possible interview topics (appendix E).

To minimise personal harm, I have shared minimal parts to my story, this was for two reasons. One, that by telling my story I would have no control over the narrative once it was published and many people that feature would not be able to consent for varying reasons. Two, as my thesis journey evolved it became less about me and more about the experiences of other families with neurodivergent children. While the continued advocacy for the rights of my neurodivergent child is paramount to me so is the bigger picture and the wider injustices that many neurodivergent children and their families face.

3 THEORY

3.1 INTRODUCTION

This chapter grounds the thesis in theory by outlining the theoretical models of health which conceptualise the system that our medical and psychological diagnostic systems function. I will discuss the broad concept of disability and the disability movement that saw rights of disabled people brought to the fore. Additionally, I outline the neurodiversity paradigm and movement from which I take my lead. I draw on social constructionism and neurodiversity to situate my approach to the literature and research.

One aim of my research serves to further understand the language within the neurodiversity paradigm and how dis/ability is constructed through language and perception, this is important because language and the use of words is the currency for communication. "Words are tools" (Walker, 2021, p. 25), in diagnostic settings, health and educational environments, funding applications, in policy making and everyday life; language is crucial to understanding. Language frames neurodivergent people's experiences when interacting with practitioners, clinicians, support workers and other policy contexts and can be used to create power imbalances. Terminology varies between communities, movements, and country, depending on how the individual neurodivergent person wants to identify (Shakespeare T. , 2018). Language is also important due to its relationship with deficit-thinking.

Deficit-thinking places the blame for a problem with the person rather than with the structures of the defective system, Valencia (1997) gives examples of eyeglasses and escalators, but their argument is also relevant to education (Valencia, 1997). Intellectual and/or linguistic limitations, lack of motivation or certain behaviours are often seen as

reasons for failure, deficit-thinking puts the responsibility for failure on the student's shoulders (Valencia, 1997). Deficit-thinking can also be thought of as a strategy to uphold hegemonic values within society due to the failure to consider the consequences and impact of oppressive systems, policies, and practices within educational settings (Davis & Museus, 2019).

When we approach a situation or person with an understanding of neurodiversity and from a strength-based standpoint, we look at positive aspects of people's lives; what they are good at rather than what might be challenging. Strengths-based practice is defined by the way it empowers individuals to succeed and flourish rather than to merely survive (Lopez & Louis, 2009). In an educational environment being strengths-based means looking at the students' academic and personal achievement, strengths, skills, and competencies rather than any lack (Epstein, 2000, p. 249). Hurlock's (1925) early work demonstrated that praising students had a much more positive effect than criticising (Lopez & Louis, 2009).

3.2 MODELS OF HEALTH

There are two differing ways of viewing ill/health: medical and social. The medical or biomedical view draws on scientific or biochemical explanations for ill/health and seeks treatment and/or intervention through traditional medicine. This is also known as medicalisation, "reducing the human experience to medical concepts and definitions" (O'Reilly, Muskett, Karim, & Lester, 2020, pp. 544-564). The social viewpoint allows for a much wider understanding of what it means to be healthy and reasons for when ill/health occurs. The social model embraces the human experience by understanding how a person interacts with society and their environment alongside possible biomedical markers. As such

the social model of health provides a more holistic view of ill/health, facilitating intervention, and/or treatment in many ways other than prescribing medication. Within the social model the neurodivergent person is a comprehensive social actor, fully involved in the interactions that take place with regards to their care (Yuill, Crinson, & Duncan, 2010, p. 17). When a person is fully present and able to participate in decision making this upholds strengths-based practice.

3.2.1 Medical model of health

In relation to policy contexts the biomedical construction of health is still the dominant way to view health and illness, despite being narrow and separating people from their environments (Doyle, 2001). The dominance of this model is carried out daily in the "rational-scientific" transactions between patients and doctors in hospitals and General practitioner clinics (Yuill, Crinson, & Duncan, 2010, p. 7).

The biomedical construction of health sees disability or impairment as an individual problem that is categorised by a person's level of functioning, believing there is a version of 'normal' functioning with which to compare. Boorse (1977) outlined a functionalist view of health stating, "it is that the normal is the natural". Galen, quoted in Boorse, believes "disease is contrary to nature", along with King who discusses normality as the possession of full capacities that are natural to humanity. Boorse's argument was used to create the idea of statistical normality. The statistical norm is freedom from disease and being able to complete typical physiological functions with competent efficiency (Boorse, 1977, p. 542). The statistical norm was used as a reference class, that being a uniform group of specific age and

sex to compare others against, to determine normal functioning. Deviation from the norm is assumed as disease (Boorse, 1977; Deacon, 2013).

3.2.1.1 The biomedical model and mental health

When we assume there is a 'normal' biological group within humanity, there is an opportunity to reference anything deviating from the 'norm' as abnormal and negative to humanity. Conditions that are diagnosable as mental disorders are seen as biological abnormalities within the brain according to the medical model of health (Chapman, 2020; Deacon, 2013, p. 847). By employing labelling theory, if we label something as 'normal' it creates the opportunity to label something as 'abnormal'.

At first the biomedical model gave hope to both psychiatrists and patients; there were seemingly biological answers for mental disorders and psychiatric medications were seen as "magic bullets". Prescription medications were written as cures for mental illness just as antibiotics are for infection (Deacon, 2013). The publication of the Diagnostic Statistical Manual of mental disorders (DSM) backed up the scientific element of psychiatric conditions by listing diagnostic criteria and corresponding medications to alleviate the symptoms. Conditions that would have previously seen people institutionalised were now seen to have some scientific standing. As relationships formed between pharmacology companies and the American psychological association commercial profits were favoured. Advertising and media campaigns were rolled out to the public promoting medications as the answer for psychological illness (Deacon, 2013, p. 848). A 1971 article in Fortune magazine described Valium as "the greatest commercial successes in the history of prescription drugs" (Horwitz,

2021, p. 38). These messages were welcomed by the public as they provided the promise of curing mental disorders (Deacon, 2013).

With medical knowledge being seen as scientific (Baxter, 2001), the model was very convincing and still dominates the way mental ill/health is treated with medication as per the DSM recommendations. The first and second publication were not met with enthusiasm but the DSM-III, published in 1980 was the game changer for diagnosis and cemented a biomedical framework for mental disorders. The DSM is now in its 5th edition (2013) and is used comprehensively worldwide by psychiatry professionals. The DSM has become the global standard for biomedical knowledge, diagnostics, and policy making (Horwitz, 2021, p. 3).

3.2.1.2   Prescription medication

Prescribing medication as a solution to illness, impairment, ailment, or infection has been on the rise since the first script was written. It is estimated that 60 million Americans take psychotropic drugs with many people taking psychotropic medication without a diagnosis and yet, many with a diagnosis, go untreated (Deacon, 2013, p. 850). Matson and Dempsey (2007) report that antipsychotic drugs have been prescribed to children as young as 2 years old that have presented with 'challenging behaviour' associated with ASD (Matson & Dempsey, 2007, p. 179). Rates of prescription anti-depressants and antipsychotic medications having increased by 50% in the past decade and the number of children suffering with psychiatric problems more than doubling between 2008-2013. With regards to the increase of prescribing, researchers are rightly asking the question "is doing more of the same a reasonable option?" (Mulder, Rucklidge, & Wilkinson, 2017, p. 1).

In New Zealand there is limited up to date data on psychotropic use however, there are two New Zealand studies that have quantified the use psychotropic medication by accessing prescription information from PHARMAC (Barczyk, Rucklidge, Eggleston, & Mulder, 2020, p. 87; Wilkinson & Mulder, 2018). Barczyk et al (2016) found that 2.36% of youth (0-17yrs) totalling 26,175 individuals were prescribed at least one psychotropic medication (Barczyk, Rucklidge, Eggleston, & Mulder, 2020, p. 89). The University of Otago found 1 in 36 New Zealanders over 15 years of age had been dispensed an antipsychotic drug in 2015, with 1 in 13 New Zealand adults being prescribed anti-depressant (Wilkinson & Mulder, 2018, pp. 61-67). The biggest increase for youth between 0-17 years old was 112% increase of prescriptions for antipsychotic medication and a 52% increase in anxiolytics (Barczyk, Rucklidge, Eggleston, & Mulder, 2020, p. 89). Prescriptions for psychotropic medication had increased by 65% since 2008 (Barczyk, Rucklidge, Eggleston, & Mulder, 2020, p. 87).

Anxiolytics are a class of medication used to treat anxiety disorders; benzodiazepines are in this category and can have a muscle relaxant property. They need to be used with care as they can be habit forming (APA, 2015, p. 303). Prescription rates for anxiolytics for 0-17yr olds worldwide remained stable but two studies in Iceland and Great Britain (2015) noted an increase. While benzodiazepine anxiolytics have shown some efficacy in procedural settings, there is limited literature and data on usage and efficacy for anxiety/mood disorders for children and adolescents (Barczyk, Rucklidge, Eggleston, & Mulder, 2020). A full list of medications in these categories can be found in Appendix A.

Antipsychotics are a group of medications used to treat mania in people with bipolar and delusions and/or hallucinations in patients with psychosis or schizophrenia (APA, 2015, p.

302). Antipsychotic medication comes with side effect warnings for adults but there is little known about the efficacy and safety for children and adolescents. The administration of these groups of medication must be closely monitored by their physician (Barczyk, Rucklidge, Eggleston, & Mulder, 2020). Despite the dramatic rise in prescription rates, Mulder et al. argue that there is no clear evidence to back up that this increase is decreasing the numbers of children and adolescent presenting with mental illness (Mulder, Rucklidge, & Wilkinson, 2017, pp. 1-2). New Zealand's 52% increase in prescription rates for this age group is questionable. Current research both quantitative and qualitative is needed to determine up to date prescription rates, usage, effects, and outcomes for these children globally (Barczyk, Rucklidge, Eggleston, & Mulder, 2020, p. 94; Matson & Dempsey, 2007, p. 182).

3.2.2 Polypharmacy

Polypharmacy is the administration of multiple medications taken daily. Polypharmacy can be associated with further risks other than the original ailments, for example, adverse drug reactions, readmission to hospital, and fatality can result from the multiplicity of medications (Bogler, et al., 2019; Masnoon, Shakid, Kalisch-Ellet, & Caughey, 2107). Definitions of polypharmacy vary but the most consistent definition is "5 or more medications daily". There is debate on whether the definition should include the appropriate and/or misappropriation of prescribing and/or over prescribing. For instance, Masnoon et al (2017) conclude that co/multi-morbidities may require multiple medications making a defining number difficult to reach (Masnoon, Shakid, Kalisch-Ellet, & Caughey, 2107).

While New Zealand has a health system that provides for all of their residents with subsidised prescriptions and free healthcare for children under 13 years old, there is limited data

regarding the multiplicity of prescription medication (Barczyk, Rucklidge, Eggleston, & Mulder, 2020; Bowden, Thabrew, & Kokaua, 2020). However, a US study of 286 autistic adolescents and adults found that over a 4.5 yr. period 70% of participants were taking a psychotropic and/or a non-psychotropic at the beginning of the study period. By conclusion of the study the rate had risen to 81% (Esbensen, Greenburg, Seltzer, & Aman, 2009, p. 1339). While this study had an older range of participants, Aman et al. (2003) found similar rates in children between 13-15 years-old (Aman, Lam, & Collier-Crespin, 2003). Internationally and in New Zealand autistic children, adolescents and adults carry a significant medication burden compared to non-diagnosed autistic persons (Aman, Lam, & Collier-Crespin, 2003; Bowden, Thabrew, & Kokaua, 2020, p. 1; Esbensen, Greenburg, Seltzer, & Aman, 2009).

3.2.3   Social model of health

The medical model of health has been and still is challenged by a social model of health; while the medical model puts emphasis on the individual, a social model deems that it is societal systems and attitudes that disable people (Lalvani P. , 2019, pp. 50-70). The social model challenges the belief that everything can be medicalised, medicated, and cured. There is evidence that the medical model of health is shifting. For example, international agencies such as the UN and WHO argue that the social determinants of health must be considered when looking at dis/ease, these can include housing, job security, access to healthcare, food security, education and discrimination (Compton & Shim, 2015, p. xv). When any of these social factors are difficult or challenging there is potential for dis/ease, physically and mentally.

The World Health Organisation pointedly states that "Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (WHO, 2022). This indicating that mental health and wellbeing cannot be reduced to a simple pathology and cured, health is a state of being that encompasses our whole lives and that includes how interactions with the structures of society impact our ill/health. Social models of disability focus on equity and participation through eliminating barriers created within society that force exclusion (Good, et al., 2017, p. 111).

3.3   DIS/ABILITY

This section seeks to understand disability in a global context and examine the social constructs that disable New Zealanders on a regular basis. Dan Goodley (2014) believes that both disability and ability require more unpacking in the current global capitalist landscape (Goodley D. , 2014).

The disability rights movement was gaining traction at a similar time as the social model of health was developed. When disability is seen through a social lens the stigma and pressure is taken from the individual and placed into the hands of society (Needham, 2016; Mulvany, 2000; Stace & Sullivan, 2020). Stace and Sullivan (2020) give the example of a wheelchair user; if a person cannot gain access to a public building it is not because of the person's paralysis or wheelchair use, it is poor building design based on exclusion. The disability rights movement belief is that personal impairments are not a tragedy or something to be fixed but rather it is society that needs to change/be fixed to accommodate all facets of neurodivergence and impairment.

The London Union of the Physically Impaired Against Segregation (UPIAS) published their manifesto in 1976 challenging the medical model of health (Stace & Sullivan, 2020). UPIAS made distinct differences in their definitions of impairment and disability,

Impairment – lacking part of or all of a limb or having a defective limb organism or mechanism of the body.

Disability – the disadvantage or restriction of activity caused by a contemporary social organisation which takes no account of people who have physical impairments and thus excludes them from mainstream social activities (Goodley D. , 2001, p. 208).

Disability is diverse and with approximately 15% of the global population being disabled, most people will know someone who experiences disability in some way (Shakespeare T. , 2018; WHO, 2022). From downs syndrome to autism, from dementia to dyslexia to epilepsy, to name a few conditions that can be subject to disabling characteristics and further disablement by society. For example, a tonic clonic (previously Grand Mal) epileptic seizure could render you dis-abled at the time of and after the seizure, yet you may be further disabled by being excluded from certain activities *because* you are an epileptic. The World Health Organisation (WHO) categorise disability as an "interaction" that takes place between individuals with "health conditions" and the environmental factors that the individual encounters (WHO, 2021). The WHO also outlines additional concerns that further disable people in relation to attitudinal, physical, communication and financial barriers with regards to healthcare (WHO, 2021). The WHO recognise that "people with disability" are more likely to face stigma and discrimination within the health systems (WHO, 2021).

Jones (2018) cited in Goodley et al. (2019) argue that disability is a politicised phenomenon shrouded by "precarity, crisis and uncertainty" (Goodley, Lawthorn, Liddard, & Runswick-

Cole, 2019, p. 972). Situating this within feminist epistemology; the personal becomes political, the interaction between people and the policy contexts of healthcare, education, funding streams and care systems locates people with health conditions in further precarity and at the mercy of others. Personal lives can become scrutinised at the most vulnerable and uncertain of times. Disability becomes political when our neurodivergent children with 'health conditions' are further disabled by being continually excluded from school at a higher rate than students without health conditions (Goodley, Lawthorn, Liddard, & Runswick-Cole, 2019, p. 973).

Situating disability within a social model of health calls for research and analysis of the restrictions neurodivergent people face daily, this research must be ecologically situated within the relevant social, political, and economic landscape (Mulvany, 2000, pp. 582-601). To understand an ecological perspective, we can employ Bronfenbrenner's (1979) conceptualisation of human development. Humans are a product of interactions between the individual and four environmental systems: micro, meso, exo and macro (Maidment, 2013, pp. 171-172). The micro system is a person's immediate surroundings; the meso system is a connection of two or more settings within a person's environment; the exo system begins to incorporate education, health and welfare institutions and the macro system are the overarching belief systems that exist within society (Maidment, 2013, pp. 171-172). An ecological framework acknowledges that these systems are interactive with one another and the individual and with each interaction is an outcome; these outcomes can affect the individual in both positive and negative ways.
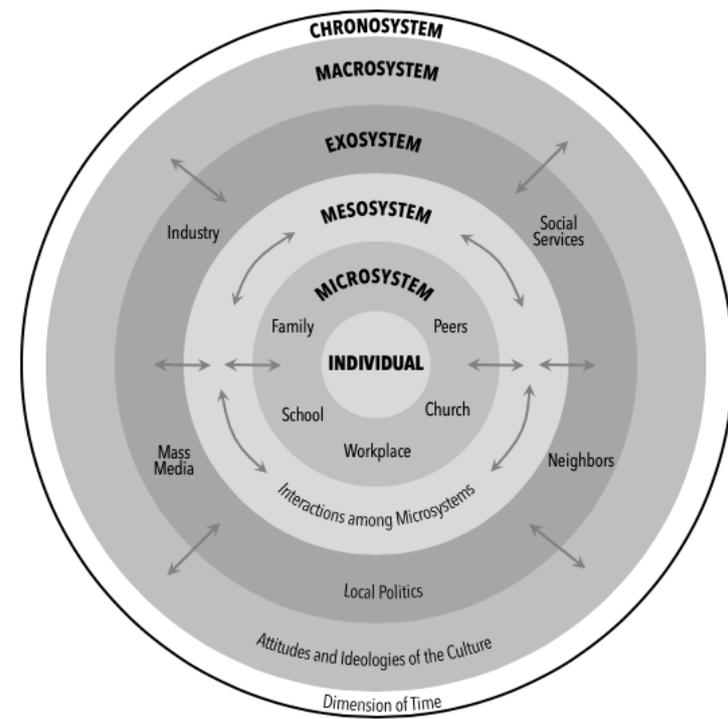
Figure 2: Ecological model (Davis & Francis, 2022)

By taking an ecological approach and locating a neurodivergent person within the context of their environment and then further within the structures of society in which they must conduct their lives, we can begin to understand what true inclusivity means. Social inclusivity became the buzz word as the disability movement took hold globally in the 1970's and 80's. Despite the intervening years Davis, cited in Mulvany (2000) argues that further analysis is needed to unpack the gap between social inclusivity as an ideal versus the reality of resource delivery and support (Mulvany, 2000, pp. 582-601).

Disability studies scholars over the years have been producing research to counter the hegemonic views of disability within society; those being to individualise and pathologize dis/ability (Goodley, Lawthorn, Liddard, & Runswick-Cole, 2019). The individualisation of disability sits squarely within the medical model of health, by identifying *problems* within the individual with the aim to treat or cure (Lalvani P. , 2019, pp. 50-70). Individualisation is also

a key tenet within the capitalist mode of production that the global neo-liberal market takes its lead. Goodley et al. (2019) go so far as to say that hegemony seeks to depoliticise disability by making stigma and discrimination the norm (Goodley, Lawthorn, Liddard, & Runswick-Cole, 2019, p. 973). Oliver and Barnes (1993) argue that disability can no longer be seen in medical terms affecting small numbers of people but as a "civil rights issue" that should be central to sociological thought just as class, race and gender (Barnes & Oliver, 1993; Priestley, 2016).

3.3.1   Ableism

Ableism is the way in which certain abilities and ideals such as cognition, physicality, independence, and autonomy are favoured within society. There can be negative feeling towards people who do not possess such qualities (Goodley D. , 2014). Ableism believes in the 'norm' whether it is the scientific 'species-typical', the political 'normative citizen', or the lawful 'reasonable man'. By aspiring to these norms, we internalise ableist thinking, the idea being the more you can emulate this version of 'normal' human, the more you will function and prosper (Goodley D. , 2014).

Ableism leads us to an understanding of ourselves based on ability, with the lack of ability becoming dis-ability. Ability and function are tied to the neo-liberal able self; able to work, able to perform, able to produce and consume. From the beginnings of our days at school we are sorted, sifted, and tested to become "pliant workers and active consumers" (Goodley D. , 2014). Reworking Shakespeare, "all the world's a *neoliberal* stage and all men and women merely players".

3.3.2 Stigma

Disability is multi-dimensional and should be viewed as such when accessing healthcare, education and/or other societal systems yet when disability is seen as one-dimensional, this can result in stigma and prejudice (WHO, 2021). The World Health Organisation (WHO) disability report (2011) showed that people with disabilities were,

- Twice as likely to find their healthcare providers inadequate (skills and equipment)

- Three times more likely to be denied care,

- Four times more likely to be treated badly in comparison to their non-disabled counterparts,

(Shakespeare T. , 2018).

Erving Goffman's theory on stigma is particularly relevant to disability. Goffman makes a distinction between the 'virtual social identity' – the stereotypical beliefs we hold and the 'actual social identity' – attributes that an individual *actually* possesses. Stigma occurs when there is a discrepancy between the two (Nettleton, 2021). Goffman wrote that stigma could take the holder from a "whole and usual person to a tainted, discounted one" (Goffman, 1963) and can extend to other persons associated with the stigmatised person. Therefore, parents, invariably mothers due to the ratio of care, can feel stigma, judgement and blame just for being the parent of a neurodivergent child, this can be perceived or enacted due to negative labelling and shame (Francis, 2012, p. 929). Zhang et al. (2022) identify this as 'affiliated stigma' in Chinese parent's experience of children with mental illness. Affiliated stigma is when both the mentally unwell child feels stigma but also associated persons. Feelings of affiliated stigma can be real or perceived (Francis, 2012; Goffman, 1963; Zhang, Wu, & Sheng, 2022).

3.4 NEURODIVERSITY – MOVEMENT AND PARADIGM

The term neurodiversity is credited to Australian sociologist Judy Singer. Singer (1998) related neurodiversity to the theory of biodiversity and explained that just as there is diversity within an ecosystem, there is also diversity within humanity. Singer believed this application may be useful when considering neurological differences such as ADHD and Aspergers (Milton, 2020, p. 3). Diversity within ecosystems provides richer environments, the same can be said for humanity, our everyday interactions can be enriched by experiences with neurodivergent persons and diverse groups of people.

The neurodiversity movement and the autistic rights movement have overlaps but are no means the same thing as the term neurodivergent is not synonymous with the term autistic. The autism rights movement was born out of response to an advertising campaign from NYU Child Study Center with Ari Ne'eman and Jim Sinclair as prominent people of the movement (Soloman, 2008). Jim Sinclair's speech[14] "Don't mourn for us" predates the neurodiversity movement in which he invited parents to explore what *is* rather than what *could have been*, he talked of parental grief and trauma in learning that their child is autistic. He says "I invite you to look at our autism, and look at your grief, from our perspective…" (Sinclair, 2012). The power in this speech comes from the challenge of letting go; letting go of what you *thought* was 'normal', what you *thought* your relationship *was* going to be like with your child, letting go of your *expectation.* Only once you have started letting go can you truly see the child that is in front of you (Sinclair, 2012). This speech is about acceptance; acceptance is the beginning; without accepting who your child *is,* you spend a lot of time fighting;

---

[14] https://www.autreat.com/dont_mourn.html

fighting yourself, fighting with your child, fighting the system, everything. Acceptance opens possibilities of what could be.

Walker (2021) distinguishes between neurodiversity as a movement and the neurodiversity paradigm. The movement seeks acceptance and inclusion through "civil rights, equality, respect, and full societal inclusion for the neurodivergent" (Walker, 2021, p. 25). Whereas the neurodiversity paradigm is the perspective or approach on which the movement is based. There are 3 fundamental principles of the neurodiversity paradigm; neurodiversity is a natural and valuable part of human diversity; the idea of 'normality' in relation to neurocognitive functioning is culturally constructed; and lastly that the dynamics relating to other forms of human diversity such as power inequality are also relatable. Walker acknowledges that social dynamics can be positive as well as negative and when diversity is embraced fully it can act as a source of creative potential (Walker, 2021, p. 36). Kapp et al. (2020) suggest the term 'neurodiversity' refers to a principal of inclusion and that inclusivity should extend to all corners of life be it education, employment, housing, freedom from abuse and the right to make decisions for themselves (Kapp, 2020).

Nick Walker clearly distinguishes between terms used within the neurodiversity paradigm to help people better understand new terminology[15]. Walker's distinctions are important as words being used incorrectly may cause further confusion, especially when new concepts/paradigms are emerging (Walker, 2021, pp. 31-46). A paradigm is more than an idea or method, it is a mindset or frame of reference that shapes the way someone thinks about a particular subject. A paradigm is a lens in which we see reality and shapes the way we interpret information (Walker, 2021, p. 36).

---

[15] https://neuroqueer.com/neurodiversity-terms-and-definitions/

To fully reach the potential of the neurodiversity paradigm we must let go of the cemented ideas of the dominant pathology paradigm, Walker calls this 'throwing away the master's tools' and draws on Audre Lorde (1984) to emphasis his point. The pathology paradigm is in embedded in the medical model of health and comes downs to believing in a 'normal' human brain and correct way of functioning therefore if you are seen as deviating from that 'norm', there is something 'wrong' with you (Walker, 2021, pp. 16-28). The pathology paradigm is the master tool and to work within it upholds values of deficit-thinking. For example, in the current edition of the DSM autism is considered a disorder with deficits in certain areas. This not only upholds the idea of normal-order in comparison to dis-order but gives reference points to measure the deficit against. The inclusion of autism, ADHD and other neurodivergences in the DSM upholds the pathology paradigm meaning that it will be extremely difficult for autism, ADHD, and other neurological differences to be classified as a divergence rather than a disorder.

3.4.1   Neurotypicality

Neurotypical is the term used for the style of cognitive functioning that is social constructed as normal or standard with neurodivergent being the opposite of neurotypical. Neurotypicality is what neurodivergent people diverge from (Walker, 2021, p. 40). Murray (2020) states that there are very few neurotypical people in the world as most people will have traits that mean they diverge from the 'average' or the 'norm'. The 'norm' being the idea of a 'default human' – one that is "white, male, well-off, cis, straight, abled, and neurotypical" (Murray, 2020, p. 105).
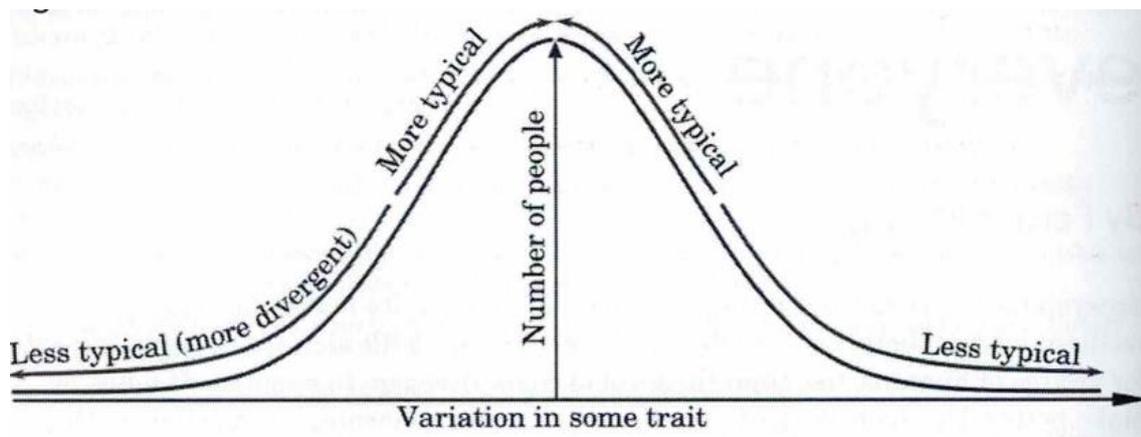
Figure 3: Trait variation bell curve (Murray, 2020, p. 106)

In relation to Murray's description, it is not difficult to diverge from the 'norm' yet depending on how close you can get to the tip of the bell curve by acting or masking[16] can depend on your ability to 'function' within society. Out of this constructed fictional reference point of 'norm' comes labels such as 'high functioning' and 'low functioning'. These terms are often used in relation to autism, yet Walker asks, "who gets to decide what the proper 'function' of any individual human should be?" (Walker, 2021, p. 27). In the pathology paradigm 'high functioning' is the term used when neurodivergent people can 'pass' as neurotypical. Walker dismisses terms based on functioning as this upholds the masters tools and insists that the neurodiversity rhetoric will never be dominant if neurodivergent people use the language of the pathology paradigm where they are continually compared against a fictional idea of 'normal human' (Walker, 2021, p. 27). Terms such as high or low functioning reinforce ableism by favouring a norm or typical way of being, i.e., high functioning as able and low functioning as disabled in accordance with a reference point.

---

[16] Masking is the act of hiding neurodivergent traits in order to function within a world designed for neurotypical people (Moriah, 2022)

3.4.2 Neurodivergences

There can be confusion in the literature regarding what constitutes as neurodivergence and the terminology surrounding the neurodiversity paradigm, this could occur for a couple of reasons. Firstly, there is no definitive list of neurodivergences under the neurodiversity umbrella which I understand as a testament to inclusivity. Kassiane Asasumasu intended the term *neurodivergent* to be as inclusive as possible and to understand neurodiversity as a "variation among minds" (Walker, 2021, p. 53). Secondly, due to specific diagnosis being required for some support structures, the neurodivergent person is likely to be directed to a psychiatrist. A psychiatrist utilising criterion set out by the DSM to diagnose specific neurodivergences such as autism or ADHD can be seen as pathologizing the neurodivergent person.

An example is an ADHD individual being understood as neurodivergent yet diagnosis for ADHD sits within the DSM and can be written about within the mental health realm. Is ADHD a mental health disorder or a neurodivergence? ADHD New Zealand, describe ADHD as a neurodevelopmental delay in which the pre-frontal cortex maturation is delayed (ADHD, 2022), the DSM puts ADHD in a chapter called "disorders that start in childhood" (APA, 2015, pp. 10-14) and Walker would say that ADHD is a neurodivergence – a mind that diverges from a socially constructed norm (Walker, 2021, p. 27).

How a neurodivergent individual is framed can impact many aspects of their life from participation/exclusion to essential funding eligibility. Eligibility for many funding streams still requires a diagnosis therefore while we can aim for inclusivity through the neurodiversity paradigm, the pathology paradigm is still the dominant force. Depending on who is writing,

how the writing is structured and within which field determines how ADHD and other neurodivergences are framed and perceived.

Ne'eman and Pellicano (2022) question the use of terminology such as 'neurodivergent', 'neurodiverse' and even neurodiversity. Ne'eman and Pellicano suggest that 'neurodiversity' as a descriptive term could imply a fear of the term disability (Ne'eman & Pellicano, 2022, pp. 149-157). Yet Walker states that when asked if autism were a disability, he would say no; asked if autistic people are disabled, he would say yes bringing to the fore that disability is socially dependent rather than individually dependent (Walker, 2021). This distinction illustrates that Walker's perspective is that the neurotypical world disables autistic people. Breadon (2017) uses the equation,

Autism + environment = outcome (Cameron, 2020, p. 119).

Highlighting that the weight of success for an autistic person sits squarely on the shoulders of the environment and the people within it (Cameron, 2020, p. 119).

3.4.3   Co-occurrence

The co-occurrence of neurodivergences can be common, this can add further complication when a neurodivergent person seeks diagnosis and furthermore tries to access suitable support. A few examples of co-occurrence are people with a primary diagnosis of ADHD have 25% of being dyslexic and dyslexic people have a 25-40% of also being ADHD and 25% of being dyscalculic (McBride, 2019, p. 78). The rate of co-occurrence between autism and epilepsy is between 12.1%-17.2% (Lukmanji, et al., 2019; Pan, Bolte, Kaur, Jamil, & Jonsson, 2021). In a New Zealand study of 9500 autistic young people the rate of co-

occurring mental health or other related problems was 68% (Bowden N. , et al., 2020, p. 2213).

The challenges that neurodivergent children face only intensify with co-occurrence, they can be more at risk of being held back academically, encounter more social difficulties extending to the workplace and potentially have more engagement with the law (Germano, Gagliano, & Curatolo, 2010, p. 476; McBride, 2019, p. 78). Runswick-Cole (2008) quotes the reality that one mother faces,

"If ADHD is unaddressed and untreated and particularly if a person is on the low IQ side… the prognosis is horrific and it includes depression, suicide, being in trouble with the law, jail, you name it. The worst things that happen in our society happen to people with ADHD…" (Runswick-Cole K. , 2008, p. 179).

Only by understanding the co-occurrence of neurodivergences can we support a person in a way that is best suited to them (McBride, 2019, p. 80). Diagnosis can play an important role in co-occurrence as different diagnosis have different outcomes and treatment options (Hunter, Higgenson, & Garralda, 1996, p. 199). Diagnosis can be crucial in terms of medication intervention when multiple medications or polypharmacy are used to 'treat' multiply neurodivergences.

3.4.3.1 Sensory processing

The interpretation of the senses can be hyper or hypo but either way for neurodivergent children they are often extreme. For some neurodivergent individuals the florescent lights of supermarkets and classrooms are bright. Now this is not 'a bit bright and carry on', this is

'too bright and it is piercing my eyes and burning my soul' bright. How does someone focus when that is how it feels? For some neurodivergent individuals the fabric of a t-shirt might be scratchy; this is not 'scratchy and carry on', this is 'scratchy and I feel like I need to scratch every inch of my skin that the fabric is touching and rip it off this second' but I can't because it's my school shirt. How does someone focus when this is how it feels? Some neurodivergent individuals might be sensitive to smell; this is not 'it smells a bit funny and carry on', this is a smell that is invasive, it begins as a smell, then it becomes a taste and then it becomes a feel and before long it has invaded every pore of my being. For a neurodivergent child in a New Zealand classroom, it can be a melting pot of sensory overload.

When a child experiences sensory overload, behaviours can be displayed that may not be considered 'normal' or 'acceptable' within the classroom. As a child tries to fight against the sensory overload or regulate themselves, they may 'fidget' or move a lot, they may flap their hands known as stimming and/or may physically remove themselves from the classroom, not having the capacity to ask first. The important thing to note here is capacity; when a brain is 'flooded' with sensory overload be it the lights, the t-shirt, or the smells – or a combination as it can be in a classroom – the capacity to ask, 'can I please leave the classroom?' is impossible. Sensory overload provides a huge amount of anxiety and can put a child into fight or flight mode, they are flooded with adrenaline and cortisol and self-regulation is pretty much impossible.

Delahooke (2019) notes that sensory processing is not integrated into the field of health, education, or social work despite it being a key piece of a neurodivergent child's profile. Sensory processing as a diagnosis narrowly missed being included in the latest version of the DSM (Delahooke, 2019, p. 68). Access to diagnosis could be an opportunity to build a

sensory profile that assists parents, teachers, and others understand how a neurodivergent child may respond to an environment. Diagnosis may also bring funding opportunities to make individualised accommodations to the environment so that it is more accessible for the child. However, due to the lack of diagnostic pathway for sensory processing, the tools to build a sensory profile for a child may be difficult to access, Delahooke (2019) has provided a starting point for resources in her book *Beyond Behaviours* (Delahooke, 2019).

3.4.4 Conclusion

Language/terminology can be difficult as different people prefer different words. If you asked William Shakespeare "what's in a name?" the quote continues as "that which we call a rose by any other name would smell just as sweet" (Shakespeare W. , 2004), implying that the naming of things is irrelevant. Yet Tom Shakespeare, professor of disability research would argue that the naming of things is relevant in relation to disability. "People with disabilities" is the preferred term in the UK. This is to recognise the person first rather than their 'medical condition' (Shakespeare T. , 2018). Shakespeare, Tom, also recognises the importance of the term "disabled person" as this emphasises that it is society that disables a person/people rather than their medical condition.

In relation to autism, Nick Walker (2021) argues that if we use person first language, "person with autism" or "families affected by autism" this reinforces the pathology paradigm taking up the assumption that autism is a problem to be gotten rid of. This indicates autism is an additional extra to the person; if you are "with autism" you can be "without autism". Within the neurodiversity paradigm, language of neurominorities is embraced i.e., "I am autistic", "there are autistic people in my family". Walker explicitly states, "if someone is autistic, say they are autistic. It is not a dirty word." (Walker, 2021). Farahar and Foster (2021) make the

comparison of a white British woman – you would not say "person with whiteness" therefore "person with autism" is non-sensical (Farahar & Foster, 2021, p. 198).

It is possible to use neurodiverse incorrectly, as the editors of *Neurodiversity studies* (and Walker) claim; to talk of an individual as diverse is nonsensical. Diversity can only be possessed by a group and to identify an individual as diverse puts them as 'other' in relation to a 'norm' (Rosqvist, Chown, & Stenning, 2020; Walker, 2021). Linguistically then, an individual should be referred to as neurodivergent.

Whilst new movements and paradigms can bring language confusion, it is particularly important that correct terminology is used when writing policy. Language is the policy vehicle that either opens or closes doors to neurodivergent people especially in relation to financial support but also physical support. This chapter has covered a wide range of topics from the deficit-based language of the medical model to the strengths-based neurodiversity paradigm with discussion on polypharmacy, disability and associated concepts.

4 POLICY IN NEW ZEALAND: HEALTH, EDUCATION AND SOCIAL SERVICES

"The farther back you can look, the farther forward you are likely to see." (W. Churchill)

4.1 INTRODUCTION

The intent of this chapter is to broadly outline how policies for neurodivergent children have evolved over time within the context of Aotearoa New Zealand. Policies relating to disability, mental health, education, and child welfare are considered. For families of neurodivergent children the needs of both the child and the parents can be complex and there is potential to interact with multiple government funded agencies such as Ministry of Health, Ministry of Education, Oranga Tamariki and the police on a regular basis. Therefore, it is important to outline how each policy context has evolved and additionally how the policies come together in times of need to serve neurodivergent children and their families. The policies rarely interact seamlessly with one another when needed.

Health, education, and state funded systems all exist within the wider context of capitalism, that being the system of "ownership, production, and exchange" in accordance with market driven processes (Hyslop, 2022, p. 4). Morley et al. (2020) argue that due to the neoliberal context in which all these services operate promotes formulaic, technique-driven, competency-based practice that results in surveillance and compliance that protects the worker rather than the families (Morley, Ablett, & Noble, 2020, p. 3).

Incorporated throughout this chapter are examples of funding models within disability and education policy contexts. By no means is this an exhaustive list of funding opportunities but a snapshot of funding streams linked to policy guidelines of inclusion. I also outline collaborative services funded by Oranga Tamariki, again linked to inclusion within the structures of the family, education, and society. Finally, I will touch on the role of New Zealand police, not so much from a policy perspective but because the police are a frontline service for the most vulnerable people in society who require support when all other systems have broken down.

4.2 DISABILITY

New Zealand played an important role in the development of the United Nations Convention on the Rights of People with Disabilities in 2006 (Needham, 2016; Stace & Sullivan, 2020). The principles of this convention are reflected in the New Zealand Disability strategy, which states that, "New Zealand is a non-disabling society". The goal is that New Zealand will be a place where disabled people will have the same opportunities as a non-disabled person to achieve their goals (MSD, 2016). The New Zealand Disability strategy has eight outcomes of achievement, these are, education, employment and economic security, health and wellbeing, rights protection and justice, accessibility, attitudes, choice and control and leadership (MSD, 2016). There is considerable data missing in each of these areas to be able to provide suitable policies that bring positive outcomes for all New Zealanders. Statistics New Zealand report that disabled people continue to fare worse than non-disabled people in many aspects of daily life in New Zealand (StatsNZ, 2021).

Priestley believes there are three significant characteristics of how disability is framed in policy through a strengths-based approach, firstly, a change in thinking: moving from a medical individualised view to a societal collective responsibility. Secondly, a shift in policy from care and compensation to one of equal rights and social inclusivity and lastly, possibly the most important, a coming together of voices from the disabled community to represent themselves and be fully active in policy discussions and welfare outcomes (Priestley, 2016, pp. 439-444).

4.2.1 Enabling good lives

The enabling good lives framework was rolled out in 2011 with the vision of giving disabled people more choice and control over decisions made about them and their lives with regards to individualised funding they receive There are eight guiding principles under the enabling good lives framework, they are,

- Relationship building

- Easy to use

- Mana enhancing

- Mainstream first

- Ordinary life outcomes

- Person-centred (person-directed)

- Beginning early

- Self-determination (EnablingGoodLives, 2023).

While anyone can employ the principals of enabling good lives, the Enabling Good Lives systems transformation approach wants to see all agencies follow the eight principals for disabled persons who have been granted individualised funding. The systems transformation

approach is designed to fully support a disabled person to have a good life, recognising that a good life looks different for everyone. The systems transformation prototype, Mana Whaikaha, has been rolled out in the mid-central region of New Zealand and there are further rollouts planned for other regions (EnablingGoodLives, 2023). The Ministry of Social Development believe that this system is a transformation of disability support services due to a social investment approach and having a co-design process (MSD, 2023).

4.3 MENTAL HEALTH

New Zealand has a long history of incarcerating individuals who were deemed mentally unwell and potentially posed a threat to themselves or others, leaving a legacy of exclusion, stigma, surveillance, and removal. It is important to understand the history of mental health services in New Zealand to see how that impacts recent policy development. The first mental health legislation dates back to the Lunatics Ordinance Act of 1846 with the first lunatic asylum (not attached to a jail) opening in Karori in 1854, followed by Porirua in 1887. Lunatic asylums continued to open around the country modelled on the British system of the time (Soosay & Kydd, 2016; Stace & Sullivan, 2020).

The Mental Defectives Act (1911) classifications of unsound mind, mentally infirm, idiots, imbeciles, feeble-minded, and epileptics allowed justification for these persons to be locked away from society. Some of these categories were associated with immoral behaviour therefore, boys and girls were separated to eliminate deviance and unwanted reproduction (Stace & Sullivan, 2020). While sterilisation was never made legal, it was likely to have happened under the guise of other operations such as appendectomies. Kimberly was the last to close in 2006 where the children had grown into adults and many not knowing why they

were placed there in the first place (Stace & Sullivan, 2020). The published stories of some long-term residents such as Sir Robert Martin describe the horrific experiences of being incarcerated for so long (McRae, 2014).

1928 saw an amendment to the 1911 Mental Defectives Act that meant any children deemed "at risk" could be taken off families and families could also commit their children voluntarily (Needham, 2016; Soosay & Kydd, 2016; Stace & Sullivan, 2020). The framing of 'at-risk' children is part of our history and removal of children from the family unit is a long-standing practice (Stace & Sullivan, 2020). The removal of children highlights the entrenchment of surveillance of the family unit in New Zealand culture.

Parents of children with intellectual disabilities formed the Intellectually Disabled Children's Parents Association in 1949 with the goal of advocating for schools and community organisations that their children could attend rather than their children being committed to institutions. Originally, they faced backlash and discrimination as institutions were increasing rather than decreasing. However, concern for institutionalisation continued to grow culminating in the 1973 Royal Commission with recommendations leading to 30 years of deinstitutionalisation. During this time the Government were funding both the large institutions – with decreasing residents – as well as the community services that they were being transitioned to (Stace & Sullivan, 2020).

With the "mother of all budgets" in the early 1990's support for disabled people became an individualised problem, feeding off the wider capitalist context and emphasis on being fit for the labour market; if you were not, it was your fault. In this era the idea of 'function' was firmly rooted within the medical model of health and disability viewed as an individual

problem, and no responsibility placed on society (Stace & Sullivan, 2020; Walker, 2021) Mental health diagnosis and neurodivergent persons were very much viewed through a disability lens during this time, meaning that health policy was being shaped by deficit-thinking.

Due to major changes in mental health policy, including deinstitutionalisation, most people experiencing mental unrest live in the community (Mulvany, 2000, pp. 582-601), with many physically impaired persons living independently with/without carer support. Most care falls to family (or mothers) with varying degrees of recognition. In an American study of 40 parents, Scott (2010) found 36% of single mothers (8/22) and 50% of married mothers (9/18) had to leave the workforce to look after their disabled children. Not all disabilities were mentioned but there were families with autistic children, downs syndrome children and intellectually impaired children among others (Scott, 2010, pp. 672-696). This reinforces the patriarchal discourse within society that care of children is the woman's responsibility. In New Zealand, parents and family have long lobbied to be recognised as fulltime carers (CarersNZ, 2022). While all parents care about their children, being a *fulltime carer* to neurodivergent child or family member is a very different reality for some.

Neurodivergent people are at a higher risk of mental illness due to many factors including stigma, isolation, self-worth, and burnout (Lewis, 2022). Work to destigmatise mental health diagnosis and to understand neurodivergence for individuals and wider society continues. The Mental Health foundation have several programmes designed to support all New Zealanders as well as campaigns to reduce stigma and discrimination such as *Like minds, like mine*, indicating that mental illness can happen to anyone and at age (MHF, 2022). With regards to prejudice and discrimination relating to mental illness, one-fifth of people with mental

distress reported being discriminated against mostly in the workplace closely followed by family and friends (MHF, 2022). With almost one in two New Zealanders experiencing mental illness or distress at some time in their life, more compassion and understanding is needed. A recent World Health Organisation (WHO) report highlighted; 1 in 7 10–19-year-olds are experiencing a mental disorder, yet many go undiagnosed and/or untreated (WHO, 2021).

4.3.1   Child and adolescent mental health

In 1977, the WHO estimated between 5-15% of children aged between 3-15 years old showed prevalence of "persistent and socially handicapping mental health problems" (WHO, 1977). The WHO expert committee also recommended health policies specific to children and adolescents that included wraparound involvement from justice, education and social welfare (Baistow, 2003). In 2021, 10% of all children and adolescents worldwide are experiencing a mental disorder with many not accessing support and suicide being the fourth leading cause of death for 15–19-year-olds (WHO, 2021). These figures indicate that the number of children and adolescents presenting with mental health challenges has not decreased since 1977. National surveys from the UK, Australia, and USA report that only between 25-56% of children and adolescents with a mental health condition access specialist service (Reardon, et al., 2017, p. 623). Stigma from both having a mental health problem or accessing services has been identified as a barrier to attending a mental health service (Reardon, et al., 2017, pp. 623-647).

According to UNICEF (2020) "New Zealand is failing its children" and despite being a country that promotes academic success, internationally renowned sports teams and "the

great outdoors" NZ were rated an F for Failure. Reasons for this include our suicide rates, our childhood obesity rate sits at 1 in 3 children and only 64% of 15-year-olds have basic reading and maths proficiency. One of the strong recommendations is to address the significant gap in mental health services for children and adolescents (UNICEF, 2020). While there are community mental health services with a range of service options there are significant gaps in access, wait times and suitable wraparound support.

The need for these services in New Zealand is indicated by data suggesting children as young as 10 years old have committed suicide (Justice, 2020), along with a school-based survey between 2007-2012 reporting 31% of young people had experienced low mood, 15/7% reported suicidal ideation and 24% engaged in self-harm each year. The long-term consequences of this include disengagement with learning, social exclusion, lesser job opportunities and overall poorer life outcomes (Bowden, Thabrew, & Kokaua, 2020; Michail, 2011, p. 159).

Internationally it is recorded that half of all long-term mental disorders emerging before the age of 14 years old (Reardon, et al., 2017, p. 623), and 7 in 10 autistic people suffer with a mental health problem (Autistica, 2023). These statistics further highlight why social service provision needs firstly, to be accessible to neurodivergent children and secondly, be able to offer specific suitable support.

4.4 CHILD SOCIAL SERVICES

The caring and welfare responsibility of children in pre-colonial New Zealand fell to the whanau (family); within the whanau there were many caregivers. The governing familial

practices were whanaungatanga (kinship), whakapapa (lines of descent) and tikanga (customs). Throughout the 1800's the structure of the family changed to a more nuclear British model; the British model was supported and upheld by welfare systems established in New Zealand (Brookes, McCabe, & Wanhalla, 2019, pp. 9-14; Nash & Miller, 2013).

In the late 1800's a range of social services were set up as the state played a bigger role in people's lives. The desire for a fit, ordered society promoted eugenic ideals and saw the 'unfit' committed to asylums, including children (Dalley, 1998; Stace & Sullivan, 2020). Against this backdrop was also child protection and child saving movements; the English National society for the prevention of cruelty to children was founded in 1889, now known as NSPCC, children were seen as the future and were something to be protected. The notion of protection allowed social service agencies to remove 'at risk' children from their families also giving rise to further surveillance of families of children who were framed as 'risky' (Dalley, 1998).

At the turn of the twentieth century child welfare was subject to policy and practice from other government agencies; education, justice, and police. Providing social service provision for "neglected, destitute, and delinquent" children was ingrained in New Zealand state policy (Dalley, 1998). Social workers became the statutory profession overseeing child welfare and protection. Connelly and Harms (2015) see social work as not only helping individuals at a micro level, but that social work should also be concerned with changing the systems that continually disadvantage those individuals (Connelly & Harms, 2015, p. 14).

However, child welfare and policy are volatile subjects. Despite the 1989 Child, Young Person, and Family Act (renamed the Oranga Tamariki Act 2017) often proclaiming the

support for families along with their collaborative approach with Māori (Keddell, 2018, p. 95), child protection can still be described as clinical and adverse. Rather than being engaged with families, families are being watched (Hyslop, 2017, pp. 1800-1817). Ingrained in the Oranga Tamariki Act is the construction of the vulnerable child and by framing children in this way can justify access to services – positive and negative (Keddell, 2018, p. 99). By framing children as 'vulnerable', 'at-risk', 'risky', 'violent', and/or 'delinquent' influences the interpretation of who these children are sometimes before they are seen in person. When children are framed this way, it does not set them up for positive interactions with services geared up to support them. Instead, it can warrant inspection, intrusion and stigma for families attempting to access such services (Keddell, 2018, p. 96). When families become engaged with multiple agencies collaboration is paramount to success. Two collaborative services funded by Oranga Tamariki that can assist families in coordinating many agencies with the aim of better outcomes are Strengthening families and Family group conference.

4.4.1 Strengthening families

The Strengthening families framework provides a coordinated service for families who are involved with more than one community agency. The service is free and voluntary. The family is put in touch with a strengthening families coordinator and together they decide which agencies need to be 'at the table'. This can enable the family to address many people and many issues at once and not have to tell their story multiple times. Families can self-refer or be referred by an agency that they are already involved with. There must be more than one area of concern, two or more agencies involved and at least one child under 18 years old (StrengtheningFamilies, 2022).

Strengthening families is funded by Oranga Tamariki and previously had 38 coordinators around the country. 17 of these coordinated services have been disbanded and funding will cease in April 2023. This service will no longer be available in Tauranga, Bay of Plenty. An advocate for Strengthening families Nelson – also disbanded – says "it's ridiculous to be scrapping it… it is so powerful for the individual families" (Ridout, 2023).

4.4.2 Family group conference

A Family group conference (FGC) is a structured meeting prescribed by the Oranga Tamariki Act 1989. Depending on the needs of the family involved and/or concerns for the child, an FGC is run by either a care and protection coordinator or a youth justice coordinator employed by Oranga Tamariki. An FGC is an extensive process of information gathering and committed participation to ensure that all areas of concern are identified and can be discussed openly. This is to ensure the best possible support for the young person and their family (OrangaTamariki, 2022).

4.5 EDUCATION

The current New Zealand education system is less than 150 years old with the first Education Act (1877) establishing free, compulsory primary education (Mutch, 2008, pp. 197-211; Swarbrick, 2008). Compulsory was a loose term as children were expected to attend for half the time that the school was open as going out to work was still a priority. The curriculum was based on the British system focussing on reading, writing and arithmetic, other subjects were available (Swarbrick, 2012).

The correspondence school, Te Aho O Te Kura Pounamu (Te Kura) started in 1922 to cater for primary age school in more remote areas of New Zealand, the numbers of students attending correspondence school has grown over the years. Te Kura started with approximately 100 students and a single teacher writing to those students by hand, Te Kura now supports the educational journey for 10,000's of students across New Zealand for a variety of reasons (Kura, 2022).

The 'Tomorrow's Schools' report of 1989 saw an updated Education Act which prompted the establishment of the Ministry of education (MOE), the Education Review Office (ERO), New Zealand Qualifications Authority (NZQA), and the Education Council. This gave rise to managerialism and accountability and put the administration and daily running of schools into the hands of boards of trustees with teacher and principal representation and left policy implementation to MOE. In part, this system was believed to create competition and a 'free market of education'; if schools were in competition, it would make them strive for the best results. Little consideration was given to *how* schools were going to achieve this operationally. It was in this version of the Education Act that Kura Kaupapa Māori schools were recognised as a state school option (Tearney, 2016; Wood, Thrupp, & Barker, 2021, p. 279).

The New Zealand Curriculum framework was published in 1993 with a focus on inquiry-based learning and to foster skills that would produce inclusive, responsible citizens. The 2007 amendment of the curriculum outlined that areas of teaching should be consistent with high expectations, cultural diversity, inclusion, coherence, future focussed, the Treaty of Waitangi, community engagement and learning to learn (TKI, 2022). However, increasingly challenging problems remain within education with many reports published on declining

literacy and numeracy levels (Stanford, 2022; Wells, 2022). The NCEA system is in a process of change.

Currently New Zealand has about 50% attendance of enrolled students with the Government recently setting targets to reduce truancy. The targets are 70% of children to be regularly attending by 2024 and 75% by 2026, with extra measures to record, notify and act on chronic absence. Chronic absence is defined by missing at least three days out of a fortnight (Henry D. , 2022).

4.5.1 Inclusive education in New Zealand

A major educational policy shift was the promotion of inclusive education, the UNESCO definition of inclusive education states that "all students can access and fully participate in learning, supported by reasonable accommodation and teaching strategies tailored to meet their individual needs" (Kewanian, Creely, & Southcott, 2021). Being free of barriers to attend, participate and achieve are indicators of inclusive environments (Selvaraj, 2015, pp. 86-101). However, inclusive education in New Zealand has been and still is marred with confusion and constraint.

The Special Education 2000 (SE2000) framework was developed to better understand what an inclusive classroom should be. There was continued confusion over *who* needed extra support, *what* support involved and *who* was providing it, this prompted a new approach to funding and assessment criteria. Ideally there was to be extra support both in manpower and equipment along with curriculum adaptation and other resources provided within the classroom (Powell D. , 2012; Selvaraj, 2015). Within the NZ Disability strategy (2001) the

core goal was to eliminate societal barriers that disable people with long term impairments, this includes a commitment to inclusive education (Powell D. , 2012).

In July 2020, the Government provided $66 million for learner and educator wellbeing, one of the goals was additional support for learners with "mild to moderate, to high and complex needs including those who are neurodiverse and gifted" (MOE, 2020). While schools in New Zealand do not collect disability data for suspended students (Shivas, 2022), it is reported that autistic children are almost 3 times more likely to be stood down or suspended than non-autistic children (Crawshaw, 2022). Furthermore, media items consistently highlight the cases of children with high and complex needs being excluded. For example, headlines over the past 10 years have included:

- "*'Woefully deficient' youth services"* (Harper, 2011)
- *"Special needs girl off school after extra funds refused* (Corrie, 2011)
- *"Where's the action on the suicide crisis in New Zealand"* (Roughan, 2019)
- *"Schools' exclusion of children with high needs 'common' – advocates"* (Williams, 2021).
- *"Youth mental health crisis is getting worse"* (Doocey, 2022)

The headlines above imply that the complex needs of some learners have not been met for a very long time, long before Covid-19. The above examples could also suggest that the policies written for the diverse landscape of learners including adaptability of teaching and inclusive classrooms do not translate to real life for neurodivergent children experiencing mainstream education. However, there are two important funding streams described below that neurodivergent children and young people (and their families) can access providing the meet the criteria.

4.5.2 Exclusion

Exclusion within education can be described as both formal and informal – formal being a stand down or suspension, informal being asked to take your child home or keep them home to avoid stand down or suspension, also known as 'kiwi suspensions' (Kiernan, Mitchell, Stansfield, & Taylor, 2019, p. 183; Starr & Janah, 2016, p. 24). The relevance of school exclusions to the context of New Zealand, is illustrated by the statistic that autistic children are stood down at three times the rate of children who are not autistic (Henry D. , 2022). It is important to note that this figure does not include the number of parents who are *informally* asked to keep their child home for the day or the week to possibly avoid formal exclusion processes. Youthlaw (2016) notes that "kiwi suspensions" had tripled in the two years prior to 2016, "kiwi suspensions" are illegal (Starr & Janah, 2016, p. 24). Gerritson (2016) reported on the rise of these illegal suspensions with one principal commenting that "kiwi suspensions have their place", and the Ministry of Education spokesperson believed that in most cases "sound processes were followed" (Gerritson, 2016). Youthlaw dealt with 45 cases such as this in 2015 which had increased threefold since 2013 (Gerritson, 2016), there will be many more that have gone under the radar unbeknown that this process is illegal.

4.6 FUNDING STREAMS TO SUPPORT INCLUSION IN MAINSTREAM EDUCATION

This section outlines three funding streams available through the Ministry of Education and explains why they can be helpful to families of neurodivergent children. During the referral process there may be other agencies needed to provide written and physical support, for example Oranga Tamariki and/or Ministry of Health. The requirement for support increases the number of agencies that a family must interact with if they want access to funding.

Dealing with multiple agencies can be complex, and communication is key, this can be difficult if everyone is not available at the same time. Co-ordination of a team of people is a specialised job, Strengthening Families is a framework that can facilitate bringing together different agencies for collaborative purposes and positive outcomes. The loss of funding to several SF coordinators will be a great loss to families dealing with multiple agencies.

4.6.1 Interim Response funding (IRF)

Interim response funding is an internal process that only involves the school and Ministry of Education. This type of funding is short term to deal with a challenging situation involving a student. Criteria for this funding is that the student or others may be harmed if a change is not made quickly, this will allow schools to provide extra support for the child until a long-term plan is devised (MOE, 2023).

4.6.2 Ongoing Resource funding (ORS)

Ongoing Resource funding (ORS) is for students who have the "highest ongoing levels of need for specialist support at school" (MOE, 2023). ORS is based on criteria of need in either, learning, hearing, visual, physical, mobility and/or language use and social communication. There are nine levels of criterion with different forms corresponding to different levels of need, navigating the Ministry of Education website can be confusing with many forms to download and consider[17]. Access to ORS requires diagnosis, for example a hearing difficulty will have needed to be established, as would any physical or mobility

---

[17] https://www.education.govt.nz/school/student-support/special-education/ors/apply-for-ors/

challenges a child may face. A diagnosis relating to language use and social communication for example, could be autism (ASD).

There is research to suggest that Ongoing Resource funding can alleviate some suspensions for autistic children and with additional funding and support autistic children can be more successful in the mainstream school environment (Bowden, et al., 2022), yet the criteria can be extremely restrictive and many autistic students will never qualify.

4.6.3 High and Complex Needs funding (HCN)

Much of my knowledge of High and Complex Needs (HCN) funding comes from personal experience after it was mentioned to me by a mental health nurse at Starship hospital. I learned that there must be two referring agencies supporting the application that can be either, Ministry of Health, Ministry of Education and/or Oranga Tamariki. If the funding is approved the referring agencies agree to stay involved with the child and family for two years. 'High and complex needs' as an internet search combination is popular yet there is little information specific to the HCN funding stream therefore information for parents searching online is minimal. There are two annual reports published at www.hcn.govt.nz for years 19/20 and 2021, with no up-to-date data available and there is no specific information for referral processes. The website is copyrighted to Oranga Tamariki.

In December 2000 as part of the Labour-led government (1999-2008), Cabinet agreed to a "strategy for children and young people with high and complex needs that needed cross-sectoral services" (HCN, 2005). HCN focuses on safety, mental wellbeing, family relationships, cultural identity, social interaction, belonging, education and independence

(HCN, 2005). The interagency strategy outlines that HCN exists due to consistent "unmet need" from government agencies towards children and young people with "mental health and behavioural problems" and "the most challenging" children. This funding stream is designed to allow better collaboration between agencies and achieve better outcomes. The strategy does not consider itself a crisis service (HCN, 2005) however, consistent unmet need often leads to crisis and 'crisis point' is how some families find themselves involved with this area of funding. The HCN unit supports approximately 100 children a year with plans lasting for up to two years.

My experience of the HCN process from referral through to *discussion* of the eight-point plan lasted about ten months. Ten months in meetings and ten months without the funding. Ten months is a long time when you are trying to access support for your neurodivergent child that had already reached crisis point. It was at this point that I withdrew from the HCN process as I had managed to gain support and funding in other areas, ten months was too long to wait. Complications arose with meeting times, all parties being available at the same time, place of meeting, and agreement on the eight-point plan. The plan is rigid.

4.6.4 Referral process/Outcome

Funding, such as IRF, ORS, and HCN, can be imperative for a neurodivergent child to be successful in the mainstream education environment however, the process of referral through to completion can be stressful and challenging. It is at the point of referral that families of neurodivergent children interact with state and government driven agencies such as Ministry of Education, Ministry of Health and/or Oranga Tamariki. Understanding the needs of families with neurodivergent children is complex and having relationships with such agencies

can be traumatic, stigma inducing and/or triumphant. The way relationships are formed with these agencies can be dependent on the referral process, i.e., whether the referral has been behaviour driven or diagnosis driven. While all pathways respond to a child's need, the way in which children are framed within the referral process determines which primary agency they deal with and which policy contexts they become entangled with. Framing is an integral part of the outcome.

Neurodivergent children can meet multiple criteria across funding streams but sometimes not all criteria on one list, this can be tricky. In some cases, diagnosis can help with the tick box nature of criteria. Criteria dependent on hearing capacity or visual capacity or behaviours attached to an ASD diagnosis (ORS) is very different to criteria that frame children as 'challenging' (HCN). ORS is framed around accommodations to the curriculum and the educational environment – it is designed to provide what the child needs to access and participate in mainstream education. The HCN funding model also has a driving force towards participation in mainstream school, however, the language in the HCN policy reflects a deficit-thinking model. For example, children that are referred through the HCN pathway, are referred based on being "the most challenging group of young people" with many presenting behaviours that are framed as "extremely challenging" (HCN, 2005). This framing immediately situates behaviour at the forefront of the referral rather than recognition of a neurodivergent child with potentially a complex mix of co-occurring conditions that needs very specific accommodations to be successful. In the two available financial reports it states between 69%-78% of children had diagnosed neurodevelopmental disorders present, including intellectual disability[18], ADHD, ASD, and others (HCN, 2021).

---

[18] Children with an intellectual disability may have trouble learning and everyday tasks, they may struggle to communicate and express themselves. This can prove frustrating and may cause the individual to behave in atypical ways (APA, 2015).

4.7 NEW ZEALAND POLICE

New Zealand Police are a frontline service to keep the peace, maintain safety, enforce the law and prevent crime along with community support and emergency management. The NZ police mission is to "prevent crime and harm through exceptional policing" (NZPolice, 2023). The police are also frontline support for someone in mental distress or crisis due to the risk they can pose to others and themselves. Neurodivergent people are at higher risk of mental illness (Lewis, 2022), therefore if mental distress reaches crisis point, neurodivergent people will invariably encounter police and/or ambulance staff. A recent New Zealand study found that police and ambulance staff were struggling to keep up with mental health demand and that these services found it difficult to work with mental health services (Kuehl, Kim, & Every-Palmer, 2023).

Despite the difficulties identified in working with mental health services, engagement with CAMHS is often essential, this includes their 24-hour crisis line. However, the crisis team may only see you in the emergency room of a hospital and depending on the level of crisis transport to the hospital may involve police and/or ambulance. As such, consideration of the role of the police and other frontline services is central to understanding the experiences of neurodivergent children and their families. The way that neurodivergence is framed through the medical model means that a neurodivergent child in crisis can be framed from a deficit position. Sometimes in a crisis, behaviour that is a call for help can be self-injurious and/or deemed to be violent, such behaviour can be framed as *challenging*. This makes police intervention necessary in certain situations but not always helpful.

An Australian study into carers perspectives on police handling of mental health call outs highlighted that while necessary there were several challenges. This included a lack of

expertise in mental illness and therefore the ability to respond appropriately was hindered, often exacerbating a situation. In addition, excessive use of force was reported, again this is possibly due to not understanding the situation from a neurodivergent mental health perspective but from a criminal/dangerous perspective (Brennan, et al., 2016).

There have been pilot programmes in New Zealand to trial a co-response model whereby police, DHB mental health services and paramedics jointly attend a mental health call out. A similar programme, the 'PACER' (police, ambulance, clinician early response) model operates in several Australian states with studies showing good outcomes (Every-Palmer, Kim, Cloutman, & Kuehl, 2023). The Wellington co-response trials proved successful with over 80% of people, professionals, and clients of services, saying the experience was better than the 'business-as-usual' model of single response (Cornish, 2022). However, it is important to note that this has not been rolled around across the country.

4.8 CONCLUSION

The context of my research is structured through New Zealand policy development regarding disability, mental health, education and caring for children. These policies need to be examined to better understand the ways in which families interact with those policy structures today. New Zealand has a policy field marred by surveillance grounded in deficit-based thinking that has potentially led to the removal of children from their family homes. Framing children in certain ways such as 'risky', 'challenging', 'delinquent' gives power to the organisation rather than the family. Neurodivergent children can often be framed in this way having detrimental effects to them, their family and society.

While only a snapshot of disability, education and care policies are considered in this chapter, all recent policies are invested in inclusion, social justice, and equity. However, historically the policy contexts of health, care and education reflect experiences of incarceration, marginalisation, and colonisation. These experiences are influenced by the way blame is assigned to individuals and families for their differences, labelling them as deviant perpetuates stigma and gives rise to exclusion, from not just education but society itself.

Despite the positive direction of recent health and education policy, research suggests that the reality for neurodivergent children and their families is different. Assumptions and values from the historical contexts of these systems still colour policy language and practice. This is exemplified by the ways in which, often it is our frontline services such as Police and/or ambulance staff that engage with neurodivergent individuals regularly, despite their training being minimal and relationships with mental health services being strained. The tension between policy aims and actual practice can have a serious impact on neurodivergent children and their families.

5 A LITERATURE REVIEW OF LIVED EXPERIENCES OF NEURODIVERGENCE

"Life is a succession of lessons which must be lived to be understood."

(Ralph Waldo Emerson).

5.1 INTRODUCTION

The parental experience of living with a neurodivergent child/ren and experiences of interactions when accessing suitable support services is well documented (Blum, 2007; Goedeke, Shepard, Landon, & Taylor, 2019; Good, et al., 2017; Harden, 2005). Many families face similar issues when accessing social services for neurodivergent children, highlighting that this is a public issue and not an individual problem (Mills, 1959, pp. 3-24). It is important to look beyond the individual and be aware that when inclusive policies are enacted by state driven agencies such as education and health, they collectively continue to exclude neurodivergent children; it is never one child or one family.

Parents can be made to feel like their child is the only one who displays 'difficult behaviour', is 'challenging to have in the classroom' or reacts the opposite way to a medication yet as you unpack the literature and listen to professionals, you realise that they are not the *only one.* It will always appear easier to remove *one* child from a classroom instead of changing a system but there are many *single* children being removed. It is estimated that autistic children are stood down at 3 times the rate of non-autistic children – that is a lot of single children. High and complex needs funding support approximately 100-150 of the 'most challenging' children across the country at any one time, in the financial year 2021, 78% had a

neurodevelopmental disorder – that is a lot of single children. Ongoing-resource funding supports approximately 1.2% of the school population, ORS funded students are seen to have extremely complex needs – 1.2% is a lot of single children. In 2021, CAMHS services across the country saw 51,000 patients – that is a lot of single children.

This chapter reviews literature from Singapore, England, Australia, America, China, and New Zealand. The overarching themes included, challenging behaviour, the significance of diagnosis, parental blame, a lack of support and understanding from professionals, the role of advocacy, and the social construction of parent and motherhood (Harden, 2005; Kiernan, Mitchell, Stansfield, & Taylor, 2019; Rafferty & Sullivan, 2017; Runswick-Cole & Ryan, 2019; Wodehouse & McGill, 2009). Parental accounts mostly involve the voice of mothers (Blum, 2007; Goedeke, Shepard, Landon, & Taylor, 2019; Good, et al., 2017, p. 107; Harden, 2005, p. 364). The role of mothers in the literature highlights the continued additional care load that women face perpetuating women in poverty due to their lack of earning potential as they are at home caring for and often educating their neurodivergent children (Litt, 2004, pp. 621-644).

Not all literature used the term "neurodivergent", however this literature was still included because the authors discussed children with diagnoses such as autism and ADHD which fall under the neurodivergence umbrella, and within the neurodivergent paradigm. The non-use of these terms may be due to date of publication and terminology of the neurodiversity paradigm not yet being embraced.

5.1.1 "Challenging behaviour"

Sometimes neurodivergent children can display behaviours that others find difficult, in these cases neurodivergent children may be referenced as "children with intellectual disabilities and challenging behaviour" (Kiernan, Mitchell, Stansfield, & Taylor, 2019, p. 175) or "comorbid challenging behaviours" (Lanovaz, Rapp, Gendron, Prefontaine, & Turgeon, 2017, pp. 145-169) or "school responses to students' challenging behaviours" (Michail, 2011) to name a few. This framing of behaviour as 'challenging' impacts negatively on the child and family when beliefs are internalised about the child's character (Chan, et al., 2012, p. 37).

Kiernan et al. (2019) acknowledge that terminology such as 'challenging' contributes to the marginalisation of neurodivergent people. The term is often used within childcare teams to describe "an individual and their presentation" but it can become a powerful label that leads to further stigma and prejudice (Chan, et al., 2012, p. 36; Kiernan, Mitchell, Stansfield, & Taylor, 2019, p. 185). By labelling neurodivergent children and/or their behaviours as 'challenging' squarely puts the emphasis on the child and not on the oppressive structures and environments that surround them, also known as deficit-thinking.

In a school environment repetitive behaviour that interferes with optimal learning in the classroom or prosocial interactions in the playground can be perceived as challenging (Michail, 2011, p. 157). Repetitive behaviours, both injurious and not, can be a form of 'stimming' for autistic children, stimming can be a method of self-regulation due to the child finding the environment overwhelming. Stimming behaviours can be labelled as challenging, yet Becker would argue that the behaviour is only challenging because an external person has labelled it so (Haralambos, Holburn, & Heald, 2000).

Chan et al (2012) advocate for a change in language from "challenging behaviour" to "behaviour of concern" acknowledging that language shapes our thoughts, feelings, and reactions (Chan, et al., 2012, p. 37). Delahooke (2019) states that all too often "we fail to determine the etiology of the behaviour before we try to change them" and very quickly blame can be attributed to both parent and child along with 'treatment' options being stricter parenting or other medication without knowing the *why* and the *what* (Delahooke, 2019, p. 10). Delahooke argues that instead of asking "how do we get rid of it?" we should be asking "what is this telling us about the child?" (Delahooke, 2019, p. 11). Changing the repressive response to behaviour to one of compassion and acknowledgement can lead to more appropriate support for children targeted as having behavioural difficulties (Chan, et al., 2012, p. 37). A change in language to 'behaviours of concern' is a proactive, preventative way of responding to concerning behaviour that is often labelled as challenging. Unfortunately, some people will only receive referrals once their behaviour has escalated to such a point (Chan, et al., 2012, p. 37).

5.1.2   Diagnosis

In New Zealand, unless you can pay for a private diagnostic assessment, you are likely to be referred to a community mental health organisation such as child and adolescent mental health services (CAMHS) or Marinoto[19] for diagnosis of ASD, ADHD and other neurodivergences. Costs of private assessments can run into thousands, that many people cannot afford. However, reaching the point of diagnosis is also difficult due to the many referrals being rejected at the first instance. Current Chair of ADHD NZ, Darrin Bull, in a recent interview with RNZ called the referral process "nightmarish; virtually impossible is

---

[19] There are different names for similar services in different parts of the country.

probably an understatement" (Bull, 2023). When asked if delays in getting help was causing loss of life, the answer was "yes… loss of life and significant harm" (Bull, 2023).

According to Ryan and Runswick-Cole (2008) the search for diagnosis has two key common motivations; one being the ability to access funding and support and two, gaining access to knowledge that positions the child's differences as neurodivergence rather than being the parent's fault (Ryan & Runswick-Cole, 2008, pp. 199-210). Diagnosis is significant and happens when a child is impacted across a range of environments, school, home, their friendships, and adaptive skills are all affected (Miller, 2023). Diagnosis can help parents understand that their child interprets the world differently due to being neurodivergent.

Diagnosis is a vital step towards accessing support services. While seeking diagnosis can be seen as buying into the medical model of disability, it can also be used as barrier removal when parents engage in conversations with professionals across different agencies (Ryan & Runswick-Cole, 2008, pp. 199-210). Once a diagnosis is in place funding opportunities for families may be accessed. For instance, carer support hours, where guardians can apply for reimbursement if they pay someone to look after their child. However, the eligibility criteria for the number of carer-support days per year depends on diagnosis (MOH, 2022), for example, more days per year are allocated for an autism diagnosis v's an ADHD diagnosis. Eligibility and number of days is determined at a local level by the Needs Assessment Service Coordination service (NASC). The regional nature of resource allocation has led to a huge disparity across New Zealand regarding who is eligible for carer support and what additional funds can be spent on. Carers NZ, an advocacy agency for carers of all kinds, is continuing work to level the playing field in this area of funding stream (CarersNZ, 2022).

5.1.3 Parental blame

Parental blame is a common feature across literature (Lowe, Lee, & Macvarish, 2015; Moses, 2010; O'Reilly & Kiyimba, 2021; Reardon, et al., 2017; Runswick-Cole & Ryan, 2019; Wilhelmsen & Nilsen, 2015). These feelings of blame can occur as an internal self-blame, guilt and shame or they can arise from interaction from agencies when seeking help. For example, diagnosis can work to alleviate some of the self-blame that parents can feel as it places the child's behaviour and difference in a wider context. However, the steps taken to gain a diagnosis may also be a source that generates further feelings of shame, this can stem from interactions with clinicians who tend to be positioned as the expert in contrast to the parent as layperson. Another way for these feelings to be internalised is if parents are asked to go on parenting courses before, and during acceptance into a service such as CAMHS. The forced participation in these programmes can imply that their parenting skills or lack thereof are at fault for the situation in which they find themselves (Lowe, Lee, & Macvarish, 2015; Moses, 2010; Wilhelmsen & Nilsen, 2015).

Parents feeling blamed for their child's challenges was a common reason for parents to *not* seek support (Reardon, et al., 2017, p. 644). Freeman (2019) echoes these findings in her blog, 'no magic wand UK', describing it as "a real kick in the teeth" when you approach services, only to be judged rather than helped (Freeman, 2019).

Self-blame is when parents continue to hold themselves to account despite there being other explanations (Moses, 2010, p. 103). These internalised feelings of shame and guilt relate to ideal constructions of parenting, societal norms regarding child and parent behaviour and the construct of the normal/problem child (O'Reilly, Muskett, Karim, & Lester, 2020, pp. 544-

564). This kind of parental self-blame can occur in a wide range of contexts and for a wide range of reasons.

Mother blame culture can be linked to the construction of a 'good parent' or more specifically 'good mothering' (Moses, 2010, p. 104; O'Reilly & Kiyimba, 2021; Runswick-Cole & Ryan, 2019). O'Reilly and Kiyimba (2021) locate this narrative of 'good mothering' within western culture as the responsibility and construction of children's behaviour – normative and non-normative – sits with the parents (O'Reilly & Kiyimba, 2021, pp. 52-69). Sheng et al. would argue that parental blame is not synonymous with western culture and that Chinese parent's shoulder similar responsibility and judgement (Zhang, Wu, & Sheng, 2022).

Harden (2005) goes as far as calling childhood a "socialisation project" (Harden, 2005, p. 352) and when multiple agencies become involved parenting becomes both a private and public judging arena. When seeking diagnosis parents can wrestle with feelings of not wanting to be seen as medicalising their child's behaviour yet diagnosis is often essential for additional support and funding. This is at the same time as not wanting to be seen as an overanxious or 'helicopter' parent due to the weighty rhetoric of mother-blaming (O'Reilly, Muskett, Karim, & Lester, 2020, pp. 544-564)

In New Zealand when neurodivergent children come to the attention of many agencies the 'surveillance of competency' within families, particularly of mothers, can be relentless (Harden, 2005; Ryan & Runswick-Cole, 2008, p. 204). The relentless nature of pressure can stem from the multiple agencies that can be involved. For example, at a minimum, these agencies could include General practitioner (GP), schoolteachers and CAMHS but may extend to speech and language therapists, play therapists, police, and child welfare.

Surveillance from several agencies along with unexplained behaviours can be an added

stressor, this stress can be exacerbated by a seemingly lack of understanding from some

professionals within support services.

5.1.4   Lack of support and understanding

Kiernan et al (2017) interviewed 10 mothers as part of a qualitative study for their

perspectives of lived experience of neurodivergent children. While the term neurodivergence

was not used, the children they spoke of were diagnosed with ADHD, Autism, intellectual

disabilities, and cerebral palsy. The lack of support and understanding by professionals was

exacerbated by the complex nature of a child's behaviour potentially due to co-occurring

conditions (Kiernan, Mitchell, Stansfield, & Taylor, 2019, pp. 175-189). Recognising the

main developmental condition was also a perceived problem resulting in lack of support and

understanding (Bonfirm, Giacon-Arruda, Hermes-Uliana, Galera, & Marcheti, 2020). This

provides multi layered stigma and multiple ways in which their children could be excluded

(Kiernan, Mitchell, Stansfield, & Taylor, 2019, p. 183).

Youthlaw (2016) highlighted the lack of support and understanding from principals, teachers,

and teacher aides in relation to accessibility, adaptability, and acceptability within education.

The most common groups of children that experienced most barriers to inclusive education

were children with intellectual disabilities, autistic children, and children with 'behavioural

needs' (Starr & Janah, 2016, p. 24).

An important area of support for parents of neurodivergent children, specifically autism was

the support of other parents. Partners, family, and friends can often be of greater support than

professionals (Eggleston, Thabrew, Frampton, Eggleston, & Hennig, 2019; Goedeke, Shepard, Landon, & Taylor, 2019). In Singapore, a review found similar results with peer support being considered valuable and finding someone on a similar journey with shared lived experiences was helpful (Wong & Shorey, 2022).

5.1.5   Parents as advocates

The dual roles of parent and advocate can become the norm for parents of neurodivergent children (Harden, 2005; Kiernan, Mitchell, Stansfield, & Taylor, 2019; Rafferty & Sullivan, 2017). The ability to stay informed of relevant research and knowledge specific to your child is considered a big responsibility, with one mother suggesting you have "got to become a professional" yourself (Kiernan, Mitchell, Stansfield, & Taylor, 2019, p. 179; Rafferty & Sullivan, 2017, p. 1156). The role of advocate has been socially constructed through parental narratives that have been developed through interactions and relationships with other people – family and professionals (Rafferty & Sullivan, 2017, p. 1152).

Advocacy can become an extra full-time job and is not always welcomed by professionals especially if parents disagree with professionals. When parents are seen to disagree with professionals, they (the parents) are more likely to be considered a problem (Lalvani P. , 2014, p. 1224) which could lead to difficulty or delays in getting support. Advocating for a child within teams of people can be stressful and keeping a "paper trail" is often recommended but is not always easy to do. Documentation of appointments, daily life, medication, and behaviours can be an arduous task especially while dealing with 'challenging behaviours' but it can hold people within the care team to account if needed (Graves & Graves, 2014).

The high level of advocacy that is required by parents is often due to the lack of support and transparency from some professionals. Due to the level of advocacy needed only some parents can achieve this which can lead to disparity across service provision (Good, et al., 2017, p. 120). Knowing of the disparity can lead to advocacy extending beyond the private realm of your own family, Runswick-Cole and Ryan (2019) note that once some mothers learn that it is the world that needs fixing rather than their child, they take on this burden of responsibility for all families. It becomes about the value of humanity along with equity in education, health, and social care for all children not just their own (Runswick-Cole & Ryan, 2019).

Blum (2007) coined the term "vigilante" to describe the position that mothers often find themselves in. For Blum, vigilante encompasses the constant monitoring both parents and child experience along with the feeling of taking the law into their own hands while trying to access care and support for their children (Blum, 2007, p. 212). The continual monitoring, appointments, medication regimes, unexplained behaviours, possible school exclusion and other factors can lead to parental burnout. Parental burnout can be described as "a lasting mismatch between perceived stressors and resources in the parenting domain" (Mikolajczak, Gross, & Roskam, 2021, p. 334), it is a chronic and overwhelming stress due to the constant monitoring, parental blame and lack of support that long-term can have a significant impact on both the parent and child/ren (Freeman, 2019; Mikolajczak, Gross, & Roskam, 2021, p. 334).

5.1.6   The social construction of parent and motherhood

Like the role of parents as advocates the construction of parenting is also a response to external situations and parts of the life course. For example, Harden (2005) discusses in detail the construct of past, present, and future in terms of parenthood and how at different stages you must reconstruct who you are and what you thought life would be like. The re-construction of roles can also come as a response to a significant diagnosis, or the realisation of how different life might be dependent on diagnosis (Harden, 2005, p. 352). Harden elaborates that while no parent *wants* a significant diagnosis the importance of acceptance is key. As one parent in her study stated, you just have "to get on with it"; this process of normalisation can be seen as a coping mechanism (Harden, 2005, p. 358).

In addition to the construct of parenthood and advocate, there are many additional roles that parents, usually mothers due to the ratio of care, of a neurodivergent child must manage that parents of neurotypical children may not experience and "lived experience of daily caregiving is a valuable source of knowledge" (Loftis, 2019). Jacquelyn Litt (2004) documents a study with 15 parents, one parent outlines her daily routine from 6am to 8pm structured around her son's ADHD medication. Litt goes on to say that this is not a 10-day course of antibiotics, ADHD is a lifelong neurodivergence of which only some people find relief from medication (Litt, 2004, pp. 621-644). If medication is a suitable option, then it means constant daily management and monthly visits to the pharmacy. ADHD medication is a controlled drug and previously only had a 30-day script allowance which meant monthly visits to the GP and pharmacy with 3 payments. There has been lobbying in New Zealand for a 3-monthly script cycle, The Pharmaceutical Schedule has just agreed to subsidise the 3 monthly script as long as it is sent electronically meaning only one cost but still monthly visits to the pharmacy

(ADHD.org.nz, 2023). Having a child with special/additional needs is a strong predictor for parental burnout (Mikolajczak, Gross, & Roskam, 2021, p. 335).

5.1.7 Media case study

The experiences highlighted in this research also appear in the news media and reflect my own experiences. To gain insight into the challenges faced by some families I share the following story that garnered media attention last year. In 2022, a Waikato family felt that they had no other choice but to go to the media to share their family journey of trying to access support for their neurodivergent child and wider family. This family went as far as recording some of their most challenging moments in an attempt for social services to understand what they dealt with on a daily basis. The mother's account is raw and at times difficult to watch especially when I share so much of her experience. Her son was 11 and from a young age recognised as neurodivergent with a clinical diagnosis of ASD, ADHD, and Global development delay. As he got older, he became violent towards siblings and his parents, the mother describes her house as "living in a warzone". The family has engaged with over 20 agencies, been sent on parenting courses, and tried many family therapies. Those 20 agencies spanned education, mental health, police, Oranga Tamariki and many community organisations in between. Her son was currently in state care. Risk played a significant factor in this decision as she feared for her other children and herself (Perera, 2022).

Waikato DHB acknowledged there were many other families struggling and said they were working with agencies to improve service. This is not only a problem in the Waikato, as I also experienced similar struggles in the Bay of Plenty. I too was engaged with over 20 agencies to try and access correct diagnosis and furthermore, correct support for my then 11-

year-old son. Risk and safety associated with violent behaviours due to a range of reasons was a top priority. Age was a factor as both of our children were 11 years-old at the time of accessing support and considered "too young to be properly accessed for his mental health" (Perera, 2022).

5.2 CONCLUSION

By understanding the challenges that parents of neurodivergent children face when interacting with health, education, and support agencies we can further understand how best to care and support both neurodivergent children and their families. While the big institutions may have closed fundamentally these smaller community organisations uphold the same punitive measures (Lampshire, 2018, p. 65). It is argued that these community structures were not ready to include neurodivergent people and that is possibly why neurodivergent children, and their parents still feel the stigma, blame and exclusion. Institutionalisation was not about bricks and mortar but about attitudes and policy, this still has a long way to go to uphold the mantra of inclusion (Lampshire, 2018, pp. 64-69; Martin, 2010).

Put simply, when an autistic child is stood down from school – at three times the rate of non-autistic students (Crawshaw, 2022) and some schools discouraging enrolments (Gerritson, 2016); this is exclusion. Coupled with "extraordinarily long wait times" for mental health services (Cardwell, 2021) this adds stress to families in already precarious positions, sometimes dangerous depending on certain behaviours. Precarity can lead to risk and 'at-risk' can lead to notifications to child welfare. This is not an assumption, this is reality.

6 INTERVIEW FINDINGS

"They're not being naughty" (Joan)

6.1 INTRODUCTION

There were consistent themes that came up in conversation despite their differing areas of service provision. Consistent areas of thought/discussion included personal experience of neurodivergence, and all participants had worked with parents of neurodivergent children. Three out of the four also worked directly with neurodivergent children. During our conversation about parents of neurodivergent children the importance of collaboration between parents/practitioners and practitioners/practitioners was widely discussed along with the importance of advocacy for and by the parents in multi-disciplinary meetings. There was strong consensus for a specialist service for neurodivergent children and their parents that was not clinician based. The significance of diagnosis was also discussed with varying thoughts.

6.1.1 Personal experience

All my participants had personal experience with neurodivergence either themselves having a diagnosis or were parenting neurodivergent children. While I will not share personal stories or quotes in this section, it is a worthy observation in that while none of my participants held their positions due to their own experience per se, they have a level and depth of understanding of neurodivergence that cannot happen without lived experience.

6.1.2 Working with parents

All four participants were closely involved with parents of neurodivergent children, in capacities such as support, advocacy, assessment and sometimes unfortunately due to a legal requirement. Joan worked with families for lengths of time anywhere from 3 months to 8 years, the reason being,

> "I don't turn families away" (Joan)

> "when they find someone they trust and will advocate on their behalf, they will return to that person" (Joan).

Lydia acknowledged the time it takes to work with parents and the need for flexibility. Working in private practice, while her day might not start until 10am as the families she supports are getting ready for work and school, she will still be working at 9pm because,

> "I don't need to be available then (morning), I need to be available when families are available which is in the evening" (Lydia)

Callum acknowledged the difficulty sometimes of being at the end of a phone and feeling like all he could do was,

> "just giving a bit of advice to parents, I suppose that's all I could do, it's about calming down, but it's difficult saying that on the phone to someone who's doing it every day" (Callum).

6.1.3 Importance of collaboration

Having a neurodivergent child can sometimes result in multiple agencies, practitioners, and clinicians becoming involved, including an occupational therapist, psychiatrist, senco,

paediatrician, social worker, and in extreme cases the police and Oranga Tamariki. All of my

interviewees have been involved in numerous multi-disciplinary team meetings,

strengthening families' meetings and some family group conferences (FGC). Lydia runs

multi-disciplinary panel meetings at the same time each week, which can include

audiologists, speech and language therapists, paediatricians – whoever needs to be there. The

reason this type of collaboration is so important is because,

> "we cannot separate the neuro pathways" (Lydia).

Joan found collaboration effective,

> "because sometimes you can draw on resources that would normally be closed
> off" (Joan)

Due to the many people that can become involved, it is also important to know who does

what in the team surrounding a family to ensure the collaboration is effective. To ensure this

happens some of the questions Joan asks herself as she is first engaging with a family are,

> "who else is working with them?... How's that relationship going? What's
> working? Do I need to be here? How can I assist and how can we work
> together?" (Joan)

Getting this information was important to Joan so that everyone knew what they were doing,

Lydia was also emphatic about practitioners needing to,

> "stay in their lane of service provision, know what their role is and embrace
> that role within the bigger mechanism" (Lydia).

6.1.4   The role of advocacy

The importance of either being able to advocate for your family yourself or having someone to walk with you as an advocate was discussed by all participants. Joan and Kate both discussed the frustration that they had observed from parents when trying to access support for their neurodivergent children and/or support for themselves, acknowledging that,

> "there's a lot of closed doors I guess and hard to access help when you need it" (Joan).

Therefore, after asking multiple times and being knocked back families can become discouraged and frustrated. In those times it can be helpful to have someone who,

> "asks those questions, to be a bit more direct… make sure your client is getting what they're entitled to… 'why is it you can't do that?' Or 'why is it you haven't done that yet?'" (Kate).

Callum shared reflections on the incredible amount of time it takes for parents to do research into certain conditions and how that alone can become a full-time job. He joked that,

> "you become like an X files cop" (Callum)

If a family were unable to advocate for themselves or carry out the depth of research that is often required bad things can happen. Callum gave an example of a potentially dangerous situation. He said,

> "if you weren't (on to it) the kid will be on a certain med and think that's right because that person says so because he's a doctor but all that time it's wrong" (Callum).

When I discussed advocacy within a school environment Lydia said,

> "our biggest issue is that there isn't anyone impartial being an agent for the non-prioritised family. Not anyone who isn't employed by those agencies holding the purse strings" (Lydia).

When I asked specifically, 'so who is advocating for these families?' her answer was,

> "No-one really" (Lydia).

Kate mentioned a wealth of services that are in fact available to families, but the navigation of these services can be difficult. She mentioned two agencies specifically that she found helpful, one was Strengthening families,

> "because it took that pressure off the family having to be the one to hold all that information" (Kate).

Kate also mentioned a local group in Tauranga, Mockingbird, which she described as,

> "a great place for informal advocacy, you have a community of people that understand how much of a struggle it is doing it on your own" (Kate).

6.1.5 Need for specialist service

All participants mentioned the need for a specialist service that would have specific understanding of neurodivergence. Children and their families would be able to attend whether it be for general support, intervention, advocacy or diagnosis. The current process being that referrals are often made from schools and general practitioners directly to clinicians to diagnose neurodivergences such as ADHD, ASD and dyslexia without proper

observations across environments leaving families disappointed when they are turned away from services such as child and adolescent mental health (CAMHS). While Joan said,

> "it would be nice if they could have some place where you could have a standard test… put some funding into parenting…" (Joan).

Callum and Kate were emphatic about the need for a specialist service, not only for the children but acknowledging that parents need and often want support too. Unless you live with neurodivergence before having children, it could be a new concept and that can be difficult to adapt to.

> "specialised support too, someone that works specifically with neurodivergent children and knows how to support parents" (Kate).

> "you need a crew, specialists… it all comes back to CAMHS, this is the problem, they're fobbing people off" (Callum).

Notably on the point about community mental health organisations such as CAMHS or Marinoto in other areas of New Zealand and the suggestion of 'fobbing people off', Lydia rather thought that it's not that CAMHS or Marinoto are refusing to diagnose but,

> "Marinoto refuse to diagnose unethically" (Lydia).

Lydia had a slightly different view, perhaps because she is a practitioner in this space, providing a specialist service incorporating classroom observation, assessments, discussion with parents and practitioners along with facilitating collaborative meetings for the families she supports. Lydia believes that there needs to be more practitioners like her yet they,

> "need to be supported, we need to be recognised, we need to be referred to by the Ministry of Education, we need the ability to make ACC claims as well as MOE funding claims, Why? because we fall into the grey area" (Lydia).

The point was made by a couple of participants that while there were a lot of good people/services doing good things,

> "there's still not a lot for neurodivergent" (Joan).

Both participants in private practice discussed the nature of true wraparound support with multiple people involved all trained to do a specific job as they recognise that,

> "diagnosis and medication" (Kate).

are not a solution for all. It is about the young person and their family grasping an understanding of,

> "these are my strengths and these are my weaknesses, and this is why I get overstimulated…" (Kate).

> "might be strengths, might be weaknesses, might be difference or just desirables" (Lydia).

6.1.6   Significance of diagnosis

The significance of diagnosis was discussed by all interviewees with varying thoughts. Most believed in diagnosis as necessary to access intervention, support and medication if needed, with Joan explicitly saying,

> "because to me I would think if you had a diagnosis that that would open the door for something else" (Joan).

Going on to explore the benefit of diagnosis,

> "it means the school can help them more, give the teachers some understanding that they're not being naughty, there's actually something going on for this kid then it makes it easier to have adapted programmes" (Joan).

Acknowledging also, that in her experience a diagnosis by a clinician can alleviate some parental blame and stigma. She gave an example where in one particular case, up until the point of diagnosis,

> "it was a mum problem" (Joan).

Kate echoed this stating,

> "there's really amazing services that could come in and wraparound, but they needed some diagnosis" (Kate).

Kate also emphasised,

> "sometimes just for validation that it's not their parenting" (Kate).

Lydia took a slightly different approach and said when parents are seeking diagnosis, we should always ask the question,

> "what do you want to achieve?" (Lydia).

Clarifying, that educational support in particular, can be accessed without diagnosis and if the correct assessments are carried out then the child can achieve success in the classroom. Through correct assessment you can understand the whole child ecologically and specifically find what individual needs they have,

> "it doesn't mean that we want to diagnose them for the rest of their life"
> (Lydia).

Reflecting the risk of labelling and deficit-thinking that can be part of the diagnosis pathway. While Kate recognised that diagnosis can lead to support she also echoed that true positive change went further than diagnosis and medication, recognising that,

> "there should be coaching, support, someone sitting with that child during the
> day and helping them to try different approaches to learning if that's the issue"
> (Kate).

On another note, when discussing ADHD and ASD diagnosis specifically and whether or not it should be diagnosed as per the DSM-V, Lydia believed,

> "that neurodiversity, needs to be the diagnosis… neurodivergence" (Lydia).

This would be the umbrella term and specific needs and accommodations would be listed *as per the individual child.* This would then encompass and explain that this child's,

> "neurodiversity means that the brain is processing the world differently to
> their peers the majority of the time, resulting in certain clusters or 'tribes' of
> presentations of behaviours" (Lydia).

The point of ethical diagnosis was only mentioned by Lydia, this is further discussed in the next chapter as a significant point of difference. What she says regarding diagnosis is,

> "one has to consider the data over a period of time, after intervention. It is
> unethical to conclude from a once off office environment, once off setting, a
> once off choice meeting with a once off form, no, that's not evidence. That's
> not testing, it's not ecological assessment" (Lydia).

7 DISCUSSION

"To learn the truth, we must put all the parts together".

7.1 INTRODUCTION

This research contributes to the evidence-based narratives of policy and social service provision for neurodivergent children and their families in Aotearoa New Zealand. By examining key policies and literature and by speaking with employees from within social services, I hoped to gain a fuller picture of their experience of the policy context and systems of service provision. Accessing social services for a neurodivergent child is often complex and challenging as illustrated by international accounts (Lowe, Lee, & Macvarish, 2015; Rafferty & Sullivan, 2017; Wilhelmsen & Nilsen, 2015) and in accordance with my own experience. I hoped to better understand these challenges to provide recommendations for further research in this area.

From my review of literature on the families with neurodivergent children, reflections on my own experience and discussions with my participants the aspirations of these families were to gain access to relevant and appropriate education and healthcare services for their children. This could be within the mainstream systems or in more suitable alternative options available in community settings. For the purpose of my discussion, I will refer to these aspirations within the intersecting policy systems of education, health, and mental health as accessibility and suitability principles. In my discussion I argue that the social services set up for families with neurodivergent children need to be governed by these principles of accessibility and suitability. I further argue that these principles offer a way to assess the strengths, weaknesses and opportunities present in the current provision of social services.

The challenges that families of neurodivergent children face are directly linked to these two principles, accessibility, and suitability. There were shared themes across literature and interviews illustrating measures that either promote or hinder accessibility and suitability. Those that promote accessibility, and suitability are strengths-based approaches that understand the principles of the neurodiversity paradigm. While those that hinder are the tension between inclusive policies and exclusionary practice, deficit-thinking, challenges with diagnosis including polypharmacy, and parental blame. One solution to some of these challenges is a specific support agency for neurodivergent children outside of community mental health services. However, for accessibility and suitability to be achieved transparency between professionals and parents is paramount. My research has found that parents felt a lack of support and understanding from professionals, suggesting that greater transparency regarding available support in terms of funding and/or practical resources after diagnosis is needed.

7.2 ADDRESSING THE TENSION BETWEEN INCLUSIVE POLICIES AND EXCLUSIONARY PRACTICES

Current education policy promotes inclusive environments for neurodivergent children in mainstream education, yet lived reality described by parents through grey literature paints a different picture (Corrie, 2011; Gerritsen, 2022). Funding streams such as HCN and ORS are designed to enable inclusion by providing funding and practical support through adaptive curriculums and environment modification within mainstream education however parents continually report exclusion (Corrie, 2011; Crawshaw, 2022; Gerritson, 2016; Williams, 2021). Formal exclusion from education can begin as early as early childhood education.

The Education Review Office found one in five disabled learners have been discouraged from enrolling at their local school with similar numbers of parents have been asked to keep their child home from school. Reviews of education services over the past 18 years have consistently suggested that education is not delivering for our disabled students and that improvements are needed (Gerritsen, 2022). Lack of teacher aides and/or accessibility issues were key barriers to inclusion, alongside teachers and principals not fully understanding their legal obligations towards disabled learners (Gerritsen, 2022).

This tension between inclusive policy and exclusionary practice could be addressed in several ways including extra funding opportunities, upskilling teachers, and promoting the neurodivergence paradigm shift. Neurodivergence needs to be an integral part of teacher training based on the principles of the neurodiversity paradigm – recognising and accepting a divergence of minds. This leans away from deficit-thinking and towards an appreciation of divergence. There will need to be considerable funding in this area to break the cycle of negative framing and exclusionary practice.

7.3 STRENGTHS-BASED APPROACH V'S DEFICIT-THINKING

Reframing the way neurodivergent children are labelled can draw attention away from deficit-based thinking and towards a strengths-based approach. Two key areas influenced by deficit-thinking highlighted in my research include the decision to suspend or stand down children from schools and the diagnostic process.

As discussed in interviews children are not wilfully naughty, a child will do well if they can. However, neurodivergent children process and receive information differently and it can be

extremely difficult to 'do well' in certain environments. As a result, neurodivergent children can be identified as misbehaving and complex behaviours can be misunderstood and framed as "challenging". This becomes a barrier to inclusive education (Chan, et al., 2012; Kiernan, Mitchell, Stansfield, & Taylor, 2019; Wodehouse & McGill, 2009). Labels such as *challenging* are the backbone of deficit-thinking. One reason why a neurodivergent child could appear non-compliant, could be because of sensory overload. Sensory overload is often associated with autistic persons but is also a feature for ADHD children, epileptic children, and other neurodivergent children.

The deficit-based discourse that frames certain behaviours as challenging can foster internalised feelings of blame towards and within parents for their neurodivergent child's behaviour. These feelings of failure and inadequacy, alongside awareness of societal intolerance, can hinder parents from accessing support in the first instance. These feelings of blame can further hinder getting suitable support when professionals 'judge and scrutinise' as well as direct parents to parenting courses (Freeman, 2019; Reardon, et al., 2017).

For some, gaining diagnosis can be seen as a validation tool and a way to alleviate parental blame, yet diagnosis can only be gained if access to an agency such as CAMHS is achieved. Access can also be hindered by wait times, caused by a range of issues including the growing number of clinicians leaving professions such as mental health nurses, doctors and psychiatrists (Witton, 2022). Parental blame and long wait times are ongoing issues, all the while youth mental health is getting worse and lives are being put at risk (Cardwell, 2021; Doocey, 2022).

7.4 CHALLENGES WITH DIAGNOSIS

Gaining a diagnosis can be a game-changer for families seeking assistance. However, my research has highlighted that the process is complex, uncertain, and fraught with challenges. Firstly, diagnosis is often framed on a deficit-based model by asking 'what is a person missing?' or 'what can a person *not* do?'. There are often lists and questionnaires to measure a child's competence in certain areas to then qualify for a diagnosis as per the DSM. For example, a diagnosis of autism is based on one's "impaired" or "lack of" verbal/non-verbal communication and "restricted" behaviours (APA, 2015, p. 7). Walker argues the inherent risk in this stance is "the masters tools will never dismantle the master's house" (Walker, 2021). In other words, when diagnosis is framed by medicalised language and definitions, genuine change from pathology to neurodiversity will be hampered (Walker, 2021).

Secondly, gaining diagnosis can lead to polypharmacy – the use of up to five or more medications. While there is no 'medical cure' for neurodivergences such as autism, dyslexia and/or ADHD (and others), children with these diagnoses are medicated at an astonishing rate (Barczyk, Rucklidge, Eggleston, & Mulder, 2020, p. 94). Despite minimal evidence of effectiveness for medical intervention, internationally neurodivergent children can be subject to polypharmacy (Aman, Lam, & Collier-Crespin, 2003; Barczyk, Rucklidge, Eggleston, & Mulder, 2020, p. 94; Bowden, Thabrew, & Kokaua, 2020, p. 1; Esbensen, Greenburg, Seltzer, & Aman, 2009; Matson & Dempsey, 2007; Spencer, et al., 2013).

A third challenge with diagnosis was raised during the interviews in a nuanced response regarding the issue of professional ethics. Due to the way the system is set up a referral to CAMHS usually comes from their family General Practitioner (GP). These referrals can occur without any intervention or assessment completed across the multiple environments

that the child engages with. This may result in a situation where families that have gained a referral to CAMHS yet are declined by the service. Being exited from the service understandably leaves parents feeling frustrated, unheard, and with no clear pathway to gain support to meet the needs of their neurodivergent child. However, my participant emphasised that it is important to understand that services like CAMHS may not simply be refusing to diagnose but potentially are refusing to 'diagnose unethically'.

This insight made very clear to me that expectations of what can be provided by CAMHS needs to be communicated more clearly to parents and to GPs. The need to have prior intervention and assessment also needs to be discussed more widely within a range of contexts such as health, education, and policy development. Given the complex intersections of these policy contexts it is difficult to ascertain who is or should be responsible for carrying out observations across multiple environments to understand the child ecologically.

7.5 NEED FOR SPECIALIST SERVICE

One solution to some of the challenges discussed, in particular the complex policy puzzle mentioned above is the provision of a specialist service for neurodivergent children and their families. Based on my research I recommend that this specialist service operate outside of community mental health organisations, focus specifically on neurodivergent children and their families and draw on a Strengthening families framework. This kind of specialist service could provide ways to foster inclusion in education and wider society from a strengths-based approach. This would be a co-design process with in-depth knowledge of what parents of neurodivergent children need and want within a service of this kind.

Recognition and enactment of the neurodiversity paradigm principals could guide social service provision. When understood correctly and responded to effectively neurodiversity can provide a richer life experience (Milton, 2020). The social model of health is in line with Walker's principals of the neurodiversity paradigm that promote a strengths-based approach to language and humanity. By employing the neurodiversity paradigm, we understand that neurodiversity is a part of human nature, it can be enriching and strengths-based whereby everyone has access to suitable support. The three fundamental principles of the neurodiversity paradigm are,

- Neurodiversity is a valuable form of human diversity.

- The idea that there is a norm or one 'right' style of neurocognitive function is a culturally constructed fiction.

- Dynamics relating to other forms of human diversity such as power inequality are relatable here too. Walker acknowledges that dynamics can be positive as well as negative and when diversity is embraced fully it can act as a source of creative potential (Walker, 2021).

The types of services this agency could include are detailed below.

7.5.1   Access to diagnosis

This service could broker diagnosis when it is required, as diagnosis is still needed for some funding streams and access to other supports such as the carer support service. However, the access to diagnosis would need to be accompanied by work with families to provide knowledge regarding the challenges and ethics of diagnosis. By doing so the service would adhere to the transparency principle and aspiration discussed in the introduction.

Many support services are only offered and/or accessed when your child and/or family is at crisis point. Being in crisis can also be a barrier to accessing suitable support services as approaching a situation from a crisis management perspective while necessary at the time does not offer long term solutions. This specialist service could promote an early intervention model to prevent crisis by staff being knowledgeable about suitable supports in the surrounding area and being transparent with families about what is on offer. While a diagnosis has many benefits, it is often the long-term support and understanding that is needed to prevent a crisis.

7.5.2   Advocacy

Having to organise and navigate multiple meetings or having a multidisciplinary meeting where multiple agencies are at a single meeting can be emotive and complex. Findings in literature also demonstrate that many parents of neurodivergent children often hold the dual roles of parent and advocate (Harden, 2005; Kiernan, Mitchell, Stansfield, & Taylor, 2019; Rafferty & Sullivan, 2017; Runswick-Cole & Ryan, 2019). The importance of advocacy was further discussed during interviews, acknowledging that holding this duality of roles can be exhausting for parents. Professional or dedicated advocates can be impartial and as such they are invaluable in multidisciplinary meetings, oftentimes it is the simple task of taking notes that can take a layer of stress off an already pressured family.

7.5.3   Collaboration – A potential model to follow

Loss of funding to Strengthening Families coordinators across New Zealand means there is a gap in advocacy services, yet my research suggests that there is a need for expanded services rather than a decrease, especially within the neurodiversity context.

The Strengthening families (SF) framework is an agency based on increasing already held strengths and providing advocacy for families - SF has been described as a "lifeline" to some families experiencing multiple meetings with multiple agencies with one article describing it as "a pioneering approach to helping at-risk children" (Powell S. , 2016). A cut to funding in 2016 saw 32 SF providers lose contracts, the latest funding cut sees another 17 SF coordinators ceasing their positions this year (Powell S. , 2016; Ridout, 2023). Strengthening families is one way that families can access suitable support from multiple agencies while providing advocacy for the families. It is concerning that this social service is being defunded over time when for the families of neurodivergent children it provides an effective option for the kinds of advocacy that literature and the interviews indicated is needed when accessing social services.

When there are multiple people involved in a child's life collaboration is key, to know who is doing what and why allows everyone to be productive with their time and resources. This was identified strongly by all my interviewees, not least because our neural pathways and physical bodies do not exist independently of each other, and our children do not exist independently of their environments. As Strengthening families works from an ecological and strengths-based approach the framework also fosters collaboration between family/practitioner and practitioner/practitioner, which my research has identified as being essential. This kind of collaboration across policy silos can promote the aspirational principles of accessibility, suitability, and transparency.

One way to support collaboration across services such as health and education is to utilise Bronfenbrenner's ecological approach that places the family and child at the centre. An

ecological approach (Maidment, 2013, p. 172) addresses all the interconnecting relationships that a person has, be it family, school, paediatrician, psychologist, after school care; anything that involves the child and their family. When everyone is secure in the knowledge of their position within the team, know what is achievable, understand specific goals for the child and family they can commit to working together to achieve transparency leading to accessible and suitable support.

7.6 CONCLUSION

All points discussed here are interwoven and it is difficult to discuss one without the other for example, diagnosis can open doors to support and funding yet accessing diagnosis can be challenging. Diagnosis can also be seen as medicalising neurodivergence which is something that the neurodiversity paradigm moves away from – you can't take down the master's house with the master's tools. Society and the governing systems must be on board with the neurodiversity paradigm for real shifts to happen, which also includes rewriting the DSM.

Collaboration and advocacy go hand-in-hand and could be a starting block for a specialist service taking its lead from the neurodiversity paradigm and the strengthening families framework to build a strengths-based practice. A place of understanding and like-minds where neurodivergent children and parents are welcomed and guided, and not blamed.

8 CONCLUSION

While this research was born out of personal experience it extends to the wider injustice within social service provision for neurodivergent children experienced by many. As a parent of a neurodivergent child, I have faced many barriers; to diagnosis; to education; to health; to social services. That is a single personal experience. Injustice is discovering that I am not the only parent, and my son is not the only child to face misdiagnosis, exclusion, blame and non-acceptance simply for being human. There are deeply rooted deficit-based perceptions that perpetuate negative framing through the language used to describe, discuss, and manage our neurodivergent children. This framing further disables neurodivergent children and exacerbates the challenge to access suitable support.

My research has highlighted several challenges and opportunities for families of neurodivergent children in relation to accessing suitable supports. A major challenge is transparency of information and accessibility to suitable support for neurodivergent children and their parents on the neurodivergent rollercoaster that no-one signed up for. To be supported through the process of diagnosis if you decide that is suitable. To be supported in grief when you grieve the life you thought you would have. Instead of having a diary full of sports events, birthday party invites, holidays, and dinner's out, you have appointments with psychiatrists, social workers, doctors, speech therapists, and sometimes, medication schedules more complex than the periodic table.

The waitlists for services such as CAMHS, MOE psychologists, mentors, counselling services and other social services would suggest that there are many parents and children asking for support. Wait times are a significant barrier to all families. The money being

poured into mental health services for children and adolescents would suggest there is great need. The money allocated for school attendance would suggest a large portion of children are not attending school, what percentage are neurodivergent? Comparing the increase in prescription rates of stimulant, anti-psychotic and, anti-depressant medication against our long wait lists and suicide rates indicates that something needs to change, and it is not our children.

Families that can access funding such as disability payments, carer support hours, ORS and others can be afforded flexibility. Both flexibility and time are needed with neurodivergent children to find the most suitable supports. Positive impacts that my participants highlighted to me from their own experiences included supports such as SPELD[20] assessments, psychologists, and Riding for disabled courses. There were also some positive stories about accessing medication through correct diagnosis and this making a real difference for some families.

Policies aimed towards neurodivergent children, and their families have been reworded and developed over time to foster inclusivity and promote accessible supports within health, care, and education settings. Literature, specifically media accounts, would suggest that either, these policies have not gone far enough or that the agencies employed to enact them are misguided as more and more neurodivergent children are stood down from school and excluded from society. The doors of institutions may have closed but the doors to inclusivity are not yet fully open.

---

[20] SPELD is a national agency that offers assessments for dyslexia and other learning difficulties

A major barrier to the true inclusive nature of policy is that these systems often work in silo. For example, inclusive education often requires input from multiple practitioners that can become involved in a neurodivergent child's life however, each practitioner will work under guidelines or policy from their individual institution. Not only do time restraints make it difficult to have multidisciplinary meetings, the individual policy structures and funding streams do not always align to create the best outcomes for the child and family.

The neurodiversity paradigm and movement present a way forward for social services to embrace inclusivity and celebrate the variations of neurodivergence. It is not the fault of a neurodivergent child that the world feels so intense that sometimes it is too much; too much to be in the classroom and unfortunately sometimes, too much to be in the world. Research suggests that Autistic people commit suicide at a much higher rate than non-autistic people and autistic people with ADHD at an even higher rate than autistic people and the number is not decreasing with current policies in place. That is why continued acknowledgement about neurodiversity and specific accommodations written in policy is important.

There have been some recent research developments within this area with the goal being to direct policymakers on best practice for neurodivergent children. There is a current ongoing survey developed by *the education hub*[21] to better understand how the education system is serving our neurodivergent children. There is also the *neurodiversity in education coalition*[22] group which is an integrated group made up of other agencies that acknowledge the education system is failing neurodivergent children and are devising strategies and ways forward for policy makers in this area. It is not too much to ask that our children not feel like the world is

---

[21] https://theeducationhub.org.nz/how-well-are-new-zealands-neurodivergent-young-people-served-by-our-education-system/

[22] https://www.nzcge.nz/meet-our-young-neurodiversity-champions

'too much'; that they are 'too much'. For our children to be able to attend school and not just 'get through the day' but to succeed at their day. To not feel exhausted from masking while pretending to be something they are not. To not get to 11 years old, suicidal and say, "I have done everything that everyone wanted me to do, and I can't do it anymore".

The perspectives of the professionals that I interviewed is that more research, more time, and more compassion within social service provision is needed for neurodivergent children to feel safe in this world. They also highlighted that there are many neurodivergent children; in our houses, in our classrooms and as adults in our community and our education, health and child services need to change to embrace neurodivergent children.

As outlined in the discussion, all participants felt strongly that a way forward for families of neurodivergent children was a specialist service outside of community mental health services. A specialist service dedicated to being accessible, knowledgeable, and transparent with information regarding suitable supports for neurodivergent children.

8.1   CHALLENGES I FACED IN THE RESEARCH JOURNEY

A key limitation I had to deal with included not being able to reach as many participants as I would have liked. It would have been useful to access other participants across a wider range of professions. However, I understand the pressure that social service provision is facing at the present time.

8.2 FUTURE RESEARCH DIRECTIONS

My research highlighted gaps in current research, in particular, further research specific to New Zealand could include in depth studies into the outcomes of polypharmacy for neurodivergent children. Clear understanding of the reasons behind prescription rates of anxiolytics, anti-psychotics, and benzodiazepines for neurodivergent children. The intent being to learn about the efficacy of these medications and/or possible paradoxical reactions. Without knowing what and how these medications are working within this neurominority of children the prescriptions rates should not be increasing.

Further research into the cost of 'crisis point'. A better understanding of how we can support neurodivergent children within education, health, and care services before it reaches crisis point. To understand how we fund at the top of the cliff rather than the bottom, with transparency, accessibility, and suitability to better serve this neurominority of children.

There also needs to be research into how the principles of the neurodiversity paradigm could be understood and implemented throughout all training of teachers, doctors and anyone who is involved with neurodivergent children, this includes New Zealand Police. New Zealand Police are a frontline service that deserve to be equipped with the knowledge and training of neurodivergence seen as they can often be the first point of call on recommendation from crisis-line support.

9 REFERENCES

ADHD. (2022, October 1). *ADHD New Zealand*. Retrieved from www.adhd.org.nz: https://www.adhd.org.nz/what-is-adhd.html

ADHD.org.nz. (2023, January 26). *Additional costs caused by changes to three month prescriptions for ADHD medication*. Retrieved from ADHD.org.nz: https://www.adhd.org.nz/scripts-for-adhd-medication-to-be-extended-from-one-month-to-three.html

Aman, M., Lam, K., & Collier-Crespin, A. (2003). Prevalence and patterns of use of psychoactive medicines among individuals with autism in the autism society of Ohio. *Journal of autism and developmentla disorders*, 527-534.

APA. (2015). *Understanding mental disorders: your guide to the DSM-5*. Arlington: American Psychiatric Publishing.

Arowolo, S. O. (2017, June 23). Understanding framing theory. Lagos: Researchgate.

Asthma.org. (2022, October 1). *asthma.org.nz*. Retrieved from Asthma New Zealand: https://www.asthma.org.nz/pages/what-to-do-in-an-emergency

Autism, A. (2022, October 8). *Altogether autism*. Retrieved from www.altogetherautism.org.nz: https://www.altogetherautism.org.nz/what-is-autism/

Autistica. (2023). *Autistica*. Retrieved from autistica.org.uk: https://www.autistica.org.uk/

Baistow, K. (2003). Promoting children's mental health. In T. Macdonald, *The sociala significance of health promotion* (pp. 88-110). London: Routledge.

Barczyk, Z., Rucklidge, J., Eggleston, M., & Mulder, R. (2020). Psychotropic medication prescription rates and trends for New Zealand children and adolescents 2008-2016. *Journal of child and adolescent psychopharmacology*, 87-96.

Barnes, C., & Oliver, M. (1993). Disability: A sociological phenomenon ignored by sociologists.

Baxter, M. (2001). Lay concepts of health. In M. Purdy, & D. Banks, *The sociology of politics and health* (pp. 184-187). London: Routledge.

Betty, D. B. (2023, May 10). ADHD referrals "virtually impossible": GPs & advocates. (RNZ, Interviewer)

Blum, L. (2007). Mother-blame in the Prozac nation; Raising kids with invisible disabilites . *Gender & Society*, 202-226.

Bochner, A., & Ellis, C. (2016). *Evocative autoethnography.* Routledge.

Bogler, O., Roth, D., Feinstein, J., Strzelecki, M., Seto, W., & Cohen, E. (2019). Choosing medications wisely: Is it time to address paediatric polypharmacy? *Paediatrics and child health*, 303-305.

Bonfirm, T., Giacon-Arruda, B., Hermes-Uliana, C., Galera, S., & Marcheti, M. (2020). Family experiences in discovering autism spectrum disorder: implications for family nursing. *Revista Brasileira de Enfermagem*, 1-9.

Boorse, C. (1977). Health as a theoretical concept. *Philosophy of science*, 542-573.

Bowden, N., Gibb, S., Audas, R., Clendon, S., Dacombe, J., Kokaua, J., . . . Taylor, B. (2022). Association between high-need education-based funding and school suspension rates for autistic students in New Zealand . *JAMA Pediatrics*, E1-E8.

Bowden, N., Thabrew, H., & Kokaua, J. a. (2020). National prescribing rates and polypharmacy for children and young people in New Zealand with and without autism spectrum disorder. *Research in autism spectrum disorders*.

Bowden, N., Thabrew, H., Kokaua, J., Audas, R., Milne, B., Smiler, K., . . . Taylor, B. G. (2020). Autism spectrum disorder/Takiwatanga: An integrated data infrastructure-based approach to autism spectrum disorder research in New Zealand. *Autism*, 2213-2227.

Brabazon, T. (2022). *12 rules for (academic) life.* Singapore: Springer Nature.

Brennan, A., Waren, N., Peterson, V., Hollander, Y., Boscarato, K., & Lee, S. (2016). Collaboration in crisis: Carer perspectives on police and mental health professional's responses to mental health crisis. *International journal of mental health nursing* , 452-461.

Brennan, A., Warren, N., Peterson, V., Hollander, Y., Boscarato, K., & Lee, S. (2016). Collaboration in crisis: carer perspectives on police and mental health professional's responses to mental health crisis. *International journal of mental health nursing* , 452-461.

Brookes, B. (2019). Contextualising caring in New Zealand. In B. Brookes, J. McCabe, & A. Wanhalla, *Past caring? Women, work and emotion* (pp. 17-36). Dunedin: Otago University Press.

Brookes, B., McCabe, J., & Wanhalla, A. (2019). Introduction: care matters. In B. Brookes, J. McCabe, & A. Wanhalla, *Past caring? Women, work and emotion* (pp. 9-15). Dunedin: Otago University Press.

Brown, E. (2022, March 9). *High rates of undiagnosed autism might be contributing to suicide risk, study uncovers*. Retrieved from www.mentalhealthtoday.co.uk: https://www.mentalhealthtoday.co.uk/news/awareness/high-rates-of-undiagnosed-autism-might-be-contributing-to-suicide-risk-study-uncovers

Bull, D. (2023, May 10). ADHD referrals "virtually impossible": GPs & advocates. (RNZ, Interviewer)

Burr, V., & Dick, P. (2017). Social constructionism. In B. Gough, *The Palgrave handbook of critical social psychology* (pp. 59-80). London: Palgrave Macmillan.

Cameron, C. (2020). An act of resistance. In D. Milton, *The neurodiversity reader* (pp. 111-120). Hove: Pavillion.

Cardwell, H. (2021, July 16). *RNZ*. Retrieved from www.rnz.co.nz: https://www.rnz.co.nz/news/national/447009/fears-lives-are-being-put-at-risk-due-to-mental-health-wait-times

CarersNZ. (2022, May 26). *CarersNZ*. Retrieved from www.carers.net.nz: https://carers.net.nz/carer-support-update-ministry-healths-disability-team/

Chan, J., Arnold, S., Webber, L., Riches, V., Parmenter, T., & Stancliffe, R. (2012). Is it time to drop the term 'challenging behaviour"? *Learning disability practice*, 36-38.

Chapman, R. (2020). Neurodiversity, disability, wellbeing. In H. B. Rosqvist, N. Chown, & A. Stenning, *Neurodiversity Studies; A critical paradigm* (pp. 57-72). Abingdon: Routledge.

Childmind. (2022, October 1). *childmind.org*. Retrieved from Childmind institute: https://childmind.org/article/sensory-processing-issues-explained/

Chong, D., & Druckman, J. (2007). Framing theory. *Annual review of political science*, 103-126.

Christians, C. (2000). Ethics and politics in qualitative research. In N. Denzin, & Y. Lincoln, *Handbook of qualitative research* (pp. 133-155). California: Sage publications.

Cixous, H. (1976). The laugh of the medusa. *The university of chicago press journals*, 875-893.

Collins. (2009). *Dictionary and thesaurus.* Glasgow: HarperCollins.

Collyer, F., & Scambler, G. (2015). The Sociology of Health, Illness and Medicine: Institutional Progress and Theoretical Frameworks. In F. Collyer, *The Palgrave Handbook of Social Theory in Health, Illness and Medicine* (pp. 1-15). London: Palgrave Macmillan .

Compton, M., & Shim, R. (2015). *The social determinants of mental health.* Arlington: American psychiatric publishing .

Connelly, M., & Harms, L. (2015). *Social work; from theory to practice.* Cambridge: Cambridge University Press.

Cooper, K. (2019). Feeding the family: Pakeha and Maori women in rural districts, c.1900-1940. In B. Brookes, J. McCabe, & A. Wanhalla, *Past caring? Women, work and emotion* (pp. 135-161). Dunedin: Otago University press.

Cornish, S. (2022, January 25). *Police, health services to jointly respond to critical incidents after pilot success.* Retrieved from Stuff.co.nz: https://www.stuff.co.nz/national/127566060/police-health-services-to-jointly-respond-to-critical-incidents-after-pilot-success

Corrie, T. (2011, July 15). *The New Zealand Herald.* Retrieved from nzherald.co.nz: https://www.nzherald.co.nz/nz/special-needs-girl-off-school-after-extra-funds-refused/YCDS3R7HRA5B2LZDHRLCT3IIGE/?c_id=329&objectid=10738509

Costley, C. E. (2010). Key concepts for the insoder-researcher. In C. E. Costley, *Doing work based research: Approaches to enquiry for insider-researchers* (pp. 1-7). Sage publications.

Crawshaw, M. (2022, May 17). *nzherald.co.nz.* Retrieved from www.nzherald.co.nz: https://www.nzherald.co.nz/nz/autistic-students-in-nz-three-times-more-likely-to-be-stood-down-suspended-new-research/KB7MJR2WPAB7KDXQPLTO3JG6NU/

Dalley, B. (1998). *Family Matters: Child Welfare in Twentieth-century New Zealand.* Auckland: Auckland University Press in association with the Historical Branch, Dept. of Internal Affairs.

Davis, B., & Francis, K. (2022). Ecological systems theory. *Discourses on learning in education*.

Davis, L., & Museus, S. (2019). What is deficit thinking? An analysis of conceptualisations of deficit thinking and implications for scholarly research . *Currents*, 117-130.

Day, S. (2012). A reflexive lens: exploring dilemmas of qualitative methodology through the concept of reflexivity. *Qualitative sociology review*, 60-85.

Deacon, B. (2013). The biomedical model of mental disorder: A critical analysis of its validity, utility, and effects on psychotherapy research. *Clinical psychological review*, 846-861.

Delahooke, M. (2019). *Beyond Behaviours.* Eau Claire: PESI publishing and media.

Denzin, N., & Lincoln, Y. (2000). Introduction: The discipline and practice of qualitative research. In N. Denzin, & Y. Lincoln, *Handbook of qualitative research* (pp. 1-28). California: Sage publications.

DFNZ. (2023). *Dyslexia foundation New Zealand* . Retrieved from

www.dyslexiafoundation.org.nz/: https://www.dyslexiafoundation.org.nz/

Diemer, M., Rapa, L., Voight, A., & McWhirter, E. (2016). Critical consciousness: A

developmental approach to addressing marginalisation and oppression. *Child

development perspectives*, 216-221.

Doocey, M. (2022, February 1). *New Zealand Herald*. Retrieved from www.nzherald.co.nz:

https://www.nzherald.co.nz/nz/politics/matt-doocey-calls-for-youth-mental-health-

summit/2JNDD2LF4XOCERZ5ON5W2KHCDM/

Doyle, L. (2001). What makes women sick. In M. Purdy, & D. Banks, *The sociology and

politics of health* (pp. 88-94). London: Routledge.

Drake, R. (2001). *The principles of social policy.* Hampshire: Palgrave Macmillan.

Eggleston, M., Thabrew, H., Frampton, C., Eggleston, K., & Hennig, S. (2019). Obtaining an

autism spectrum disorder diagnosis and supports: New Zealand parents' experiences .

Research in autism spectrum disorders , 18-25.

Ellis, C., & Bochner, A. (2000). Autoethnography, personal nrrative, reflexivity . In N.

Denzin, & Y. Lincoln, *Handbook of qualitative research* (pp. 733-768). Thousand

Oaks: Sage publications, Inc.

Ellis, C., Adams, T., & Bochner, A. (2011). Autoethnography: an overview. *Forum;

qualitative social research*.

EnablingGoodLives. (2023, March). *Enabling Good Lives* . Retrieved from

www.enablinggoodlives.co.nz/: https://www.enablinggoodlives.co.nz/

Epilepsy.org. (2022, October 1). *www.epilepsy.org.nz*. Retrieved from Epilepsy New

Zealand: https://epilepsy.org.nz/understanding-epilepsy/seizures/types-of-

seizures/generalised-onset-seizures/

Epstein, M. H. (2000). The behavioural and emotional rating scale: A strengths-based

approach to assessment. *Diagnostique*, 249-256.

Esbensen, A., Greenburg, J., Seltzer, M., & Aman, M. (2009). A longitudinal investigation of

psychotropic and non-psychotropic medication use among adolescents and adults with

autism spectrum disorders. *Journal of autism developmental disorders*, 1339-1349.

Every-Palmer, S., Kim, A., Cloutman, L., & Kuehl, S. (2023). Police, ambulance and

psychiatric co-response versus usual care for mental health and suicide emergency

callouts: A quasi-experimental study. *Australian and New Zealand journal of*

psychiatry, 572-582.

Farahar, C., & Foster, A. (2021). #AutisticsInAcademia. In N. Brown, *Lived Experiences of*

Ableism in Academia (pp. 197–216). Bristol: Policy Press.

Francis, A. (2012). Stigma in an era of medicalisation and anxious parenting: how proximity

and culpability shape middle-class parents' experiences of disgrace. *Sociology of*

health and illness, 927-942.

Freeman, E. (2019, November 21). *No magic wand UK*. Retrieved from

nomagicwanduk.com: https://nomagicwanduk.com/why-parent-blaming-is-so-

damaging/

Freidson, E. (2001). The profession of medicine. In M. Purdy, & D. Banks, *The sociology*

and politics of health (pp. 130-134). London: Routledge .

Germano, E., Gagliano, A., & Curatolo, P. (2010). Comorbidity of ADHD and dyslexia. *Developmental neuropsychology*, 475-493.

Gerritsen, J. (2022, September 28). *RNZ*. Retrieved from www.rnz.co.nz: https://www.rnz.co.nz/news/national/475612/some-schools-discourage-enrolments-of-children-with-disabilities-education-review-office

Gerritson, J. (2016, October 17). *www.rnz.co.nz*. Retrieved from RNZeducation: https://www.rnz.co.nz/news/national/315796/illegal-school-suspensions-on-the-rise-report

Goedeke, S., Shepard, D., Landon, J., & Taylor, S. (2019). How percieved support relates to child autism symptoms and care-related stress in parents caring for a child with autism. *Research in autism spectrum disorders*, 36-47.

Goffman, E. (1963). *Stigma.* New York: Aronson.

Good, G., Hollis-English, A., Attwell, A., Dickson, A., Gibbs, A., Gordon, J., & Taylor, J. (2017). Social-model mothers: Disability, advocacy, and activism. *Counterfutures: left thought and practice Aotearoa*, 107-135.

Goodley, D. (2001). 'Learning difficulties', the socil model of disability and impairment: challenging epistemologies. *Disability and society*, 207-231.

Goodley, D. (2014). *Dis/ability studies.* Abingdon: Routledge.

Goodley, D. (2014). *Dis/ability studies: theorising disability and ableism.* London: Routledge.

Goodley, D., Lawthorn, R., Liddard, K., & Runswick-Cole, K. (2019). Provocations for critical disability studies. *Disability & Society*, 972-997.

Graves, C., & Graves, J. (2014). *Parents have the power to make special education work.* London: Jessica Kingsley publishers.

Hannam, J. (2014). *Feminism.* Abingdon: Routledge.

Haralambos, M., Holburn, M., & Heald, R. (2000). *Sociology; themes and perspectives.* Hammersmith: HarperCollins.

Harden, J. (2005). Parenting a young person with mental health problems: temporal disruption and reconstruction. *Sociology of health and illness*, 351-371.

Harper, P. (2011, June 1). *New Zealand Herald*. Retrieved from nzherald.co.nz: https://www.nzherald.co.nz/nz/woefully-deficient-youth-services/XX7MYMGCO2TQZRFDO4WPMDSIQY/

Harris, A., Cuervo, H., & Wyn, J. (2021). Policy frames. In A. Harris, H. Cuervo, & J. Wyn, *Thinking about belonging in youth studies* (pp. 71-101). Switzerland: Palgrave MacMillan .

HCN. (2005). *Governance protocol.* Wellington : HCN.

HCN. (2005). *Intersectoral strategy for children and young people with high and complex needs .* Wellington: High and COmplex needs unit.

HCN. (2021). *Annual report.* Wellington : High and Complex needs .

Healey, N. (2016, October 27). Reflections on the value of insider research as a qualitative research methodology. *Reflections on the value of insider research as a qualitative research methodology*. Sage Publications.

Henry, D. (2022, May 17). *NZHerald*. Retrieved from www.nzherald.co.nz: https://www.nzherald.co.nz/nz/autistic-students-in-nz-three-times-more-likely-to-be-stood-down-suspended-new-research/KB7MJR2WPAB7KDXQPLTO3JG6NU/

Henry, D. (2022, October 12). *www.nzherald.co.nz*. Retrieved from New Zealand Herald: https://www.nzherald.co.nz/nz/truancy-crisis-government-sets-attendance-targets-in-new-strategy-to-get-kids-to-school/CL7PYWN7VRES3BZXCQI73AZVWA/

Horwitz, A. (2021). *DSM: A history of psychiatry's bible.* Baltimore: Johns Hopkins University Press.

Hunter, J., Higgenson, I., & Garralda, E. (1996). Systematic literature review: outcome measures for child and adolescent mental health services. *Journal of public health medicine*, 197-206.

Hyslop, I. (2017). Child protection in New Zealand: A history of the future. *British Journal of social work*, 1800-1817.

Hyslop, I. (2022). *A political history of child protection; Lessons for reform from Aotearoa New Zealand.* Bristol: Bristol University Press.

Jones, S., & Harwood, V. (2009). Representations of autism in Australian print media. *Disability adn society*, 5-18.

Justice, M. o. (2020). *Annual provisional suicide statistics for deaths reported to the Coroner between 1 July 2007 and 30 June 2020.* Wellington : Coronial services .

Kapp, S. (2020). *Autistic community and the neurodiversity movement; stories from the frontline.* Exeter: Palgrave Macmillan .

Keddell, E. (2018). The vulnerable child in neoliberal contexts: the construction of children in Aotearoa New Zealand child protection reforms. *Childhood*, 93-108.

Kewanian, A., Creely, E., & Southcott, J. (2021). Affirming strengths-based practices in

    disability and inclusion; A shared autoethnographic study of the experiences of a

    teacher . *The qualitative report*, 2538-2557.

Kiernan, J., Mitchell, D., Stansfield, J., & Taylor, C. (2019). Mothers perspectives on the

    lived experience of children with intellectual disability and challenging behaviour.

    Journal of intellectual disabilities, 175-189.

Kuehl, S., Kim, A., & Every-Palmer, S. (2023). 'An accident waiting to happen' - experiences

    of police officers, paramedics, and mental health clinicians involved in 911-mental

    health crisis: a cross-sectional survey. *Journal of psychiatric and mental health*

    nursing, 1-14.

Kura, T. (2022, November 12). *Te Kura*. Retrieved from www.tekura.school.nz:

    https://www.tekura.school.nz/about-us/who-we-are/our-history/

Lalvani, P. (2014). The enforcement of normalcy in schools and the disablement of families:

    unpacking master narratives on parental denial. *Disability and Society*, 1221-1233.

Lalvani, P. (2019). Exploring meanings of disability. In *Undoing ablism* (pp. 50-70).

    Routledge.

Lampshire, D. (2018). Evolution or revolution. *Psychosis*, 64-69.

Lanovaz, M., Rapp, J., Gendron, A., Prefontaine, I., & Turgeon, S. (2017). Comorbid

    challenging behaviours. In J. Matson, *Handbook of treatments for autism soectrum*

    disorders (pp. 145-169). Cham: Springer.

Lewis, M. (2022, March 23). *University of Surrey* . Retrieved from www.surrey.ac.uk:

    https://blogs.surrey.ac.uk/librarynews/2022/03/23/neurodiversity-and-mental-health/

Litt, J. (2004). Women's carework in low-income households; The special case of children with attention deficit hyperactivity disorder. *Gender and society*, 625-644.

Loftis, S. F. (2019). Dear neurodiversity movement; put your shoes on. In K. Ellis, R. Garland-Thomson, M. Kent, & R. Robertson, *Manifestos for the future of critical disability studies; volume 1* (pp. 20-28). Abingdon: Routledge .

Lohmeyer, B., & Hallahan, L. (2021, August 8). *Making & breaking social policy*. Retrieved from Spotify: https://open.spotify.com/episode/1XJdn0FheT1H8hoU6DWmw9?si=pIC1YLtMTGy 9Eu8ba4FASQ&dl_branch=1

Lopez, S., & Louis, M. (2009). The principals of strengths-based education. *Journal of college and character*, 1-8.

Lowe, P., Lee, E., & Macvarish, J. (2015). Biologising parenting: neuroscience discourse, English social and public health policy and understandings of the child. In G. Brady, P. Lowe, & S. Olin Lauritzen, *Children, Health and Well-being: policy debates and lived experience* (pp. 27-40). Chichester: Wiley Blackwell.

Lukmanji, S., Manji, S., Kadhim, S., Sauro, K., Wirrell, E., Kwon, C., & Jette, N. (2019). The co-occurence of epilepsy and autism: a systematic review . *Epilepsy and behaviour*, 238-248.

Lupton, D. (1997). Foucault and the medicalisation critique. In R. P. Bunton, *Foucault, medicine and health* (pp. 94-110). Taylor & Francis Group.

Maidment, J. (2013). Cross-cultural practice. In M. Connolly, & L. Harms, *Social work contexts and practice* (pp. 163-176). Victoria: Oxford University press.

Martin, R. (2010). Foreward. In P. F. Zealand, *A place of our own: living with the legacyy of institutionalisation* (pp. 9-11). Wellington: People first NZ.

Masnoon, N., Shakid, S., Kalisch-Ellet, L., & Caughey, G. (2107). What is polypharmacy? A systematic review of definitions. *BMC Geriatrics*.

Matson, J., & Dempsey, T. (2007). Autism spectrum disorders: pharmacotherapy for challenging behaviours. *Journal of developmental and physical disabilities*, 175-191.

McBride, C. (2019). Comorbidity. In C. McBride, *Coping with dyslexia, dysgraphia and ADHD* (pp. 78-89). Routledge.

McRae, J. (2014). *Becoming a person.* Nelson: Craig Potton Publishing.

MHF. (2022). *Mental distress prejudice and discrimination in Aotearoa; key statistics 2022*. Retrieved from www.mentalhealth.org.nz: https://www.nokuteao.org.nz/

MHF. (2022, December 14). *Mental health foundation*. Retrieved from www.mentalhealth.org.nz: https://mentalhealth.org.nz/wellbeing-campaigns-&-resources

Michail, S. (2011). Understanding school responses to students' challenging behaviour: A review of literature. *Improving schools*, 156-171.

Mikolajczak, M., Gross, J., & Roskam, I. (2021). Beyond job burnout: Parental burnout. *Science & Society* , 333-336.

Miller, C. (2023, January 9). *Childmind Institute*. Retrieved from www.childmind.org: https://childmind.org/article/what-is-neurodiversity/

Mills, C. W. (1959). *The sociological imagination.* New York: Oxford University Press.

Milton, D. (2020). Neurodiversity past and present - an introduction to the neurodiversity

    reader. In D. Milton, *The Neurodiversity reader* (pp. 3-6). Hove: Pavilion.

Mind. (2018, March). *Mind UK*. Retrieved from www.mind.org.uk:

    https://www.mind.org.uk/information-support/guides-to-support-and-

    services/advocacy/what-is-advocacy/

MOE. (2020, July 3). *www.education.govt.nz*. Retrieved from Ministry of education:

    https://www.education.govt.nz/news/66-million-for-learner-and-educator-

    wellbeing/#sh-neurodiverse

MOE. (2023, February 16). *education.govt.nz*. Retrieved from Ministry of Education:

    https://www.education.govt.nz/school/funding-and-financials/resourcing/interim-

    response-fund-irf/#sh-interim%20response%20funding

MOH. (2022, October 14). *Ministry of health*. Retrieved from www.health.govt.nz:

    https://www.health.govt.nz/your-health/services-and-support/disability-

    services/types-disability-support/respite/carer-support

MOH. (2022, October 10). *www.health.govt.nz*. Retrieved from Ministry of Health:

    https://www.health.govt.nz/about-ministry/what-we-do/budget-2022-vote-health

Moriah, C. (2022). *I am autistic.* Auckland: Allen & Unwin.

Morley, C., Ablett, P., & Noble, C. (2020). Introduction: The imperative of critical

    pedagogies for social work. In C. Morley, P. Ablett, C. Noble, & S. Cowden, *The*

    Routledge handbook of critical pedagogies for social work (pp. 1-16). London:

    Routledge .

Moses, T. (2010). Exploring parents' self-blame in relation to adolescents' mental disorders.

    National council on family relations , 103-120.

MSD. (2016, November). *Office of disability issues*. Retrieved from www.odi.govt.nz:

    https://www.odi.govt.nz/nz-disability-strategy/

MSD. (2022, October 1). *www.odi.govt.nz*. Retrieved from Office for disability issues:

    https://www.odi.govt.nz/disability-toolkit/things-you-should-know-definitions-

    concepts-and-approaches/

MSD. (2023). *Ministry of Social Development*. Retrieved from www.msd.govt.nz:

    https://www.msd.govt.nz/about-msd-and-our-work/work-programmes/disability-

    system-transformation/index.html

Mulder, R., Rucklidge, J., & Wilkinson, S. (2017). Why has increased provision of

    psychiatric treatment not reduced the prevalence of mental disorder? *Australian and*

    New Zealand Journal of Psychiatry, 1-2.

Mulvany, J. (2000). Disability, impairment or illness? The relevance of the social model of

    disability to the study of mental disorder. *Sociology of health and illness*, 582-601.

Murray, F. (2020). Neurodiversity is for everyone. In D. Milton, *The Neurodiversity reader*

    (pp. 105-108). Hove: Pavillion.

Mutch, C. (2008). "Creative and innovative citizenry": Exploring the past, present and future

    of citizenship education in New Zealand. In D. Grossman, *Citizenship curriculum in*

    Asia and the Pacific (pp. 197-211). Springer Dordrecht.

Nash, M., & Miller, J. (2013). Social work: Where we have been and where we are going. In

    M. &. Connelly, *Social work; contexts and practive* (pp. 329-345). Victoria: Oxford

    University Press.

Needham, C. (2016). Welfare users and social policy. In P. Alcock, T. Haux, M. May, & S. Wright, *The students companion to social policy* (pp. 277-282). Chichester: John Wiley & Sons.

Ne'eman, A. (2021). When disability is defined by behaviour, outcome measures should not promote "passing". *AMA Journal of ethics*, 569-575.

Ne'eman, A., & Pellicano, E. (2022). Neurodiversity as politics. *Human development*, 149-157.

Nelson, R. (2021). A critique of the neurodiversity view. *Journal of applied philosophy*, 335-347.

Nettleton, S. (2021). *The Sociology of health and illness; fourth edition.* Cambridge: Polity Press.

NZPolice. (2023). *NZpolice* . Retrieved from www.police.govt.nz: https://www.police.govt.nz/about-us/nz-police/overview

Oakley, A. (1981). Interviewing women: A contradiction in terms. In H. Roberts, *Doing feminist research* (pp. 30-61). New York: Routledge & Kegan Paul plc.

OrangaTamariki. (2022, January 10). *About family group conferencing* . Retrieved from www.orangatamariki.govt.nz: https://practice.orangatamariki.govt.nz/our-work/interventions/family-group-conferencing/about-family-group-conferencing/

O'Reilly, M., & Kiyimba, N. (2021). Responsibility inoculation: constructing 'good parent' accounts when accessing child mental health services. *Human systems: therapy, culture and attachments*, 52-69.

O'Reilly, M., Muskett, T., Karim, K., & Lester, J. (2020). Parents' constructions of normality and pathology in child mental health assessments . *Sociology of health and illness*, 544-564.

Pan, P., Bolte, S., Kaur, P., Jamil, S., & Jonsson, U. (2021). Neurological disorders in autism: a systematic review and meta-analysis. *Autism*, 812-830.

Perera, R. (2022, July 19). *Newshub*. Retrieved from www.newshub.co.nz: https://www.newshub.co.nz/home/new-zealand/2022/07/waikato-whanau-in-crisis-frustrated-at-lack-of-effective-help-for-young-son-with-severe-complex-behavioural-needs.html

Pierson, J., & Thomas, M. (2010). *Dictionary of social work.* Berkshire: Open University Press.

Pillar, S., & Whitehouse, A. (2023, April 12). *The Conversation.* Retrieved from theconversation.com : https://theconversation.com/autism-and-adhd-assessment-waits-are-up-to-2-years-long-what-can-families-do-in-the-meantime-203232?utm_medium=email&utm_campaign=Latest%20from%20The%20Conversation%20for%20April%2013%202023%20-%202597026118&utm_content=Latest%

Powell, D. (2012). A review of inclusive education in New Zealand. *Electronic journal for inclusive education, 2*(10).

Powell, S. (2016, July 19). *Marlborough charity bread of life loses strengthening families contract* . Retrieved from Stuff: https://www.stuff.co.nz/national/health/82241379/marlborough-charity-bread-of-life-loses-strengthening-families-contract

Priestley, M. (2016). Disability. In P. Alcock, T. Haux, & M. &. May, *The student's companion to social policy* (pp. 439-444). Chichester: John Wiley & sons ltd.

Rafferty, K., & Sullivan, S. (2017). "You know the medicine, I know my kid": How parents advocate for their children living with complex chronic conditions. *Health communication*, 1151-1160.

Reardon, T., Harvey, K., Baranowska, M., O'Briens, D., Smith, L., & Creswell, C. (2017). What do parents percieve are the barriers and facilitators to accessing psychological treatment for mental health problems in children and adolescents? A systematic review of qualitative and quantitative studies. *European child and adolescent psychiatry*, 623-647.

Reeve-Johnson, L. (2016). The transactional nature of human healthcare. *International archives of translational medicine*, 1-6.

Ridout, A. (2023, January 18). *Stuff.* Retrieved from Stuff.co.nz: https://www.stuff.co.nz/national/130950506/so-many-kids-fall-through-the-cracks-advocate-speaks-out-over-funding-cut-for-familyfocused-service

Rosqvist, H., Chown, N., & Stenning, A. (2020). Introduction. In H. Rosqvist, N. Chown, & A. Stenning, *Neurodiversity studies* (pp. 1-11). London: Routledge.

Roughan, J. (2019, April 1). *New Zealand Herald*. Retrieved from nzherald.co.nz: https://www.nzherald.co.nz/nz/john-roughan-wheres-the-action-on-the-suicide-crisis-in-new-zealand/BT2XKDERRIZQZUHWSTLJRNBVMM/

Runswick-Cole, K. (2008). Between a rock and a hard place: parents' attitudes to the inclusion of children with special educational needs in mainstream and special schools. *British journal of special education*, 173-180.

Runswick-Cole, K., & Ryan, S. (2019). Liminal still? Unmothering disabled children. *Disability & society*, 1125-1139.

Ryan, S., & Runswick-Cole, K. (2008). Repositioning mothers: mothers, disabled children and disability studies. *Disability & society*, 199-210.

Schuster, J. (2017). Why the personal remained political: comparing second and third wave perspectives on everyday feminism. *Social movement studies*, 647-659.

Scott, E. (2010). The emotional impact of changed employment trajectories of mothers caring for children with disabilities. *Gender & society*, 672-696.

Selvaraj, J. (2015). Inclusive education in New Zealand: policies, politics and contradictions. *International journal of inclusive education*, 86-101.

Shakespeare, T. (2018). *Disability; the basics.* Abingdon: Routledge.

Shakespeare, W. (2004). Romeo and Juliet. In W. Shakespeare, *The complete works of William Shakespeare* (pp. 168-187). New Lanark: Geddes & Grosset.

Shivas, O. (2022, June 2). *Stuff limited*. Retrieved from Stuff.co.nz: https://www.stuff.co.nz/pou-tiaki/128623375/no-disability-data-collected-when-students-are-suspended-ministry-of-education-reveals?fbclid=IwAR15dhPmAOkVnLerYV3Ktfj9xrpZy452f7ePWTnibUD1cLhunJxqFIC0qJc

Sinclair, J. (2012). Don't mourn for us. *Critical journal of interdisciplinary autism studies*.

Soloman, A. (2008, May 23). *New York magazine*. Retrieved from nymag.com: https://nymag.com/news/features/47225/

Soosay, I., & Kydd, R. (2016). Mental health law in New Zealand. *BJPsych international*, 43-45.

Spencer, D., Marshall, J., Post, B., Kulakodlu, M., Newschaffer, C., Dennen, T., . . . Jain, A. (2013). psychotropic medication use and polypharmacy in children with autism spectrum disorderss. *Pediatrics*, 833-840.

Stace, H., & Sullivan, M. (2020, October). *Office for disabiltiy issues.* Retrieved from odi.govt.nz: https://www.odi.govt.nz/guidance-and-resources/a-brief-history-of-disability-in-aotearoa-new-zealand/

Stanford, E. (2022, May 6). *National.org.nz.* Retrieved from www.national.org.nz: https://www.national.org.nz/literacy-and-numeracy-are-still-declining

Starr, K., & Janah, N. (2016). *Challenging The Barriers: Ensuring Access To Education For Children With Special Educational Needs.* Wellington: Youthlaw Aotearoa.

StatsNZ. (2021, February 17). *Stats NZ.* Retrieved from www.stats.govt.nz: https://www.stats.govt.nz/news/disabled-people-still-faring-worse-than-non-disabled-people

StrengtheningFamilies. (2022, June 28). *How strengthening families works .* Retrieved from www.strengthening families.govt.nz: https://www.strengtheningfamilies.govt.nz/how-strengthening-families-works/

Swarbrick, N. (2008, November 24). *Te Ara - the Encyclopedia of New Zealand.* Retrieved from www.teara.govt.nz: http://www.teara.govt.nz/country-schooling

Swarbrick, N. (2012, June 20). *Te Ara - the Encyclopedia of New Zealand.* Retrieved from www.teara.govt.nz: http://teara.govt.nz/en/primary-and-secondary-education

Tearney, F. (2016). *Working paper 2016/03: History of education in New Zealand.*
Wellington: The McGuinness Institute.

TeWhatuOra. (2022, October 25). *Suicide Web Tool*. Retrieved from Te whatu ora:
https://tewhatuora.shinyapps.io/suicide-web-tool/

TeWhatuOra. (2022, November 29). *www.tewhatuora.govt.nz*. Retrieved from Te Whatu Ora:
https://www.tewhatuora.govt.nz/our-health-system/data-and-statistics/suicide-web-
tool

TKI. (2022, February 3). *Te Kete Ipurangi*. Retrieved from nzcurriculum.tki.org.nz:
https://nzcurriculum.tki.org.nz/The-New-Zealand-Curriculum

Tullis, J. (2022). Self and others; Ethics in autoethnographic research . In T. Adams, S.
Holman Jones, & C. Ellis, *Handbook of autoethnography* (pp. 101-113). New York:
Routledge .

UNICEF. (2020, September 3). *unicef.org.nz*. Retrieved from www.unicef.org.nz:
https://www.unicef.org.nz/stories/new-report-card-shows-that-new-zealand-is-failing-
its-children

Valencia, R. (1997). *The evolution of deficit thinking : educational thought and practice.*
London: RoutledgeFalmer Press.

Walker, N. (2021). *Neuroqueer Heresies.* Fort Worth: Autonomous Press.

Wells, I. (2022, March 25). *Government reveals strategy to tackle declining literacy and
numeracy rates in children.* Retrieved from Newshub.co.nz:
https://www.newshub.co.nz/home/new-zealand/2022/03/government-reveals-strategy-
to-tackle-declining-literacy-and-numeracy-rates-in-children.html

White, K. (2009). *An introduction to the sociology of health and illness.* London: SAGE
    Publications Ltd.

White, R. (2004). Discourse analysis and social constructionism. *Nurse researcher*, 7-16.

WHO. (1977). *Child mental health and psychosocial development.* Geneva: World Health
    Organisation.

WHO. (2021). *Adolescent mental health.* Geneva: World health organisation.

WHO. (2021, November 24). *World health organisation.* Retrieved from www.who.int:
    https://www.who.int/news-room/fact-sheets/detail/disability-and-health

WHO. (2022, December 25). *World Health Organisation*. Retrieved from www.who.int:
    https://www.who.int/data/gho/data/major-themes/health-and-well-being

Wilde, J. (2023, February 10). *Accomplish inclusion.* Retrieved from
    www.accomplishinclusion.com: https://www.accomplishinclusion.com/post/we-need-
    to-talk-about-bad-language-and-i-don-t-mean-swearing

Wilhelmsen, T., & Nilsen, R. D. (2015). Parents' experiences of diagnostic processes of
    young children in Norwegian day-care institutions. In G. Brady, P. Lowe, & S. O.
    Lauritzen, *Children, Health and Well-being; Policy debates and lived experience* (pp.
    69-82). Chichester: Wiley Blackwell.

Wilkinson, S., & Mulder, R. (2018). Antipsychotic prescribing in New Zealand between 2008
    and 2015 . *The New Zealand medical journal*, 61-67.

Williams, A. (2021, April 27). *www.rnz.co.nz.* Retrieved from rnz.co.nz:
    https://www.rnz.co.nz/news/national/441314/schools-exclusion-of-children-with-
    high-needs-common-advocates

Witton, B. (2022, December 7). *Hundreds of mental health nurses, doctors and psychiatrists leave profession this year*. Retrieved from stuff.co.nz: https://www.stuff.co.nz/national/politics/130696598/hundreds-of-mental-health-nurses-doctors-and-psychiatrists-leave-profession-this-year

Wodehouse, G., & McGill, P. (2009). Support for family careres of children and young people with developmental disabilities and challenging behaviour: what stops it being helpful? *Journal of intellectual disabilities research*, 644-653.

Wong, T., & Shorey, S. (2022). Experiences of peer support amongst parents of children with neurodevelopmental disorders: A qualitative systemic review. *Journal of pediatric nursing* , 1-8.

Wood, B., Thrupp, M., & Barker, M. (2021). Education policy: changes and continuities since 1999. In G. Hassell, & G. Karacaoglu, *Social policy practice and processes in Aotearoa New Zealand* (pp. 274-286). Auckland: Massey University Press.

Yuill, C., Crinson, I., & Duncan, E. (2010). *Key concepts in health studies.* London: Sage publications Ltd .

Zhang, X., Wu, Y., & Sheng, Q. (2022). 'I am not a good enough parent': The experience of self-stigma in parents of children with mental illness in China. *Research square*.

10 APPENDIX

10.1 APPENDIX A – LIST OF MEDICATIONS

List of Medications Included for Analysis by Class

Antidepressants

Amitriptyline
Citalopram hydrobromide
Clomipramine hydrochloride
Dosulepin [Dothiepin] hydrochloride
Doxepin hydrochloride
Escitalopram
Fluoxetine hydrochloride
Imipramine hydrochloride
Maprotiline hydrochloride
Mirtazapine
Moclobemide
Nortriptyline hydrochloride
Paroxetine
Phenelzine sulfate
Sertraline
Tranylcypromine sulfate
Venlafaxine

Antipsychotics

Amisulpride
Aripiprazole
Chlorpromazine hydrochloride
Clozapine
Flupenthixol decanoate
Haloperidol decanoate
Haloperidol
Levomepromazine hydrochloride
Levomepromazine maleate
Lithium carbonate
Olanzapine
Paliperidone
Pericyazine
Pipotiazine palmitate
Quetiapine
Risperidone
Ziprasidone
Zuclopenthixol decanoate
Zuclopenthixol hydrochloride

Anxiolytics

Buspirone hydrochloride
Clonazepam
Diazepam
Lorazepam
Oxazepam

Sedatives and hypnotics

Lormetazepam
Melatonin
Midazolam
Nitrazepam
Phenobarbitone sodium
Temazepam
Triazolam
Zopiclone

Stimulants/attention-deficit/hyperactivity disorder treatments

Atomoxetine
Dexamfetamine sulfate
Methylphenidate hydrochloride extended-release
Methylphenidate hydrochloride
Modafinil

(Barczyk, Rucklidge, Eggleston, & Mulder, 2020).

Private Bag 3105

Human Research Ethics Committee   Hamilton 3240

THE UNIVERSITY OF
WAIKATO
Te Whare Wānanga o Waikato

Division of Arts, Law, Psychology

Before applying for approval applicants must familiarise themselves with the Ethical Conduct in Human Research and Related Activities Regulations in the University Calendar http://calendar.waikato.ac.nz/assessment/ethicalConduct.html.

Use this application if your research project involves the collection, use, and/or reuse of human data. This form is to be completed by staff and students doing research **prior to** the collection of any data from human participants.

Upon completion of this form please submit to/or email to your Faculty/School Human Research Ethics Committee [HREC]. Health Research and Health, Sport & Human Performance applications should be submitted to the central HREC (humanresearch@waikato.ac.nz).

Checklist

A positive answer to one or more of the questions below indicates the need for review by the HRC accredited Human Research Ethics Committee. Health Applications should be submitted by email to humanethics@waikato.ac.nz.

- ✓ Are you investigating a topic that concerns health, disability or well-being?
- ❑ Are you using an instrument intended to assess health, disability or well-being?
- ❑ Is referral to a health service provider a potential outcome of participation?
- ✓ Are participants being recruited in their capacity as DHB employees?
- ❑ Is the researcher intending to collect tissue samples (e.g. bloods, saliva, urine) from healthy individuals?

❑ Is the researcher intending to utilize interventions related to exercise and nutrition?

Submit this application form when the checklist and the Application Cover Sheet is complete and has been signed.

✓ Personal details (on Application Cover Sheet)

✓ Academic Details (on Cover Sheet)

✓ Consent Form (attached)

✓ Signatures (where required)

✓ Information Sheet (attached)

✓ Research Instruments (attached)

Human Research Ethics Committee

Private Bag 3105

Hamilton 3240

THE UNIVERSITY OF
WAIKATO
Te Whare Wānanga o Waikato

Name of Principal Investigator:	**Kelly Robyns**
School / Faculty / Institute:	Division of Arts, Law, Psychology and Social Sciences (ALPSS)
Email address:	**kellyrobyns441@gmail.com**
Phone number:	021432055
Office:	**na**
Student ID (if applicable):	**1359728**
Proposed start date of field research / data collection:	September 2022
This is an application for approval of: (please tick as many as apply)	❑ Staff research project involving human participants ✓ Master's degree research ❑ PhD research ❑ Other
Name of degree / paper:	**Masters in social policy**
Supervisor's name:	**Gemma Piercy-Cameron**
Supervisor's approval (signature):	
Funding sources:	**na**
Project sponsors (e.g. equipment sponsors):	**na**

Associated Applications (record the associated application code and title):   **na**

- ✓ I request approval for this research or related activity and attach all relevant documentation necessary for evaluation under the Ethical Conduct in Human Research and Related Activities Regulations.

http://calendar.waikato.ac.nz/assessment/ethicalConduct.html

- ✓ I have read and complied with the University's Ethical Conduct in Human Research and Related Activities Regulations.

Principal Investigator's signature:

Date: **30 July 2022**

Please provide us with basic information about your project.

1. <u>Project Title:</u>

Exploring the nature of social service response in relation to neurodiverse and complex children

2. <u>Briefly state the **research topic, research questions** and/or **research objectives.**</u>

My qualitative research seeks to describe the current social policy context of neurodiverse and complex children in Aotearoa New Zealand. In particular, I would like to investigate social service provision for neurodiverse individuals in Aotearoa New Zealand, I will address this by examining key policies and literature and by speaking with workers from social service providers. By speaking with professional workers within these fields I hope to gain a fuller picture of their experience of the policy context and systems of service provision. I will also be drawing on secondary sources to analyse the language used to describe neurodiverse and complex youth and discuss the consequences of this framing on the social policy and service provision contexts. Finally, I will share minimal and relevant parts of my personal journey of being a parent of a neurodiverse child with complex needs. The aim of the personal material is to disclose my positionality within this research in line with interpretative research. I also hope that my story, which had positive outcomes, will serve as a source of inspiration for other families in similar situations.

Research questions:
- ➢ How are neurodiverse and complex children framed in literature and policy?
- ➢ What social services are provided for neurodiverse and complex children? What are the strengths and limitations of these services?
- ➢ What are the perspectives and experiences of some professionals within the social services who interact with neurodiverse and complex children?

3. <u>What research activities are you planning to undertake?</u>

Key informant interviews

136

(Auto)ethnography

Policy analysis

Literature review

4. <u>To justify your project, provide a summary of the research, its methods, anticipated benefits, value and/or its contribution to the field.</u>

This research contributes evidence-based narratives of social service provision for neurodiverse and complex children in Aotearoa New Zealand. Accessing social services for a neurodiverse and complex child is not always easy, as illustrated by these international accounts (see, (Denman, 2014) (Lowe, Lee, & Macvarish, 2015) (Lundeby & Tossebro, 2008) (Rafferty & Sullivan, 2017) (Wilhelmsen & Nilsen, 2015) and in accordance with my own experience. Part of the problem of access is long wait times, for example, a New Zealand Herald article documented the "extraordinarily long" wait times for children in crisis to access social services (Cardwell, NZHerald.co.nz, 2021). The need for these services is indicated by research such as, a New Zealand school-based survey between 2007-2012 reported 31% of young people had experienced low mood, 15/7% reported suicidal ideation and 24% engaged in self harm each year. The long-term consequences of this include, social exclusion, lesser job opportunities and overall poorer life outcomes (Bowden N. G., 2020).

There are many contributing factors to both the rise in need for social services and the long wait times, I am interested in contributing to this literature by drawing on the perspectives of professionals working on the ground in these areas, as well as my own experience when relevant. I will seek to conduct semi structured interviews with NZ Police, Social workers, Crisis team operators etc. These participants will be invited to share their experience of working with neurodiverse and complex children. By exploring the experiences of professionals working in social services, understanding how neurodiverse children are framed within literature and policy, and learning the strengths and weaknesses of provision we can better understand how neurodiverse children can prosper in their communities. In this sense my research also contributes to the wider mission of social science research being "enabling community life to prosper" (Christians, Ethics and politics in qualitative research, 2000).

While it will be a minor part of the thesis, I will be drawing on my personal experience as a parent, therefore it is important to outline how my subjective insights fit within the wider methodology of my research. Being explicit and reflexive about researchers'

experience and position is central to the methodology of qualitative research (Day, 2012). It is also important to note that in relation to feminist epistemology that "experiential accounts have been an important source of knowledge" especially when objective knowledge while often impossible to obtain is also undesirable in certain situations (Day, 2012). The process of reflexivity central to these methodologies will facilitate a critical examination of my insider status. I will draw on the practices of autoethnography to do this.

Similar to feminist epistemology, autoethnography is an approach that acknowledges "subjectivity, emotionality and the researchers influence on the research" (Ellis, Adams, & Bochner, 2011). My use of specific personal moments will add "depth, emotionality, nuance and coherence" to my research (Christians, Ethics and politics in qualitative research, 2000).

The Researcher(s)

Please tell us about your research team.

5. <u>List all members of the research team and briefly describe their roles within the research project:</u>

The research team will consist of myself and my supervisor, Gemma Piercy-Cameron.
I will undertake interviews, transcribe, and collate information.

6. <u>Outline your qualifications to undertake this research. Include such things as prior experience, training in relevant research methods, and/or personal knowledge of the subject.</u>

I hold 2 bachelor's degrees in Drama and Theatre (Royal Holloway, University of London) and in Social Sciences (University of Waikato) majoring in social policy, I also hold a graduate diploma in secondary teaching (Bethlehem Tertiary Institute). At graduate and postgraduate level, I have completed papers in counselling, anthropology, and research methods in which critical reflexive practice, interviewing and transcribing were compulsory components to completion of these papers.

In addition to my studies I have been a business owner, secondary school teacher, sales manager in the corporate sector and worked extensively with disabled adults as well as raising my son.

7. <u>What, if any, discipline-specific codes of ethics or professional standards will guide your research?</u>

The University of Waikato research code of ethics

https://calendar.waikato.ac.nz/research-assessment-graduation/ethical-conduct

The Participants

8. <u>Broadly, who will they be? (Indicate the population, not the names of participants)</u>

The population for interview selection will be key informant interviews drawn from a range of professional groups within the social service sector. These will include members of New Zealand Police, mental health professionals (DHB), educational psychologists (ministry of education) and potentially social workers and/or FGC coordinators from Oranga Tamariki.

9. <u>How many participants will there be? Provide an estimate if you are unsure of exact numbers.</u>

There will be 3-10 participants.

This estimate is broad as I am unsure how many participants will agree due to the nature of their job, time may also be a factor due to the immense strain on all social services at present. I also need to be flexible with participant numbers due to the need to recruit participants who are not part of my social network (see below).

10. <u>How will you recruit participants? Summarise your process.</u>

I will use my social contacts within social services to engage with professionals, they will be contacted by email and/or telephone to see if they are interested. They will also be asked to pass my information on to anyone else who might be interested within their networks. This practice is consistent with the snowball approach where "a random sample of individuals is drawn from a given finite population" *(Goodman, 1961)*. Including participants from outside my social network ensures that there is a measure of objectivity in relation to the interviews. To reinforce this practice I will make sure that 50% or less of participants will be known to me.

> How will you inform them about the project and their part in it? Summarise your process.

This information will be provided in the information sheet via email once they have indicated their interest, I will reiterate the project goals once they have agreed to the interview and at the time of the interview.

Attach *a copy of the information sheets for participants. Ensure that the content of the information sheet is written in language suited to the relevant participants. See a sample information sheet and guidelines* ***here***.

> Are the participants vulnerable?

> Yes

[See *Section 2.3 Vulnerable Participants*, *Section 8.3 Ethical considerations when working with children*, and *Section 8.5 Ethical considerations around the disclosure of illegal behaviours through research* for guidance].

> If yes, then

> > In what ways are they vulnerable?

There are three key ways that participants have the potential to be vulnerable

- Participants that are known to me via social networks may feel coerced to participate
- Given the small number of participants it is possible that they may be identified through their statements
- Participants may speak out against their organisation; this may put their employment/career progression at risk

Why do you need to involve them in your research?

As quoted in question 4, "experiential accounts have been an important source of knowledge" *(Day, 2012)*. Perspectives and experiences from people working in social services with neurodiverse and complex individuals is key to my research. These views are also not comprehensively featured in current research in this area.

> > How will you protect them from harm?

- I will ensure that 50% or more will be outside of my social network
- I will stress to each participant that they have the right to say no to taking part in the research at several stages of the research process, for example,

> > > Each participant will have the right to not answer any question

Each participant will have the opportunity to read the full transcript and comment on which parts they would like included/excluded after the interview; when I have selected quotes, I will contact the participants again and ask them to recheck the quotes. I will emphasis the need to protect themselves.

Each participant can withdraw from the research up to two weeks after receipt of selected quotes for checking.

- Each participant will be given a pseudonym and their organisations will not be identified in the write up of my research

11. <u>Will you select participants on the basis of their ethnicity, iwi, culture, gender, sexuality, religion, ethical belief or disability?</u>

No, they will be selected based on their profession.

If **YES**, then specify the basis for selection, and state how you will tell participants about the selection criteria.

<u>Are your participants likely to be from a particular ethnic group or other distinct population even if you are not selecting them on that basis?</u>

They are likely to be Pakeha due to the ratio of Pakeha working in these professions.

<u>What cultural and other competencies do you have to work with your selected participant group (e.g. language, membership, professional training)?</u>

While my participants are being chosen for their professional knowledge and experience, my experience of the system along with my education, allows me to be able to understand and empathise with their position. Given that up to 50% of my participants may be known to me, if I am aware that anyone is of a different culture to mine, I will seek assistance in how best to honour any cultural preferences

12. <u>Do you have any type of relationship with your participants already (e.g. employer/employee, supervisor/worker, personal relationship)?</u>

There will be a relationship with 50% of my participants due to me accessing social services as a parent, yet due to a snowball approach there will also be participants that I do not know.

> If yes, then you will have a dual role in the research, both as researcher and, for example, as friend or family member. How will your pre-existing relationship affect your role as a researcher?

My position as a dual researcher, puts me in the unique position of being able to "study a particular issue in depth and with special knowledge about the issue" *(Costley, 2010)*, along with the advantage of knowing who to contact and already having some rapport. By using my personal knowledge of service accessibility and neurodiversity enables me to communicate with my participants easily and empathise with their position which is key to a rich interview experience. As outlined in question 4, I want to make note that I am carrying this research out as a researcher and not as a parent, being able to critically reflect on my own experience as a parent adds the critical nature of real-ness and presenting that along with stories from my key informants will enhance the research in accordance with feminist and autoethnographic epistemologies.

> Consider potential ethical issues associated with your pre-existing relationship. How will you address these issues in your project?

Being known to some of my participants may bring challenges including emotional investment on both sides. For myself, I will address any emotional situations with my family counsellor and due to the nature of their profession the participants will have access to counsellors also.

They may be power dynamics to consider with the participants previously seeing me as a service user whereas I am now approaching them in the role of researcher. Due to the possibility of them speaking out against some of their organisation or others, all participants will have pseudonyms. The participants will also have the option to withdraw at any time and/or choose not to answer specific questions. They will also have chance to read the full transcript from interview and later the specific quotes that will be used in the findings. At both of these stages it will be stressed to them that they have the right to stipulate any parts they wish not to be used.

Ultimately, I wish to do no harm so ethical and emotional concerns will always be a part of the conversation and if anyone is uncomfortable, they will have the right to not answer or continue.

Due to my son also being a part of the research conversation and him being home with me, I will make sure that all telephone conversations take place out of earshot of him. He does not have access to my computer, and it is password protected.

13. Will participants receive any form of compensation or incentive for participation? (See guidelines on compensation and note that reimbursement for travel expenses can be stated, but does not need justification.)

No

If yes, what will they receive? (e.g. vouchers, prizes, shared refreshments, course credits etc.)

Consent

Please provide the following information about consent processes

14. How will you gain informed consent from your participants?

Recruitment via email/telephone

Information sheet

First point of contact – email – confirm

Second point of contact – interview – verbal consent

Signed consent form in person or via email

Who will gain consent from participants? Note that where dual roles exist (Q.12 above), coercion to participate may be avoided by asking a third party to undertake the informed consent process.

I will contact the participants directly.

When will participants give their consent?

3 points of consent – initial recruitment and expression of interest; at the interview; checking transcript /quotes

How will you record their consent?

By email – for first and second points of consent

By signing and returning the consent form as part of the interview process.

Attach a copy of the consent forms for participants. If you intend to seek oral consent, include a procedure sheet to describe the process by which consent will be negotiated.

If vulnerable, are your participants able to give informed consent? [See Section 2.3 Vulnerable Participants *for guidance.*] Yes

If no, then:

How will you obtain consent from their proxy?

What steps will you take to ensure that their participation is voluntary at all times?

15. <u>With the exception of participants who are anonymous to the researcher, participants have the right to withdraw entirely or in part from the research. Please provide the following information:</u> How long will participants have to withdraw? (e.g. three weeks after data collection, or receipt of a transcript)

Each participant has the right to withdraw up to two weeks after receiving the final quotes for checking.

How will they withdraw? (e.g. by informing the researcher)

Participants will email or telephone me to let me know that they wish to withdraw

16. <u>Data collection activities may be planned for off-campus locations. Please list all off-campus location where you will engage in data collection.</u>

Interviews will be conducted via zoom or at a suitable place nominated by the participant

17. <u>Do you need consent or permission from any organisation, community representative, or anyone other than the individual participants?</u>

As I'm using social networks and will be keeping the identity of my participants anonymous – I will not seek consent from organisations

If yes, list all the required permissions, consents, or approvals.

How and when will you gain these?

Attach *any statements, letters, or emails of permission or approval that have been secured in advance of your application to the Human Research Ethics Committee.*

Research design

Please tell us about what you will be asking your participants to do.

18. <u>What will participants be doing?</u>

The participant will read and consider the information provided to them via email and telephone conversation to determine whether they will take part.

Key informant participants will take part in a semi-structured interview that will be recorded with their consent. This will take the form of a natural conversation between myself and the participant.

The participant will read the full interview transcript. The participants will have the opportunity to check over any quotes in the thesis findings.

How long will each activity take?

Reading and checking information sheet and consent form – 30 minutes

Taking part in interview – 30-60 minutes

Reading transcript – 60 minutes

Reading quotes – 30 minutes

In total, a maximum of 3-4 hours of the participants time over a period of 3 months

Please provide these details for all of the items on your list in Q.3.

Attach all research instruments that you intend to use to collect data. (e.g. interview schedules, questionnaire/survey items). Indicate whether the research instruments are drafts or final versions. The final versions of research instruments must be lodged with the committee prior to data collection.

19. How will participants benefit from their involvement in the research?

Participants will benefit by being able to voice their experience and have a forum to discuss what provisions they believe are available for neurodiverse and complex children. By taking part in a semi-structured interview for a qualitative study gives participants an opportunity to "provide a narrative of their experience" *(Healey, 2016)*. They will also have the opportunity be able to give recommendations on what they think will make things easier for children, families, and the social services.

20. Could participants be harmed in your research? [see Section 2 for guidance.]

Yes

If YES, please describe all potential harms to your participants.

How will you minimize the risk of these harms occurring?

The risks of coercion from recruitment of participants from my social network will be mitigated by: the provision of multiple opportunities to withdraw from the research, and the inclusion of 50% or more participants who are not known to me. The risks with identification

145

and potential harm to employment and career progression will be discussed during the informed consent process at the beginning of the interview.

What will you do if a participant is harmed?
I will have informed participants of any potential risks and harms prior to and during the interview. The participants will also have multiple opportunities to review what they have said and discuss any parts that they do not want included.

Is it likely that concerns could arise regarding the health and wellbeing of your participants, through their participation in your project? How will this be managed?
There is a possibility that conversations surrounding the treatment or management of neurodiverse and complex children could trigger both my participants and me. I have addressed this on my consent form asking if they have access to workplace counsellors if needed. I too have access to a counsellor. If they do not have this provision, I will provide a list of local counselling services.

21. How will you analyse the data that you collect from your participants?
I will undertake textual analysis

22. Will your research involve comparing one group to another? [suggest moving up to Q.11]
No
If yes, then, explain how the comparison will be done.
How are the participants categorized into specific groups?
Why is it important to do this?

23. Does your research involve any deception of participants?
No
If yes, then describe the deception.
Why is it necessary to deceive participants? How and when will participants be told of the deception?

24. <u>Will the true identity of the researcher(s) be concealed from participants at any time during the researcher? (Such research is called 'covert research'.)</u>

No

    If yes, then describe the concealment.

    Why is it necessary?

    How and when will participants be told of the concealment?

    If never, then, explain why the concealment will not be disclosed to participants.

Cultural safety

Te Whare Wānanga o Waikato, the University of Waikato, through its official *Charter,* has an explicit commitment to partnership with Māori, to kaupapa and tikanga Māori, and to the interests of New Zealand-born and Island-born Pacific people.

Through the *Ethical Conduct and Human Research and Related Activities Regulations*, researchers are required to respect the **cultural, social** and **language preferences** and **sensitivities** of participants. When applying for ethical approval, researchers should demonstrate an awareness of social and cultural difference, consult advisors regarding the appropriate conduct of their research, and present the outcome of consultation in their ethics application.

Two resources that are particularly relevant to research at the University of Waikato are *Te Ara Tika – Guidelines for Māori Research Ethics* and the *Pacific Health Research Guidelines.*

25. <u>Does the research project have particular relevance or potential implications for Māori, or for other social and cultural groups?</u>

Due to the over representation of Māori featuring in mental health data, yes, this research has implications for Māori and other social groups, however this is not a kaupapa Māori project.

    If YES, then please provide the following information about your consultation processes.

    Who are the stakeholders? (That is, whom do you have to consult?)

What are the results of your consultation with them so far? (e.g. advice taken on appropriate procedures and approaches to research, decisions made about appropriate ways to return research findings)

Do you have at least one cultural advisor for this project? Please provide their name(s) and specific role(s).

If there is an issue of Tikanga I will seek advice from Gemma as my supervisor in the first instance about who could be accessed to provide cultural advice.

26. Describe how you will show respect and sensitivity towards participants (e.g. having support persons present during interviews, having an interpreter if you are not fluent in the language, being vouched for by elders, using appropriate gestures, dressing inoffensively, or participating in cultural ceremonies or rituals).

I will indicate that a support person is welcome in the interview if they wish.

27. How will the identities of participants (and their communities and/or organisations where relevant) be represented in the research?

All parties will be anonymised, and their organisation will not be named. In my critique I will remain as neutral as possible seen as my interest is of the system itself rather than the actors

28. Is it important to maintain the confidentiality of participants (and their communities/organisations where relevant) in the research reporting?

Yes.

If **YES**, how will you preserve confidentiality?

All participants will be anonymised and given pseudonyms. Their organisations will not be named.

29. In addition to the lead researcher(s), who else will see information provided by the participants? Will any of the shared information be linked to the participants' names, or will it be anonymised before sharing?

The lead researcher and supervisor will have access to the information.

*It may be appropriate to ask additional parties (e.g. student researchers, transcribers) to sign a confidentiality agreement. **Attach** the confidentiality agreement that you intend to use.*

30. <u>How and where will the data be stored and protected **during** the research project?</u>

All data will be stored on my computer, I will create a password protected folder for all information involved in this project.

Research Reporting

31. <u>List all the anticipated research outputs for the project (e.g. thesis, conference papers, journal articles, other sorts of presentation, book, media release, pedagogic materials).</u>

The main research outputs will be final thesis, I will also hope to disseminate my findings at a research conference, workshop and/or journal articles

32. <u>What provision is there to provide participants with information about the outcomes of the research?</u>

I will ask if the participants would like to know the outcome of the research and if so, provide them with a copy of my findings

33. <u>Research data must be stored for a minimum of 5 years after the completion of a research project.</u>

All data will be stored by the researcher on a personal computer.

Where and how will you store your data after the project has been completed? (Supervisors are responsible for storing research data on behalf of their students.)

If archiving is appropriate for your project data, where will you archive the data and under what conditions?

If you do not intend to store your data indefinitely, how will you ensure that your data is safely destroyed?

Legal Issues

34. <u>Ownership of Human Research Data</u>

It is usual to state that participants own the data that they provide, and that the researcher will use the data for the specified purposes, with the consent of participants. Please explain any variation from this arrangement.

There will be no variation from this arrangement.

35. Copyright

The researcher's ownership of scholarly publications and other forms of research outputs is governed by the University of Waikato's Intellectual Property Rights Policy. Crucially the policy states in Clause 8 that, *"the University recognises and endorses the traditional academic freedom of staff to publish research and scholarly documents and to produce creative and artistic works without restriction; the University does not assert ownership of copyright of such works (e.g. books, journal articles, conference papers, art works and musical recordings) unless specified in clauses 12-18 of [the] policy."*

Please explain any variation from this policy.

There is no variation from this policy.

Clause 9 states that, *"When dealing with intellectual property that includes Mātauranga Māori, and in the context of the WAI262 claim report, the principles of Te Tiriti o Waitangi will be applied by the University"*. Please indicate if intellectual property is subject to the principles of Te Tiriti o Waitangi.

There will be no intellectual property subject to the principles of Te Tiriti o Waitangi.

36. Other legal or ethical issues

Describe any other legal or ethical issues related to this project. Consider particularly relationships between members of the research team, and project funders, sponsors, or other stakeholders.

Bowden, N. G. (2020). Case identification of mental health and related problems in children and young people using the New Zealnd integrated data infrastructure. *BMC Medical informatics and decision making*.

Cardwell, H. (2021, July 16). *NZHerald.co.nz*. Retrieved from https://www.nzherald.co.nz/nz/youth-mental-health-fears-lives-are-being-put-at-risk-due-to-excessive-wait-times/3ZVVKVD5PN75ZQSK3BVKDODSKU/: https://www.nzherald.co.nz/nz/youth-mental-health-fears-lives-are-being-put-at-risk-due-to-excessive-wait-times/3ZVVKVD5PN75ZQSK3BVKDODSKU/

Christians, C. (2000). Ethics and politics in qualitative research. In N. Denzin, & Y. Lincoln, *Hnadbook of qualitative research* (pp. 133-155). California: Sage publications .

Costley, C. E. (2010). Key concepts for the insoder-researcher. In C. E. Costley, *Doing work based research: Approaches to enquiry for insider-researchers* (pp. 1-7). Sage publications.

Day, S. (2012). A reflexive lens: exploring dilemmas of qualitative methodology through the concept of reflexivity. *Qualitative sociology review*, 60-85.

Denman, S. (2014). Parents as experts on children with disabilities: being prepared for the long-haul. *International journal of disability, development and education, 61*(4), 434-440.

Ellis, C., Adams, T., & Bochner, A. (2011). Autoethnography: an overview. *Forum; qualitative social research*.

Goodman, L. (1961). Snowball Sampling. *The Annals of Mathematical Statistics*, 148-170.

Healey, N. (2016, October 27). Reflections on the value of insider research as a qualitative research methodology. *Reflections on the value of insider research as a qualitative research methodology*. Sage Publications.

Lowe, P., Lee, E., & Macvarish, J. (2015). Biologising parenting: neuroscience discourse, English social and public health policy and understandings of the child. In G. Brady, P. Lowe, & S. Olin Lauritzen, *Children, Health and Well-being: policy debates and lived experience* (pp. 27-40). Chichester: Wiley Blackwell.

Lundeby, H., & Tossebro, J. (2008). Exploring the experiences of "not being listened to" from the perspective of parents with disabled children. *Scandinavian journal of disability research, 10*(4), 258-274.

Rafferty, K., & Sullivan, S. (2017). "You know the medicine, I know my kid": How parents advocate for their children living with complex chronic conditions. *Health communication*, 1151-1160.

Wilhelmsen, T., & Nilsen, R. D. (2015). Parents' experiences of diagnostic processes of young children in Norwegian day-care institutions. In G. Brady, P. Lowe, & S. O. Lauritzen, *Children, Health and Well-being; Policy debates and lived experience* (pp. 69-82). Chichester: Wiley Blackwell.

UNIVERSITY OF WAIKATO

Division of Arts, Law, Psychology and Social Sciences (ALPSS)

PARTICIPANT INFORMATION SHEET

Introduction

I am a social policy master's student at Te Whare Wananga O Waikato and I would like to invite you to take part in a semi-structured interview for my thesis. My research is centred around exploring the nature of social service provision for neurodivergent children.

Purpose of study

I would like to invite you to take part in a semi structured conversation about services and accessibility for neurodivergent children and their families. This interview will be focussed on your experience as a professional working in social services. You will have an opportunity to voice any recommendations that could further support families of neurodivergent children and/or support professionals working on the front line.

Design of study

The semi-structured interview will take approximately 30-60 minutes. With consent, the interview will be recorded and then transcribed. The interview will take place somewhere suited to you. I will provide you with the interview transcript 2 weeks after the interview for approval. I will also email you the quotes that will be used in my research for you to approve before publication.

Confidentiality

All information will be held by the researcher, this will include the recorded interview, the transcript, any handwritten notes and any email correspondence. Consultation with the researcher's supervisor will be required. All identities will be kept anonymous, and you will not be linked to your organisation in the thesis findings.

Outcomes

My research will be presented in the form of a master's thesis and may be shared in conference papers and journal articles, as such the findings will be in the public domain.

Right to withdraw

You have the right to withdraw up to two weeks after receiving the final quotes for checking after the interview. You can decline to answer any question at any time of the interview.

Contact details

Kelly Robyns (researcher)   Gemma Piercy-Cameron (supervisor)

University of Waikato   University of Waikato

kellyrobyns441@gmail.com   Gemma.piercy-cameron@waikato.ac.nz

021432055

"This research project has been approved by the Human Research Ethics Committee of the Faculty of Arts and Social Sciences. Any questions about the ethical conduct of this research may be sent to the Secretary of the Committee, email fass-ethics@waikato.ac.nz, postal address, Division of Arts, Law, Psychology and Social Sciences (ALPSS), Te Kura Kete Aronui, University of Waikato, Te Whare Wananga o Waikato, Private Bag 3105, Hamilton 3240."

UNIVERSITY OF WAIKATO

Division of Arts, Law, Psychology and Social Sciences (ALPSS)

PARTICIPANT CONSENT FORM

[A completed copy of this form should be retained by both the researcher and the participant]

Name of person interviewed: _____

I have received a copy of the Information Sheet describing the research project. Any questions that I have, relating to the research, have been answered to my satisfaction. I understand that I can ask further questions about the research at any time during my participation, and that I can withdraw my participation at any time [up to 14 days] after the interview.

During the interview, I understand that I do not have to answer questions unless I am happy to talk about the topic. I can stop the interview at any time, and I can ask to have the recording device turned off at any time.

When I sign this consent form, I will retain ownership of my interview, but I give consent for the researcher to use the interview for the purposes of the research outlined in the Information Sheet.

Please complete the following checklist. Tick [✓] the appropriate box for each point.	YES	NO
I have read and understood the Participant Information Sheet		
I have been given sufficient time to consider whether to participate in this study		

I understand that taking part in this study is voluntary and that I may withdraw up to two weeks after receiving the final quotes		
I know who to contact if I have any questions about the study in general.		
I understand what the study involves, I consent to participate and give information		
I understand that the researcher will need to discuss the research with their supervisor		
I wish to receive a copy of the findings		

Participant :   Researcher :   Kelly Robyns

Signature :   _____ Signature :   _____

Date :   _____ Date :   _____

Contact Details :   _____ Contact Details :   kellyrobyns@gmail.com

    _____   021432055

    _____   _____

10.5 APPENDIX E – POSSIBLE INTERVIEW TOPICS

Conversation topics

- Typical day
    - o Mental health callouts
    - o Interactions with crisis team
    - o How many? Day? Week?
- Services
    - o Know of? relationship with other services?
    - o Referral process
    - o Funding?
- Collaboration
    - o Which providers do you collab with?
    - o When does collab happen?
- Cost
    - o Financial
    - o Emotional
- Neurodivergent and complex children
    - o Understanding
    - o Training
    - o Medication training?